Valuing People: A New Strategy for Learning Disability for the 21st Century

The Stationery Office

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A New Strategy for Learning Disability for the 21st Century

A White Paper

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FOREWORD BY THE PRIME MINISTER

People with learning disabilities can lead full and rewarding lives as many already do. But others find themselves pushed to the margins of our society. And almost all encounter prejudice, bullying, insensitive treatment and discrimination at some time in their lives.

Such prejudice and discrimination – no less hurtful for often being unintentional – has a very damaging impact. It leads to your world becoming smaller, opportunities more limited, a withdrawal from wider society so time is spent only with family, carers or other people with learning disabilities.

What's also a real cause for concern and anxiety is that many parents of learning disabled children face difficulties in finding the right care, health services, education and leisure opportunities for their sons and daughters. At best, they can feel obstacles are constantly put in their way by society. At worst, they feel abandoned by the rest of us.

We have to change this situation if we are to achieve our goal of a modern society in which everyone is valued and has the chance to play their full part. There has been progress – often through the efforts of families, voluntary organisations and people with learning disabilities themselves. But a great deal more needs to be done.

This White Paper sets out this Government's commitment to improving the life chances of people with learning disabilities. It shows how we will meet this commitment by working closely with local councils, the health service, voluntary organisations and most importantly with people with learning disabilities and their families to provide new opportunities for those with learning disabilities to lead full and active lives.

I know the publication of a White Paper, however good its proposals, does not itself solve problems. The challenge for us all is to deliver the vision set out in this document so the lives of many thousands of people with learning disabilities will be brighter and more fulfilling. It is a challenge I am determined this Government will meet.

Tony Blair

EXECUTIVE SUMMARY

People with learning disabilities are amongst the most vulnerable and socially excluded in our society. Very few have jobs, live in their own homes or have choice over who cares for them. This needs to change: people with learning disabilities must no longer be marginalised or excluded. *Valuing People* sets out how the Government will provide new opportunities for children and adults with learning disabilities and their families to live full and independent lives as part of their local communities.

Where we are today

Problems and Challenges

There are about 210,000 people with severe learning disabilities in England, and about 1.2 million with a mild or moderate disability. Health and social services expenditure on services for adults with learning disabilities stands at around £3 billion. In the 30 years since the last White Paper *Better Services for the Mentally Handicapped*, progress has been made in closing large institutions and developing services in the community, but more needs to be done. There are major problems, including:

- Poorly co-ordinated services for **families with disabled children especially for those with severely disabled children;**
- Poor planning for **young disabled people at the point of transition into adulthood;**
- Insufficient support for **carers, particularly for those caring for people with complex needs;**
- People with learning disabilities often have little **choice or control** over many aspects of their lives;
- Substantial **health care** needs of people with learning disabilities are often unmet;
- **Housing choice** is limited;
- **Day services** are often not tailored to the needs and abilities of the individual;
- Limited opportunities for **employment;**

- The needs of **people from minority ethnic communities** are often overlooked;
- **Inconsistency in expenditure and service delivery**; and
- Few examples of real **partnership** between health and social care or involving people with learning disabilities and carers.

The New Vision

- Four key principles of **Rights**, **Independence**, **Choice**, **Inclusion** lie at the heart of the Government's proposals. Legislation which confers rights on all citizens, including the Human Rights Act 1998 and the Disability Discrimination Act 1995, applies equally to all people with learning disabilities, and the Disability Rights Commission will work for people with learning disabilities.
- New national objectives for services for people with learning disabilities, supported by new targets and performance indicators, to provide clear direction for local agencies
- A new **Learning Disability Development Fund of up to £50 million per annum from April 2002**: £20 million capital and up to £30 million revenue. The revenue element of the Development Fund will be created from within old long-stay health funding as it is released over time. The Development Fund will be targeted on the key priorities of the White Paper, including modernising day centres, enabling people to move from long-stay hospitals to more appropriate accommodation in the community, developing supported living approaches for people living with older carers, developing specialist local services for people with severe challenging behaviour and developing integrated facilities for children with severe disabilities and complex needs. The Development Fund will be made available subject to the condition that resources may only be used where they are deployed as pooled funds under the Health Act flexibilities.
- A new central **Implementation Support Fund of £2.3 million a year for the next 3 years** that will be used to fund a range of developments including advocacy and a new national information centre and help line.

Better life chances for people with learning disabilities

Disabled Children and Young People

- Learning disabled children and their families face many barriers to full participation in society. The Government's objective is to ensure that disabled children gain maximum life chance benefits from educational opportunities, health and social care while living with their families or in other appropriate settings.
- To achieve this we will ensure that learning disabled children and their families are an integral part of the Quality Protects programme, the Department for Education and Employment's Special Educational Needs Programme of Action and the Connexions Service. Disabled children will be a priority group under the Quality Protects programme with £60 million over the next three years earmarked to provide better support. The Schools Access Initiative will provide funds to improve accessibility of mainstream schools and the Standards Fund will be used to improve provision for children with special educational needs.
- Transition from childhood to adulthood can be a particularly difficult process for both disabled children and their parents/carers. Our objective is to ensure continuity of care and support and equality of opportunity for young people and their families so that as many learning disabled young people as possible take part in education, training, or employment. The Connexions Service will provide new help and advice to disabled young people as they move into adult life.

More Choice and Control for People with Learning Disabilities

- People with learning disabilities have little control over their lives, few receive direct payments, advocacy services are underdeveloped and people with learning disabilities are often not central to the planning process. The Government's objective is to enable people with learning disabilities to have as much choice and control as possible over their lives and the services and support they receive.

- To achieve this, we are investing at least **£1.3 million a year for the next 3 years to develop advocacy services** for people with learning disabilities in partnership with the voluntary sector. We are extending eligibility for direct payments through legislation. We will also set up a national forum for people with learning disabilities and enable them to benefit from the improvement and expansion of community equipment services now under way.
- A person-centred approach will be essential to deliver real change in the lives of people with learning disabilities. Person-centred planning provides a single, multi-agency mechanism for achieving this. The Government will issue new guidance on person-centred planning, and provide resources for implementation through the Learning Disability Development Fund.

Supporting Carers

- Caring for a family member with a learning disability is a lifelong commitment. Our objective is to increase the help and support carers receive from all local agencies in order to fulfil their family and caring roles effectively.
- To help carers, we are providing **£750,000 over the next three years to fund the development of a national learning disability information centre and helpline in partnership with Mencap**. We will implement the Carers and Disabled Children Act 2000. Councils will be encouraged to identify carers aged over 70 and those from minority ethnic communities. We will also ensure that carers and their organisations are represented on the Learning Disability Task Force.
- Carers will benefit from our package of extra help worth more than £500 million over 3 years, which the Government announced in the autumn of 2000. In April 2001, the carer premium in the income-related benefits will rise to £24.40 a week, and the Invalid Care Allowance (ICA) earnings limit will rise to £72 a week. As soon as the legislative programme allows, people aged 65 and over will be able to claim ICA and entitlement to ICA will continue for up to 8 weeks after the death of the disabled person, to allow carers time to adjust.

Improving Health For People With Learning Disabilities

- Many people with learning disabilities have greater health needs than the rest of the population. They are more likely to experience mental illness and are more prone to chronic health problems, epilepsy, and physical and sensory disabilities. The Government's objective is to enable people with learning disabilities to have access to a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard and with additional support where necessary.
- We will ensure that people with learning disabilities, including those from minority ethnic communities, have **the same right of access to mainstream health services** as the rest of the population. The NHS will promote equality for people with learning disabilities from minority ethnic communities in accordance with its new general duty in the Race Relations (Amendment) Act 2000, which comes into force on 2 April 2001. **Health facilitators** will be appointed from each local community learning disability team to support people with learning disabilities in getting the health care they need. We will ensure that all people with learning disabilities are **registered with a GP** and have their own **Health Action Plan**. There will be a new role for specialist learning disability services, focusing on making best use of their expertise.

Housing, Fulfilling Lives, and Employment

- **Housing**. People with learning disabilities and their families currently have few options about where they live. Our objective is to enable people with learning disabilities and their families to have greater choice and control over where and how they live. We are legislating to improve provision of advice and information by housing authorities, and will be issuing joint DH/DETR guidance on housing care and support options. We will complete the reprovision of the remaining long-stay hospitals to enable people still living there to move to more appropriate accommodation in the community by 2004.

- **Fulfilling Lives**. Our objective is to enable people with learning disabilities to lead full and purposeful lives in their communities and develop a range of activities including leisure interests, friendships and relationships. To achieve this, we will take forward a 5 year programme to modernise local councils' day services. The Learning and Skills Council will ensure equal access to education. We will outlaw discrimination against people with learning disabilities on public transport. Services for parents with a learning disability will be improved. Department of Social Security staff will receive disability awareness training to help them work with people with learning disabilities.
- **Employment**. Very few people with learning disabilities – probably less than 10% – have jobs. Our objective is to enable more people with learning disabilities to participate in all forms of employment, wherever possible in paid work, and to make a valued contribution to the world of work. We will develop **new targets for increasing numbers of people with learning disabilities in work** and ensure that the Workstep programme meets the needs of people with learning disabilities. There will be a study of the links between supported employment and day services. The Department of Social Security will ensure careful assessment of entitlement to Disability Living Allowance. Job Brokers under the New Deal for Disabled People will have the skills needed to work with people with learning disabilities.

Quality Services

- The Government is committed to raising standards and improving the quality of services for people with learning disabilities. Good quality services that promote independence, choice and inclusion will lead to good outcomes for people with learning disabilities. We will look to the Social Care Institute of Excellence to be a leading source of expertise. Local quality assurance frameworks for learning disability will be in place by April 2002. We will issue guidance on user surveys and on physical intervention. We are taking action to assist vulnerable or intimidated witnesses to give evidence in Court and so improve their access to justice.

- At present, most of the learning disability workforce is unqualified. The Government wants to see an appropriately trained and qualified workforce. Health and social care workforce strategies will provide new opportunities for learning disability staff. We will also introduce the **Learning Disability Awards Framework** from April 2001 which will provide a new route to qualification for care staff. We will also support a range of leadership initiatives through the Learning Disability Development Fund.
- Good quality services will provide the right care for people with additional or complex needs. This includes people with severe and profound disabilities, people with learning disabilities and epilepsy, those with learning disabilities and autism, people with challenging behaviour and older people with learning disabilities.

Delivering Change

Partnership Working

- Effective partnership working by all agencies is the key to achieving social inclusion for people with learning disabilities. To promote stronger local partnerships, we will build on existing joint planning structures to establish Learning Disability Partnership Boards within the framework of Local Strategic Partnerships by October 2001. Partnership Boards will be responsible for agreeing plans for the use of the Health Act flexibilities.

Making Change Happen

- Delivering these ambitious plans will take time and requires a long-term implementation programme. At national level, we will be investing new resources in 2001/02 to support implementation. We will:
- Set up a **Learning Disability Task Force** to advise the Government on implementation;
- Establish an **Implementation Support Team** to promote change at regional and local level;
- Fund a £2 million learning disability research initiative *People with Learning disabilities: Services, Inclusion and Partnership* from 2001/02;

- At a local level, Learning Disability Partnership Boards will have lead responsibility for ensuring implementation. They will need to develop local action plans by 31 January 2002 to supplement their learning disability Joint Investment Plans;
- The Social Services Inspectorate will carry out a national inspection of learning disability services in 2001/02.

PREFACE

1 *Valuing People: A New Strategy for Learning Disability for the 21st Century* sets out the Government's proposals for improving the lives of people with learning disabilities and their families and carers, based on recognition of their rights as citizens, social inclusion in local communities, choice in their daily lives and real opportunities to be independent.

> *'You should be proud of who you are' (Eve)*[1]

2 Developing these proposals involved extensive consultation over more than a year with key interests in the learning disability field:

- The Department of Health's national Learning Disability Advisory Group and the Service Users Advisory Group were consulted on emerging ideas;
- Six working groups bringing together people with learning disabilities, carers[2], local authority, NHS, and voluntary sector representatives, and researchers, as well as the key government departments, advised us on services for children, carers, health services, supporting independence, workforce training and planning, and building partnerships;
- Seven workshops across the country attended by almost 1,000 people, including people with learning disabilities and carers;
- Seminars on particular themes such as parents with learning disabilities, and consultation with disabled children were held to produce ideas for improving services;
- Other contributions came through our dedicated website (www.doh.gov.uk/learningdisabilities).

3 People with learning disabilities played an important part in the consultation process. Their contribution has been of central importance.

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[1] All the quotes are from people with learning disabilities came from the consultation process.

[2] The carers who helped us develop the new strategy prefer to describe themselves as 'family carer' because this emphasises the family relationship. The Department of Health uses the term 'carer' to describe people who are not paid for caring and 'care worker' for people who are paid to work as carers.

4 Clear messages emerged from this consultation:

- **Children with learning disabilities** want to be treated like other children, not always seen as “special”, and to be included in ordinary activities;
- **Parents of disabled children** want better advice and information and an integrated approach from services. Their expectations are often disappointed;
- **People with learning disabilities** often feel excluded and unheard. They want to be fully part of our society, not marginalised or forgotten. They told us advocacy and direct payments were key to helping them gain greater independence and control;
- **People with severe learning disabilities and complex needs** are more likely to receive poor quality services;
- **Carers** feel strongly that they have a lifelong responsibility for their sons or daughters. They want to be treated as full partners by public agencies. They need better information and support.

Our new strategy shows how the Government will respond to these concerns.

5 We also commissioned three reports which are being published to accompany *Valuing People*:

- **Nothing about Us Without Us: the report from the Service Users Advisory Group:** For the first time, people with learning disabilities have played a direct part in formulating Government policy. The members of the Service Users Advisory Group conducted a series of visits to local groups of learning disabled people. Listening to what people with learning disabilities had to tell us about their lives has helped us understand the need for change.
- **Family Matters, Counting Families In:** The report from the family carers working group offers valuable insights into the reality of service provision based on lifelong experience of caring for someone with a learning disability.
- **Learning Difficulties and Ethnicity**,[3] by the Centre for Research in Primary Care, University of Leeds. People with learning disabilities from minority ethnic communities and their families are too often overlooked. Meeting their needs is essential to providing a good service.

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[3] The authors use the term ‘learning difficulties’ as this was the preferred term among user organisations and disability writers.

PART ONE:

WHERE WE ARE NOW

CHAPTER 1

PROBLEMS AND CHALLENGES

1.1 People with learning disabilities are amongst the most socially excluded and vulnerable groups in Britain today. Very few have jobs, live in their own homes or have real choice over who cares for them. Many have few friends outside their families and those paid to care for them. Their voices are rarely heard in public. This needs to change.

> *'It's about time we had something for ourselves' (Gary)*

1.2 It is thirty years since the last White Paper on learning disability services *Better Services for the Mentally Handicapped*, was published. Our new agenda needs to be based on social inclusion, civil rights, choice and independence. People with learning disabilities have the right to be full members of the society in which they live, to choose where they live and what they do, and to be as independent as they wish to be.

1.3 Achieving this aim requires all parts of Government to work in partnership. Social care, health, education, employment, housing, leisure and social security all have a part to play, with local councils taking a lead to ensure that partnership becomes a reality at local level.

What is Learning Disability?

1.4 *Valuing People* is based on the premise that people with learning disabilities are people first. We focus throughout on what people can do, with support where necessary, rather than on what they cannot do.

1.5 Learning disability includes the presence of:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- A reduced ability to cope independently (impaired social functioning);
- which started before adulthood, with a lasting effect on development.

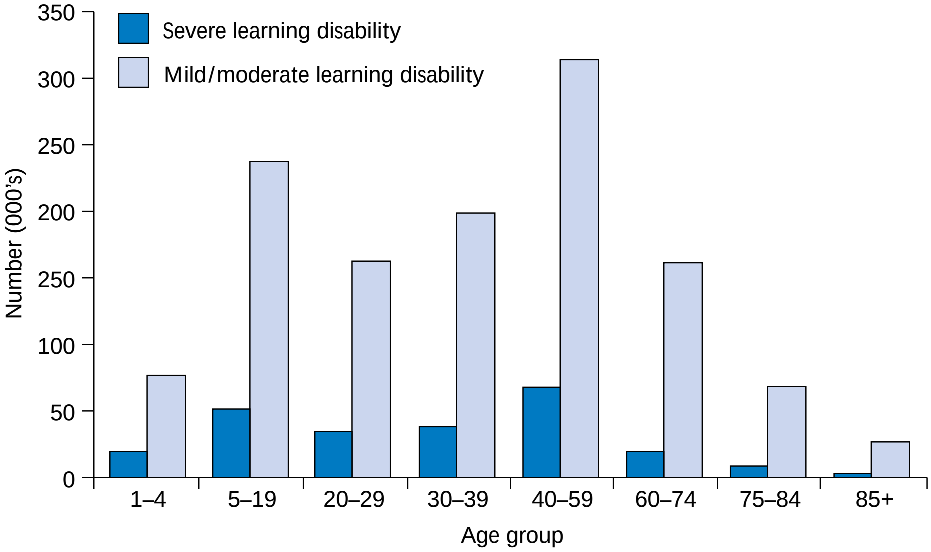
1.6 This definition encompasses people with a broad range of disabilities. The presence of a low intelligence quotient, for example an IQ below 70, is not, of itself, a sufficient reason for deciding whether an individual should be provided with additional health and social care support. An assessment of social functioning and communication skills should also be taken into account when determining need. Many people with learning disabilities also have physical and/or sensory impairments. The definition covers adults with autism who also have learning disabilities, but not those with a higher level autistic spectrum disorder who may be of average or even above average intelligence – such as some people with Asperger's Syndrome. We consider the additional needs of people with learning disability and autism in more detail in Chapter 8.

1.7 'Learning disability' does not include all those who have a 'learning difficulty' which is more broadly defined in education legislation.

How many people have learning disabilities?

1.8 Producing precise information on the number of people with learning disabilities[4] in the population is difficult. In the case of people with severe and profound learning disabilities, we estimate there are about 210,000: around 65,000 children and young people, 120,000 adults of working age and 25,000 older people. In the case of people with mild/moderate learning disabilities, lower estimates suggest a prevalence rate of around 25 per 1000 population- some 1.2 million people in England.

Figure 1 – People with learning disabilities, 1999



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[4] People with severe learning disabilities are those who need significant help with daily living. People with mild/moderate learning disabilities will usually be able to live independently with support.

1.9 Prevalence of severe and profound learning disability is fairly uniformly distributed across the country and across socio-economic groups. Mild to moderate learning disability, however, has a link to poverty and rates are higher in deprived and urban areas. The number of people with severe and profound learning disabilities in some areas is affected by past funding and placement practices, especially the presence of old long-stay patients and people placed outside their original area of residence by funding authorities.

Future Numbers

1.10 Evidence suggests that the number of people with severe learning disabilities may increase by around 1% per annum for the next 15 years as a result of:

- increased life expectancy, especially among people with Down's syndrome;
- growing numbers of children and young people with complex and multiple disabilities who now survive into adulthood;
- a sharp rise in the reported numbers of school age children with autistic spectrum disorders, some of whom will have learning disabilities;
- greater prevalence among some minority ethnic populations of South Asian origin.

Developments Since 1971

1.11 Until the 1950s, it was generally accepted that people with learning disabilities could enjoy a better quality of life living with other disabled people in segregated institutions rather than in the community with their families. The terms "mental deficiency" and "mental sub-normality" reflected the underlying attitudes of the day. Until 1959 those who lived in long-stay institutions were detained under the Mental Deficiency Act. By the end of the 1960s it became clear that the quality of care in long-stay hospitals was often extremely poor. Parental pressure became an important influence in the drive for change. The 1970 Education Act ensured that education should be provided for all children, no matter how severe their disability.

1.12 The 1971 White Paper *Better Services for the Mentally Handicapped* paved the way for change. It set an agenda for the next two decades which focused on reducing the number of places in hospitals and increasing provision in the community. It committed the

Government to helping people with learning disabilities to live "as normal a life" as possible, without unnecessary segregation from the community. It emphasised the importance of close collaboration between health, social services and other local agencies.

1.13 In 1971 the Government recognised that achieving change would require "sustained action over many years", and the White Paper set national targets (for England and Wales) for development of services which would take 15 to 20 years to achieve. These included reducing the number of long-stay hospital places for adults from 52,000 to 27,000 and increasing the number of residential care places in the community from 4,000 to nearly 30,000. Day places in the community needed to increase by nearly 50,000. Long-stay hospital places for children were to reduce from 7,400 to 6,400.

1.14 Many of the aims of the 1971 White Paper have been achieved. Very few large institutions remain and there are no children in long-stay hospitals. Services in the community have expanded and developed, and more people with learning disabilities are in work. There are active self-advocacy and citizen advocacy movements and the voices of people with learning disabilities are heard more clearly.

1971 White Paper	Services in 2000
In 1969, there were 58,850 patients (adults and children) in NHS hospitals or units	Nearly 10,000 places in NHS facilities: 1,570 NHS long-stay places 1,550 NHS specialist places 1,520 NHS campus places 5,100 places in residential accommodation managed by the NHS
4,900 places in residential care homes	53,400 places in residential care
24,500 places in Adult Training Centres	Estimated 84,000 adults receiving community based services (day care, home help, meals etc), of whom 49,600 are in receipt of social services day services 6,630 patients using NHS day care facilities

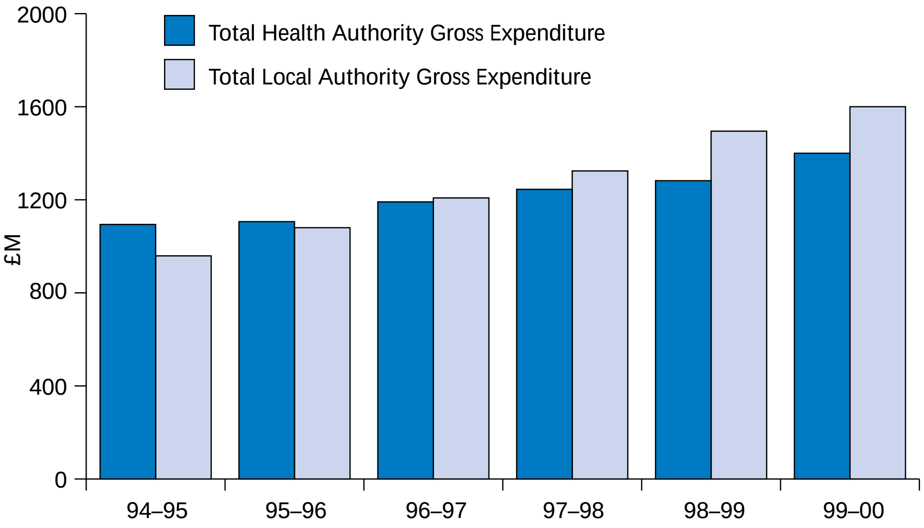
1.14 But more needs to be done. Too many people with learning disabilities and their families still lead lives apart, with limited opportunities and poor life chances. To maintain the momentum of change we now need to open up mainstream services, not create further separate specialist services. People with learning disabilities should have the same opportunities as other people to lead full and active lives and should receive the support needed to make this possible. The Government's agenda for reforming health and social care, modernising local government, promoting inclusive education and lifelong learning and Welfare to Work all offer major opportunities for improving the lives of people with learning disabilities. This can be done without losing the specialist expertise that currently exists.

Services and Expenditure

1.15 Many people with learning disabilities need additional support and services throughout their lives. This means that they have a longer and more intense involvement with public services than the vast majority of citizens. Services must provide them with safe, good quality care that delivers value for money.

1.16 Large amounts of public money are spent on learning disability services. Provisional health and social services expenditure on adults alone in 1999/2000 was over £3 billion: £1.4 billion on health and £l.6 billion on social services. In addition, about £308 million was spent by social services and £177 million by health on supporting disabled children, though not all of them have learning disabilities.

Figure 2 – Health and Local Authority Expenditure on Learning Disability



The figures for 1999/2000 are provisional.

1.17 The expansion of and improvement in some services has undoubtedly led to better outcomes for many people with learning disabilities. However, this does not mean services fully meet their needs. Research has consistently shown: variable quality of community based services; concerns about shortfalls of provision in particular services; and varying degrees of commitment to learning disability services by local authorities and health authorities.

Problems Facing Learning Disability Services

Social Exclusion

1.18 Despite the efforts of some highly committed staff, public services have failed to make consistent progress in overcoming the social exclusion of people with learning disabilities. These are some of the issues to be addressed:

Families with disabled children have higher costs as a result of the child's disability coupled with diminished employment prospects. Their housing needs may not be adequately met. There is little evidence of a flexible and co-ordinated approach to support by health, education and social services, and there is significant unmet need for short breaks.

Young disabled people at the point of transition to adult life often leave school without a clear route towards a fulfilling and productive adult life.

Carers can feel undervalued by public services, lacking the right information and enough support to meet their lifelong caring responsibilities.

Choice and Control. Many people with learning disabilities have little choice or control in their lives. Recent research shows only 6% of people with learning disabilities having control over who they lived with and 1% over choice of carer. Advocacy services are patchy and inconsistent. Direct payments have been slow to take off for people with learning disabilities.

Health Care. The substantial health care needs of people with learning disabilities too often go unmet. They can experience avoidable illness and die prematurely.

Housing can be the key to achieving social inclusion, but the number supported to live independently in the community, for example, remains small. Many have no real choice and receive little advice about possible housing options.

Day services frequently fail to provide sufficiently flexible and individual support. Some large day centres offer little more than warehousing and do not help people with learning disabilities undertake a wider range of individually tailored activities.

Social Isolation remains a problem for too many people with learning disabilities. A recent study[5] found that only 30% had a friend who was not either learning disabled, or part of their family or paid to care for them.

Employment is a major aspiration for people with learning disabilities, but less than 10% nationally are in work, so most people remain heavily dependent on social security benefits.

The needs of people with learning disabilities from minority ethnic communities are too often overlooked. Key findings from the study by the Centre for Research in Primary Care at the University of Leeds published alongside *Valuing People* included:

- prevalence of learning disability in some South Asian communities can be up to three times greater than in the general population;
- diagnosis is often made at a later age than for the population as a whole and parents receive less information about their child's condition and the support available;
- social exclusion is made more severe by language barriers and racism, and negative stereotypes and attitudes contribute to disadvantage;
- carers who do not speak English receive less information about their support role and experience high levels of stress; and
- agencies often underestimate people's attachments to cultural traditions and religious beliefs.

Inconsistency in Service Provision

1.19 The national statistics on learning disability conceal great variation across the country in terms of availability and coverage of services, as well as quality. Findings from three recent Department of Health studies of local authorities and their comparable health authorities – *Facing The Facts,*[6] *The London Learning Disability Strategic Framework* and a survey of 24 local authorities carried out during the development of the new strategy – show we are far from achieving consistency and equity for people with learning disabilities and their families.

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[5] The Quality and Costs of Residential Supports for People with Learning Disabilities, Summary & Implications (Hester Adrian Research Centre, University of Manchester, 1999).

[6] Facing the Facts: Services for People with Learning Disabilities – A Policy Impact Study of Social Care and Health Services (Department of Health 1999).

1.20 The main variations in social services and the NHS include:

- **Expenditure:** In London, social services expenditure per 10,000 population ranges from under £200,000 to £500,000. Health spend per 10,000 population ranges from under £100,000 to £450,000;
- **Day Services:** attendance at day centres ranges from 3 to 198 per 10,000 population, with higher figures generally associated with traditional day centres. Cost per attendance ranged from £18 to £112. We also know that some 20,000 people with learning disabilities – often the most severely disabled or those with challenging behaviour – do not attend a day service;
- **Short Breaks:** *Facing the Facts* found that the number of bed nights paid for by local authorities per 10,000 population ranged from 25 in a unitary authority to 492 in a shire county. For the special survey the range was 1 to 406 per 10,000 population. The last national Social Services Inspectorate inspection[7] found that short breaks were generally in short supply; and
- **Accommodation:** across the country the number of adults receiving care in publicly funded accommodation ranges from 12.74 per 10,000 population aged 18–64 to 59.20. Few places offer real choice.

1.21 The Government is committed to tackling the postcode lottery revealed here. It will be one of the key challenges in implementing the new strategy.

Management of Services

1.22 Good management of learning disability services requires:

- **strong partnership working:** while learning disability has been at the forefront of making use of the flexibilities under the Health Act 1999, many areas have yet to achieve real partnership between health and social care. Joint commissioning has been slow to take off. Few areas have partnerships involving service users, their families and the wider range of agencies.
- **good planning to ensure that services are responsive:** Few places attempt to have the individual's aspirations, needs and views as the driving force for providing services.

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[7] Moving into the Mainstream: The Report of a National Inspection of Services for Adults with Learning Disabilities (Department of Health 1998)

- **a highly skilled workforce:** we know that levels of training and qualification in the learning disability workforce remain low and there are shortages of key professionals and care staff.

The Way Forward

1.23 There is no “quick fix” solution to these problems; tackling them requires radical change from all of us. We need to develop a new approach to delivering better life chances for people with learning disabilities. We can no longer tolerate services which leave people isolated and marginalised. Good quality public services should offer new opportunities for people with learning disabilities to lead full and productive lives as valued members of their local communities. Our proposals are intended to:

- tackle social exclusion and achieve better life chances;
- ensure value for money from the large public investment in learning disability services;
- reduce variation and promote consistency and equity of services across the country;
- promote effective partnership working at all levels to ensure a really person-centred approach to delivering quality services;
- drive up standards by encouraging an evidence-based approach to service provision and practice.

CHAPTER 2

THE NEW VISION

2.1 Improving the lives of people with learning disabilities requires commitment nationally and locally to strong principles, a firm value base and clear objectives for services. Each individual should have the support and opportunity to be the person he or she wants to be.

Key Principles: Rights, Independence, Choice, and Inclusion

2.2 There are four key principles at the heart of the Government's proposals in *Valuing People*:

Legal and Civil Rights: The Government is committed to enforceable civil rights for disabled people in order to eradicate discrimination in society. People with learning disabilities have the right to a decent education, to grow up to vote, to marry and have a family, and to express their opinions, with help and support to do so where necessary. The Government is committed to providing comprehensive guidance for electoral administrators on helping disabled people, including those with learning disabilities, through the whole electoral process – from registering to vote until polling day itself.

"People with learning disabilities are citizens too"

All public services will treat people with learning disabilities as individuals with respect for their dignity, and challenge discrimination on all grounds including disability. People with learning disabilities will also receive the full protection of the law when necessary.

Independence: Promoting independence is a key aim for the Government's modernisation agenda. Nowhere is it of greater importance than for people with learning disabilities. While people's individual needs will differ, the starting presumption should be one of independence, rather than dependence, with public services providing the support needed to maximise this. Independence in this context does not mean doing everything unaided.

"All this can be done ... by believing that people with learning disabilities can move on and be independent"

"People with learning disabilities have been saying for a long time that we can speak up for ourselves"

"People with learning disabilities can live just as good a life"

Choice: Like other people, people with learning disabilities want a real say in where they live, what work they should do and who looks after them. But for too many people with learning disabilities, these are currently unattainable goals. We believe that everyone should be able to make choices. This includes people with severe and profound disabilities who, with the right help and support, can make important choices and express preferences about their day to day lives.

Inclusion: Being part of the mainstream is something most of us take for granted. We go to work, look after our families, visit our GP, use transport, go to the swimming pool or cinema. Inclusion means enabling people with learning disabilities to do those ordinary things, make use of mainstream services and be fully included in the local community.

Our Values

2.3 Our new proposals reflect these four key principles and we set out below how they can be realised at both national and local level. They are grounded in the legislation that confers rights on all citizens including people with learning disabilities:

- the Human Rights Act 1998;
- the Disability Discrimination Act 1995;
- the Race Relations Act 1976;
- the Race Relations (Amendment) Act 2000;
- the Sex Discrimination Act 1975; and
- the UN Convention on the Rights of the Child, which was adopted in the UK in January 1992.

2.4 The Disability Rights Commission established in April 2000 has a vital role to play in enabling all disabled people, including those with learning disabilities, to gain full access to their legal rights. It will ensure that the needs and views of people with learning disabilities are integral to all the Commission's work.

2.5 People who are vulnerable to exploitation have to be protected in law. The position of those who are vulnerable to sexual abuse and exploitation is considered in the report of the Sex Offences Review *Setting the Boundaries*. This includes discussion on the capacity to consent for very vulnerable people. That report recommends a new offence of a breach of a relationship of care which would cover sexual relationships between, for example, doctors and their patients, or between designated care providers and people receiving certain care services in the community.

Government Objectives for Learning Disability Services

2.6 If public services are to continue to improve we need both to set a clear direction and create clear objectives. The new Government objectives developed from our consultation process set out below provide this direction for all agencies working with people with learning disabilities. They are an essential first step in tackling unacceptable variation and promoting greater consistency and equity in services.

2.7 Our objectives reflect the partnership approach which is central to Valuing People and clarify the Government's expectations of all local agencies providing help to people with learning disabilities and their carers: social services, health, education, employment, housing, the Benefits Agency, transport and leisure services. Local voluntary groups and independent service providers also need to be part of the partnership. This approach is in line with the Government's principles for partnership working enshrined in the Local Strategic Partnerships now being introduced to co-ordinate implementation of local community strategies and the Government's strategy for neighbourhood renewal. Our partnership proposals set out in Chapter 9 will fit within the umbrella provided by Local Strategic Partnerships.

2.8 There are two categories of Government objectives for people with learning disabilities: the first deal with outcomes for people and the second concern systems needed in order to deliver better outcomes. We support the objectives with more detailed sub-objectives, which will be monitored through new performance indicators. Annex A contains the complete list.

2.9 These objectives will provide the focus for local action to implement our proposals. We will require local agencies to build on the Joint Investment Plans which are already expected to be in place for April 2001 in order to develop local action plans. Chapter 10 looks in further detail at the role and contents of these plans, along with arrangements for monitoring the implementation of the White Paper as a whole.

Objective 1: Maximising Opportunities for Disabled Children
To ensure that disabled children gain maximum life chance benefits from educational opportunities, health care and social care, while living with their families or in other appropriate settings in the community where their assessed needs are adequately met and reviewed.

Objective 2: Transition into Adult Life
As young people with learning disabilities move into adulthood, to ensure continuity of care and support for the young person and their family and to provide equality of opportunity in order to enable as many disabled young people as possible to participate in education, training or employment.

Objective 3: Enabling People To Have More Control Over Their Own Lives
To enable people with learning disabilities to have as much choice and control as possible over their lives through advocacy and a person-centred approach to planning the services they need

Objective 4: Supporting Carers
To increase the help and support carers receive from all local agencies in order to fulfil their family and caring roles effectively.

Objective 5: Good Health
To enable people with learning disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary.

Objective 6: Housing
To enable people with learning disabilities and their families to have greater choice and control over where, and how they live.

Objective 7: Fulfilling Lives
To enable people with learning disabilities to lead full and purposeful lives in their communities and to develop a range of friendships, activities and relationships.

Objective 8: Moving into Employment
To enable more people with learning disabilities to participate in all forms of employment, wherever possible in paid work and to make a valued contribution to the world of work.

Objective 9: Quality
To ensure that all agencies commission and provide high quality, evidence based and continuously improving services which promote both good outcomes and best value.

Objective 10. Workforce Training and Planning
To ensure that social and health care staff working with people with learning disabilities are appropriately skilled, trained and qualified, and to promote a better understanding of the needs of people with learning disabilities amongst the wider workforce.

Objective 11: Partnership Working
To promote holistic services for people with learning disabilities through effective partnership working between all relevant local agencies in the commissioning and delivery of services.

Action for Change

2.9 *Valuing People* sets out a major programme to improve life chances for people with learning disabilities. The Government will:

- Set out a new vision for services for disabled children and their families, to be delivered through an integrated approach by health, education and social care. Disabled children will be fully included as an integral part of the Government's major reform agenda for all children and families. The Quality Protects programme targets £60 million over the next three years on improving support for disabled children and their families;
- Enable disabled young people to have equal opportunities for moving into adult life, with new support from the Connexions Service;
- Give people with learning disabilities more choice and control by developing advocacy, extending direct payments and introducing a national framework for promoting a person-centred approach to planning. The Government is investing £1.3 million per annum for the next three years in establishing a National Citizen Advocacy Network and promoting self-advocacy, both in partnership with the voluntary sector;
- Provide £750,000 over the next three years to establish a National Learning Disability Information Centre and Helpline in partnership with Mencap;
- Enable all people with learning disabilities to have access to a health facilitator and to have a Health Action Plan;
- Complete the reprovision of the remaining long-stay hospitals to enable everyone still living there to move to more appropriate accommodation by April 2004;
- Take forward a five year programme for modernising day services to provide more individualised support, with clear targets and bridging finance;
- Set a new Government target for increasing employment for people with learning disabilities, backed by the development of local employment strategies;
- Introduce the new Learning Disability Awards Framework in April 2001 to provide a new route to qualification for care workers in the learning disability field; and

- Strengthen partnership working by giving local councils lead responsibility for establishing new Learning Disability Partnership Boards. These will build on existing partnership structures to bring together public, voluntary and independent agencies and the wider community within the overall framework of Local Strategic Partnerships. Partnership Boards will be responsible for implementation of the White Paper and will need to submit updated Joint Investment Plans (JIPs) setting out plans for local action to the Department of Health by 31 January 2002.

2.10 Making these changes happen requires a long-term implementation programme over at least the next five years. The Government will provide a strong national lead and will:

- Introduce a new Learning Disability Development Fund of up to £50 million from April 2002: up to £30 million per annum revenue and £20 million capital. The revenue element of the Fund will be created from NHS old long-stay funding as it is released overtime. Resources from the Fund may only be used where they are deployed as part of pooled budgets under the Health Act flexibilities enabling them to be targeted on supporting our key proposals;
- Establish a Learning Disability Task Force, bringing together a wide range of expertise including people with learning disabilities and carers;
- Set up a national Implementation Support Team; and
- Introduce a new Implementation Support Fund of £2.3 million a year for the next 3 years.

2.11 Chapters 3 to 8 set out the problems and challenges facing people with learning disabilities, their families, their carers and agencies providing services, describe what is currently being done and list the key actions to be taken to help address the problems.

PART TWO:

BETTER LIFE CHANCES FOR PEOPLE WITH LEARNING DISABILITIES

CHAPTER 3

DISABLED CHILDREN AND YOUNG PEOPLE

Government Objective: To ensure that disabled children gain maximum life chance benefits from educational opportunities, health care and social care, while living with their families or in other appropriate settings in the community where their assessed needs are adequately met and reviewed.

3.1 This chapter sets out the Government's proposals for maximising opportunities for disabled children and supporting young people's transition into adult life. It focuses in particular on the needs of learning disabled children and their families, but does so within a framework which applies equally to all disabled children. Many disabled children have more than one impairment and a majority have a learning disability. There are an estimated 1.7 million pupils in schools with special educational needs, of whom some 250,000 have statements of special educational need. Most of those children with statements will also be defined as disabled. We will build on existing health, social services and education programmes to develop an integrated approach to supporting disabled children. Children and their families want services that are not only efficient and effective, but also joined up and responsive. We propose to set new Government objectives and sub-objectives to be applied from April 2002. (See Annex A).

Problems and Challenges

3.2 Society creates many problems and poses many challenges for disabled children and their families. Despite these, many families are very successful in providing a good start in life for their disabled children. There is a compelling body of evidence from research and inspection reports that disabled children and their families face many barriers to full participation in society:

- too little family support, help in the home and too few short breaks especially for more severely disabled children;
- too often living in poverty;

- lack of key workers leading to poorly co-ordinated inter-agency support;
- frequent delay in diagnosis and identification of the child's impairments;
- lack of good information about what help is available;
- limited expectation of children's educational achievements;
- some children live in residential placements, which can increase isolation from home and family and increase vulnerability to abuse;
- too few opportunities to participate in sport, culture and leisure activities;
- inequalities in access and quality of NHS services;
- minority ethnic families experience these barriers disproportionately;
- lack of opportunities for disabled young people moving into adulthood.

3.3 Three main messages have come out of consultation with disabled children:

- treat us more like our brothers and sisters,
- we want to do the things other children do, not always 'something special', and
- give us a chance to be independent, get a job and have a home.

3.4 Research findings show parents of disabled children would like:

- key workers to help co-ordinate services;
- early identification of impairments and early intervention;
- simple accessible information about available services;
- greater access to family support, short breaks and support.

What more needs to be done

KEY ACTIONS – DISABLED CHILDREN

- New priority in Quality Protects programme: £60m of children's services grant earmarked for more support for families of disabled children from 2001/2 to 2003/4, resulting in more home based help and more access to key workers.
- Major Government programme to improve educational outcomes for children with special needs, based on collaborative working across health, education and social services.
- £220 million from 2001 to 2004 to improve the accessibility of mainstream schools for disabled children.
- A new duty on all LEAs to provide parent partnership services for families of children with SEN, supported by £18m Standards Fund grant in 2001/02.
- Joint DH/DFEE work on position of children in residential placements.
- Additional family support through statutory and voluntary sectors including co-ordinated health and social care packages to an additional 6,000 severely disabled children by 2002.
- From April 2001 the introduction of direct payments to give parents and disabled 16- and 17-year-olds greater choice in how they receive services.
- New National Information Centre for families of disabled children to be launched in 2001 by Contact a Family. Government funding of £500,000 per annum.
- Action to enable more disabled children to use sport, culture and leisure activities.
- £4m ringfenced in National Childcare Strategy for children with disabilities and SEN, enabling more staff to be employed to support disabled children.
- A multi-agency working party to develop practical guidance for professionals involved in identifying the special needs of children in the 0–2 age bracket.
- Early support and intervention to tackle the social exclusion of disabled children through cross Government programmes (Sure Start, The Children's Fund and Connexions).

- Improved social security benefits for families with disabled children, helping reduce child poverty.
- A new National Service Framework for children to reduce health inequalities and ensure that all children have fair access to and high standards of health care.
- Development of integrated services for children and young people with severe disabilities and complex needs a priority for use of the capital element of the Learning Disability Development Fund.
- New transition arrangements, through the Connexions Service, to improve opportunities for disabled young people to take part in education, training or employment.

Quality Protects Programme

3.5 The Quality Protects programme set up to improve children's social services will:

- increase provision of a wider range of flexible support services for families of disabled children including short breaks;
- help integrate disabled children into mainstream leisure and out of school services;
- provide more and better information for families and increase the availability of key workers and other measures to improve co-ordination.

3.6 From April 2001 disabled children will be included in the priority areas for the grant. £60m has been earmarked for services for disabled children and their families – £15 million in 2001/2002 and 2002/2003 and £30 million in 2003/2004.

Family Support

3.7 The Government has set a target for an additional 6,000 severely disabled children by 2002 to receive support by a co-ordinated care package from health and social services.

3.8 The Government is increasing funding to the Family Fund Trust which provides grants to help reduce the stress on families with severely disabled children, including grants to pay for holidays, washing machines and other services. In 2000/2001, the Government contributed funding of £25.4 million. This funding will be increased by £1m in 2001/02, £2m in 2002/03 and £3m in 2003/4.

The Cheviots Centre

The Cheviots Centre in Enfield provides a range of services to children who have severe learning disabilities, very challenging behaviour problems and life limiting conditions. They provide a range of core services to give families the support they need to be able to look after their disabled child at home. The Centre provides a service which is seamless, fast and responsive and includes:
holiday play schemes;
home care support;
a counselling service and
a range of activity groups which runs 7 days a week.

3.9 The Government will continue to support the Diana Children's Community Nursing Teams. These teams work in partnership with other local agencies and provide physical, social and emotional support to children with life limiting disorders in their own homes as an alternative to hospital-based care.

3.10 From April 2001 through the SEN Programme of Action, the Government will provide local education authorities with £18m to support the development of parent partnership services, and will invest a further £2m to pilot arrangements for independent parental supporters in the expectation that these will be available in all areas from 2002/03.

3.11 The implementation of the Carers and Disabled Children Act 2000 will allow direct payments to be made from April 2001 to parents of disabled children, giving greater choice and flexibility in how they receive services.

3.12 Families need to be able to make informed choices about the services and support they need for their children and for themselves. From 2001, the Government is funding the charity Contact a Family by £500,000 per annum for three years, to set up a new National Information Centre for families with disabled children. This will include a national telephone help and advice line for disabled children and parents.

The Markfield Project

'To make the **best** playscheme ever we all promise:

To be nice and kind. To be treated with respect. To not swear or spit. Not to shout. To call people by their names and not 'oi'. Not to play with peoples wheelchairs. To have FREEDOM to play. A lot of excitement and fun. To be included. TO play FUN games. To not kick, hit or bully each other. To play with everyone and make new friends. To listen and be listened to. To have a GOOD time! TO be helped when needed. To go on trips, have adventures and learn new things.'

Promised by the children and staff on the summer playscheme 2000

Play, Leisure, Culture and Sport

3.13 Disabled children want support to do the things their peers do, such as going swimming or to a youth club. Participation in play and sporting activities can help build self-esteem and social skills. The Government is taking action by: increasing through the Quality Protects programme the numbers of disabled children involved in leisure and play activities; supporting 13% of New Opportunities Fund places going to children with special needs; ensuring that all children in Sure Start areas will have access to good quality play opportunities, including one to one support and adapted toys and equipment.

Education Services

SEN PROGRAMME OF ACTION

3.14 Education, as a key service for children, must be characterised by its inclusiveness and its high expectations for all children, including those children with special educational needs, and those who are disabled. The Government's aim is to encourage disabled children to reach their full potential. The SEN Programme of Action is committed to:

i) improving early identification and early intervention;

ii) supporting parents and carers;

iii) improving the SEN framework;

iv) developing a more inclusive education system;

v) developing knowledge and skills;

vi) working in partnership.

3.15 Through the programme the Government has pledged additional resources to improve the education of children with disabilities. From April 2001 £220m has been allocated, over three years, through the Schools Access Initiative, to improve the accessibility of mainstream schools. Further, for 2001–02, £82m in the Standards Fund is earmarked to improve provision for children with special educational needs.

3.16 The Government's Special Educational Needs and Disability Bill will:

- strengthen the right of children with SEN to be educated in mainstream schools;
- require LEAs to provide parents of children with SEN with advice and information, and a means of settling disputes with schools and LEAs;
- require schools to inform parents where they are making special educational provision for their child and allow schools to request a statutory assessment of a pupil's SEN;
- place duties to increase physical accessibility to school premises and to not treat disabled children less favourably compared to non disabled children;
- place new duties on schools and LEAs to make reasonable adjustments so disabled pupils are not placed at a substantial disadvantage to their non-disabled peers.

3.17 From 2002, the Government will use revised statistical arrangements to monitor the progress and attainment of children, including those with learning disabilities. All schools will set targets for the achievement of children working below age related expectations on the National Curriculum. Further, the Qualifications & Curriculum Authority will issue guidance to schools on target setting and assessment for children working below these age related expectations. This will help ensure higher expectations of and higher attainment by all children with special needs. The revised SEN Code of

Practice, together with practical guidance, will help schools better identify needs early and provide for those needs.

3.18 During 2001/02 the Department for Education and Employment and the Department and Health will build on this substantial programme by:

- developing guidance on good practice in early identification of SEN;
- issuing – alongside the revised SEN Code of Practice – practical guidance on involving disabled children in decisions about their education;
- working with the Disability Rights Commission on the production of a Code to help schools make reasonable adjustments to include disabled children fully in the life and curriculum of their school;
- helping schools share effective practice on the delivery of inclusive education;
- developing measures of attainment and personal and social development for children with SEN;
- ensure that health services, social care and family support services are provided as far as possible, in school, or in other ways which support children's education and the well being of families.

HEALTH CARE IN SCHOOLS

3.19 Many children with special needs in mainstream schools require considerable support from health and social services. Children should not be disadvantaged in terms of access to health care as a result of parents' choice of school. It is particularly important that a child's health treatment/therapy should be provided with minimum disruption to their education and, wherever possible, necessary health care support should be delivered through schools and in a way which supports families. The NHS Plan sets out the Government's commitment to provide 6,500 more NHS therapists and related professional staff by 2004, with 4,450 more training places. In the summer the Department of Health will issue guidance on implementation. This will encourage wider use of the Health Act flexibilities in order to develop more integrated partnership working.

3.20 The Department for Education and Employment is sponsoring a network of eleven SEN Regional Partnerships across England. These bring together groups of local education authorities, local health and social services plus the private and voluntary sectors. We will promote full collaboration in these partnerships and also across the Department of Health's regional task forces to ensure joined-up child centred services for disabled children.

3.21 *Saving Lives: Our Healthier Nation* set out a child-centred public health role for school nurses, working with individual children and young people, families, schools and communities to improve health and tackle inequality. Schools can have a tailored health plan agreed in partnership with the school nurse to address the health needs and education priorities of the school. School nurses will assess an individual child's health needs and initiate and develop programmes for children with medical or special education needs to maximise their learning potential, and to promote health and inclusion in school life.

Residential Placements

3.22 Some disabled children are placed in residential schools; others live in residential homes. Whilst many of these placements are highly valued by children and families, they may result in their isolation from normal childhood support. We do not know enough about these children. In 2001/02 the children in need census will help enable councils to identify how many disabled children are in residential homes. In 2001/02 the Department of Health and Department for Education and Employment will work together to find out more about the numbers, characteristics and outcomes relating to these children. We will develop arrangements which will create better linkages between children living in residential placements and their family, and ensure they are properly supported and protected by key agencies.

3.23 Disabled children living in residential placements are known to be particularly vulnerable to abuse. The Care Standards Act 2000 strengthens the safeguards for children living away from home. From April 2002, the new National Care Standards Commission will register children's homes (including those homes for disabled children currently registered as care homes) and inspect the welfare of children in all boarding schools and Further Education colleges with boarding provision. Separate standards will be introduced for residential special schools.

Early Years Developments

3.24 Early Years and Childcare Development Partnerships have a responsibility to ensure that all sectors of the community have equal access to childcare, regardless of their special educational needs or disability. From April 2001, £144.75 million will be available to support Partnerships' Plans. Included in this sum, is a ring-fenced amount of £ 4 million to provide childcare services for children with special educational needs or disabilities and other special groups. In addition Partnerships can, at their discretion, supplement this amount using their general childcare grant.

3.25 Current childcare tax credit rules do not support parents who use formal childcare in their own home. This poses a specific barrier to work for families with particular needs, such as those with disabled children who need home-based care. The Government announced in the 2001 Budget that it is to consider how these families might be helped, for example by extending the childcare tax credit to cover formal childcare in the home where it meets standards similar to those that will govern the regulation and accreditation of childminders.

3.26 The Early Excellence Centres programme is a test-bed for developing high quality integrated services for the early years. Participating centres offer integrated early education and childcare, family support and dissemination of good practice. There are now 35 centres with a key role in: supporting children and families with special educational needs; improving early identification of needs; promoting inclusion; enabling parents to cope. Evaluation of the pilot Early Excellence Centres found that they had increased the rates of inclusion in mainstream education for children identified as having SENs in early childhood and were cost effective.

3.27 The Government intends to establish a multi-agency working party, with representation from specialist organisations with an interest, to develop practical guidance for the range of professionals involved in identifying the special needs of children aged 0–2 and offering support to the children and their families. The guidance will provide examples of good practice and set out practical advice to help agencies enhance joint working.

Cross Government Programmes for Children and Young People

3.28 Disabled children will also benefit from three cross government programmes to help prevent vulnerable children and young people from becoming socially excluded:

- Sure Start partnerships help in identifying young children (0–4 year olds) with disabilities and ensuring the provision of early intervention and support. Targeted efforts are then made to ensure that identified children receive relevant support to help them enter successfully into early years education. The support by Sure Start includes support for families with special needs;
- The £450 million Children's Fund will help families of disabled children (primarily in the 5 to 13 age group) by support through multidisciplinary teams and local voluntary groups. Services might include support for parents of disabled children and mentoring schemes;
- The Connexions service will be available to help all young people (primarily 13–19-year-olds) make a successful transition from school to the world of work, training and further education. The Connexions Personal Advisers will have a key role in supporting disabled young people into adulthood.

Child Poverty

3.29 From April 2001, families with disabled children will benefit from the following:

- An increase in the disabled child premium in income related benefits by £7.40 per week on top of normal uprating. 80,000 families with disabled children will see a rise in this premium from £22.25 to £30 a week. This change will be mirrored by an increase from April 2001 of £7.40 a week over and above inflation of the disabled child tax credit in Working Families' Tax Credit and Disabled Person's Tax Credit;
- The Disabled Income Guarantee will be paid to families on low incomes with severely disabled children receiving the highest care component of Disability Living Allowance. Extra £11.05 a week for each eligible child;
- Severely disabled 3- and 4-year-olds will benefit from entitlement to the higher rate mobility component of Disability Living Allowance.

Health Services

ACCESS TO HEALTH CARE

3.30 Disabled children have exactly the same health care needs as other children in addition to any arising from their particular disabilities. The NHS provides a universal service for all based on clinical need and the Government is determined to ensure disabled children have the same access to services as other children. Discrimination on any grounds, including disability, has no place in the NHS. The Government has announced the development of a National Service Framework (NSF) for children. This will help us improve services for all children and families and ensure we reduce unacceptable variations in the standards of care and in access to care. As promised in the NHS Plan, the Government has also set targets for reducing inequalities in childhood mortality and is developing targets for reducing morbidity inequalities. From 2001 fair access to health care will be measured and managed through the NHS Performance Management Framework. We will also look further at how Patient Advocacy Liaison Groups (PALS) will help disabled children and their families.

Rosehill and Littlemore Sure Start is developing work on early identification of special needs in children via a special needs support worker (a commissioned service from the LEA) who uses a particular form of intervention therapy. The Asian Families Liaison Worker (a commissioned service from Oxford City Council) found that identifying learning difficulties is a significant issue among children from Asian families. She is working with the special needs support worker via home visits, nursery and playgroup settings to offer individual and group support to adults and children in liaison with the locality health team.

DIAGNOSIS IN EARLY CHILDHOOD

3.31 The NHS programme of surveillance and screening of children enables children with disabilities to be identified at an early stage. We provide funding for the development of training packages and information aimed at all health professionals to improve their knowledge of disability and to enhance their skills in sharing this information sensitively with the child, their parents and other family members. Liaison nurses are increasingly being used to help families through the trauma of major medical surgical interventions and to provide ongoing support.

COMPLEX HEALTH NEEDS

3.32 The Government is concerned to support the increasing numbers of children with complex medical needs, some of whom are dependent on technology. We will take steps to establish the numbers and socio-economic characteristics of these children. Support for these families will be given through the Quality Protects programme and through the New Opportunity Fund providing grants for projects offering palliative care to children with life limiting illness and their families.

3.33 In order to make further progress in improving services for children with complex needs and their families, we have made developing integrated health and social services facilities for such children and young people a priority area for the use of the capital element of the Learning Disability Development Fund.

CHILD AND ADOLESCENT MENTAL HEALTH SERVICES (CAMHS)

3.34 Children with physical or learning disabilities are more vulnerable to the full range of mental health disorders and the additional social, family and emotional stresses of everyday life. £50 million has already been allocated to improve child and adolescent mental health services over the period 1999 to 2001. The Government is committed to improving services for children and young people with mental health problems through the implementation of the NHS Plan. By May 2001, all health authorities and local councils must have an agreed joint CAMHS Development Strategy which sets out how local and national priorities are to be met, including 24-hour cover and outreach services and increasing early intervention and prevention programmes for children. Arrangements to provide CAMHS for learning disabled children will be included in all relevant planning arrangements for children.

TRANSITION INTO ADULT LIFE

Government Objective: As young people with learning disabilities move into adulthood, to ensure continuity of care and support for the young person and their family; and to provide equality of opportunity in order to enable as many disabled young people as possible to participate in education, training or employment.

Problems and Challenges

3.35 Disabled young people and their families often find the transition to adulthood both stressful and difficult. For many, there has been a lack of co-ordination between the relevant agencies and little involvement from the young person. Some young people are not transferred from children's to adult services with adequate health care plans, which results in their exclusion from adult services. This is likely to affect young people with severe learning disabilities and complex health needs in particular. Starting adult life should be a time of opportunity for young people. The Government wants to see more young people taking part in education and training, which will help them lead productive adult lives and find employment.

What more needs to be done

Making the Connexions Service work for Young People with Learning Disabilities

3.36 From April 2001, the new Connexions Service will be rolled out to provide all 13–19-year-olds with access to advice, guidance and support, through the creation of a network of personal advisers. These advisers will identify young people with learning disabilities; they must be invited to and attend annual reviews of all year 9 pupils with statements of SEN; and will work with the school and other relevant agencies to draw up the transition plans. Each Connexions Partnership must have sufficient Personal Advisers with the appropriate skills, experience and training to work with disabled young people. For young people leaving care the Children (Leaving Care) Act places a duty on councils to provide qualifying young people aged 16 and over in and leaving care with a personal adviser. There is such a significant overlap between the roles envisaged for the Act's advisers and Connexions advisers that the advisers provided by councils will also be well placed , with training, to act as Connexions advisers.

Connecting with Connexions – a Community Care Development Centre Project

Connexions pilot Personal Advisers (PAs) in Lewisham are exploring how to prepare young people with learning disabilities for the world of work. Two PAs appointed by London South Bank Careers to special schools are linking with two experienced supported employment agencies (Sabre and STATUS). The PAs are learning about supported employment and meeting job coaches and people with learning disabilities who have jobs. The outcome will be information about guidance and materials to help link Connexions with work options and how to support PAs to work with young people with learning disabilities.

3.37 Connexions Partnerships will have responsibility for arranging with the local Learning and Skills Council and the Employment Service a review for the young person with learning disabilities in their 19th year, to agree arrangements for appropriate transition from the support provided by the Connexions Service, whilst ensuring continuity. Adult social services may need to be involved in some cases. Where young people are not ready to use the adult guidance services, Connexions Partnerships will continue to support them, with the aim of helping them make use of the adult systems and to reduce dependency on the Connexions Service. These arrangements can extend up to their 25th birthday.

Young People and Person-centred Planning

3.38 Chapter 4 sets out the Government's proposals for a person-centred approach to planning services for adults with learning disabilities. Local councils will take the lead in ensuring that local Learning Disability Partnership Boards responsible for planning and commissioning services for adults agree a framework for the development of person-centred planning. This will build on the assessment and planning for young people already undertaken by Connexions. The Government will issue further guidance on person-centred planning for adults with learning disabilities in 2001. Local agencies will be expected to have introduced person-centred planning for all young people moving from children's to adult's services by 2003.

3.39 There will also need to be effective links in place between children's and adults services in both health and social care. We will expect Learning Disability Partnership Boards to identify a member with lead responsibility for transition issues. Ensuring continuity in health care will be a key element of the new Health Action Plan for people with learning disabilities discussed in Chapter 6. For social care, the Director of Social Services will be required to ensure that good links are in place between children's and adult services for people with learning disabilities as part of his/her new responsibility for quality under the Social Care Quality Framework.

CHAPTER 4

MORE CHOICE AND CONTROL FOR PEOPLE WITH LEARNING DISABILITIES

Government Objective: To enable people with learning disabilities to have as much choice and control as possible over their lives through advocacy and a person-centred approach to planning the services and support they need.

The proposals in this chapter will be central to delivering the Government's four key principles. The rights of people with learning disabilities need to be promoted. They also need help in order to achieve greater choice, independence and inclusion in all aspects of their lives. Services should respond to the wider aspirations of people with learning disabilities and give them more choice and control.

Problems and Challenges

4.1 People with learning disabilities currently have little control over their own lives, though almost all, including the most severely disabled, are capable of making choices and expressing their views and preferences. The current problems are:

- Services have been too slow to recognise that people with learning disabilities have rights like other citizens;
- Provision of advocacy services is patchy;
- People with learning disabilities have little involvement in decision making;
- Few people with learning disabilities receive direct payments;
- People with learning disabilities and their families are not central to the planning process;
- Not enough effort to communicate with people with learning disabilities in accessible ways.

4.2 The challenge for public services is to find ways to give people with learning disabilities more control over their lives through:

- Developing and expanding advocacy services, particularly citizen advocacy and self-advocacy;
- Fully involving them in decisions affecting their lives;
- Increasing the number who receive direct payments;
- Developing a person-centred approach to planning services;
- Improving information and communication with people with learning disabilities.

What More Needs To Be Done

KEY ACTIONS – CHOICE AND CONTROL FOR PEOPLE WITH LEARNING DISABILITIES

- Disability Rights Commission to work for people with learning disabilities.
- £1.3 million per annum for the next three years to develop and expand advocacy services in partnership with the voluntary sector.
- Legislation to extend eligibility for direct payments supported by implementation programme to promote take up.
- Department of Health guidance to be issued in 2001 on a person-centred approach to planning services.
- Transfer of responsibility to local councils for people with preserved rights: Councils required to offer direct payments.
- The Learning Disability Development Fund will provide resources to support development of person-centred planning.
- National Forum for people with learning disabilities set up in 2001.
- Advice on involving people with learning disabilities in decision making to be issued.
- People with learning disabilities to benefit from expansion and integration of community equipment services.

Disability Rights Commission

4.3 The Disability Rights Commission will play an important role in helping individuals enforce their rights under the Disability Discrimination Act. A group is being set up to advise the Commission on issues relating to people with learning disabilities. It has drawn up a programme to ensure that the voices of people with disabilities are heard by:

- Involving them in developing the Commission's strategic plan and consultations on major policy issues;
- Producing materials in accessible formats;
- Advising the public sector and business on best practice in involving and communicating with people with learning disabilities.

4.4 The Department of Health will also work with the Commission to consider the way forward for advocacy for all disabled people.

Swindon People First

Established in 1988 since 1995 this self-advocacy group has had about 120 members involved in activities such as consultation with members about the services they use; sitting on advisory panels and being members of a large Joint Working Group; interviewing managers with social services for their jobs; lay assessing and consultation with members who don't use words to communicate. They currently run a Direct Payments Support Scheme as well as a research project into how direct payments are working for people with learning disabilities across the UK. They have been very successful in obtaining funding from trusts and charities for project development and are in a promising position to build for the future.

Advocacy

4.5 Effective advocacy can transform the lives of people with learning disabilities by enabling them to express their wishes and aspirations and make real choices. Advocacy helps people put forward their views and play an active part in planning and designing services which are responsive to their needs. This applies to people with severe and profound disabilities and to the less severely disabled.

4.6 With the right support, many people with learning disabilities can become effective self-advocates. The growth of the self-advocacy movement[9] shows how people with learning disabilities can make a real difference to service development and delivery. Citizen advocates[10] make a vital contribution to enabling the voices of people with more complex disabilities to be heard.

4.7 Both citizen advocacy and self-advocacy are unevenly developed across the country. Barriers to future development include: insecure funding; limited support for local groups; and potential for conflicts of interest with statutory agencies who provide funding. This must change.

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[9] Self-advocacy is people speaking up for themselves

[10] Citizen advocates (ie volunteers) create a relationship with a person with learning disabilities', seeking to understand and represent the person with learning disabilities' views

4.8 The NHS Plan states that by 2002 an NHS-wide Patient and Advocacy Liaison Service (PALS) will be established in every NHS Trust, beginning with every major hospital. This will include all those Trusts offering specialist learning disability services and other health services to people with learning disabilities. PALS will be an accessible and visible service whose role will be to resolve patients', families', and carers' problems and concerns as quickly as possible. PALS will not replace external advocacy services for learning disabled people, but, where necessary, it will be able to provide signposting to independent advocacy services.

4.9 The Government's long-term aim is to have a range of independent advocacy services available in each area so that people with learning disabilities can choose the one which best meets their needs. To achieve this, we will work in partnership with citizen advocacy and self-advocacy groups to promote and sustain development of independent local advocacy schemes. We are investing at least £1.3 million for each of the next three years for this purpose. We will monitor and evaluate the impact of this funding. The new funding will be used to:

- establish a National Citizen Advocacy Network for Learning Disability led by a consortium of leading voluntary organisations. It will be charged with distributing funds to local groups in an equitable and open manner, operating within criteria drawn up after consultation with relevant interests and agreed by the Department of Health. The aim will be to work towards at least one citizen advocacy group in each local authority area. We will take steps to ensure this funding is not used to replace existing funding sources for citizen advocacy;
- increase funding for local self-advocacy groups and strengthen the national infrastructure for self-advocacy. The Department of Health will invite bids from self-advocacy groups in each of its eight regions. The Government will work in partnership with the self-advocacy movement to promote the development of a clear national voice for people with learning disabilities.

4.10 Development of, and support for, advocacy services will also be a priority area for the Learning Disability Development Fund.

4.11 People with learning disabilities from minority ethnic communities can find it particularly difficult to gain access to the advocacy support they need. The Government will ensure that our new initiatives are responsive to their needs. The Department of Health will issue good practice materials to help with this.

'The Government has got to understand how we feel about these things.' (Malcolm)

'The [advocate] explains to me what I don't understand, what social services are talking about. If I didn't understand what the questions were, she'd repeat it and explain it. She was brilliant. Helped me with debts. Had problems with money-still have problems. Calming me down when I get stressed. Any problems I tell her and she tried to help me. If I'm in bad distress I tell [her] and she tells me who to get in touch with. I've never had anyone better.' (Ruby)

Direct Payments

4.12 Direct payments give local councils power to offer people money to pay for the support they have been assessed as needing in lieu of providing the services direct. The Carers and Disabled Children Act 2000 extends direct payments to carers and to disabled 16- and 17-year-olds. The Health and Social Care Bill includes provisions to extend the scope of direct payments. Subject to Parliamentary approval the legislation will:

- require local councils to make direct payments where an individual who requests and consents to one meets the criteria;
- enable local councils to make direct payments to disabled parents to meet their child's needs and for local council provided rehabilitation services.

4.13 Direct payments are highly effective in enabling people with learning disabilities to gain greater control over their lives, because they can choose how they want their support needs met. In autumn 2000 only 216 people with learning disabilities were receiving such payments out of a total of over 3,700 people. This needs to change. The provisions in the Health and Social Care Bill are intended to result in more people with learning disabilities receiving direct payments.

4.14 The success of direct payments for people with learning disabilities depends on good support services. Most local councils operate support schemes, but often these are focused on the types of support people with physical disabilities may need. Schemes must be accessible to people with learning disabilities, so that they too have the right support to manage a direct payment and remain in control. Our proposals for developing and expanding advocacy services will enable more people to access direct payments. Subject to the Health and Social Care Bill completing its passage through Parliament, the Department of Health will issue guidance on the new provisions and how people with learning disabilities can be helped to use direct payments. This will include provision of support services.

4.15 Promoting direct payments is a key element of our new vision for people with learning disabilities. The national Implementation Support Team will focus on working with local councils to achieve higher take-up. The Department of Health will consult on a performance indicator in the Personal Social Services Performance Assessment Framework.

Hampshire Social Services operates a flexible system to make direct payments available to people with learning disabilities. This minimises potential blocks. People have the option to purchase care from agencies rather than employing personal assistants. Existing networks support the person receiving the direct payment or, where these do not exist, arrangements are made to provide the individual support required.

Two examples

One young man, living with his parents, receives a direct payment to employ a support worker from an agency for short breaks. Breaks can be a few hours in the evening and weekends or longer. He chooses how to spend his time with the support worker and his mother has a break.

One man living with his mother wanted to move on from the day service and have more control over what he did and when. He now purchases the services of a support worker from a local agency to help him go to local leisure facilities in the evening. The local self-advocacy group, which has set up a support system for people receiving direct payments provides the support.

People with Preserved Rights

4.16 People in residential care on 31 March 1993 have preserved rights to receive a higher rate of income support from which they can purchase their care. Around 30,000 are younger disabled people. Following the announcement in the NHS Plan, the Health and Social Care Bill contains provisions to transfer responsibility for their assessment and care management to local authorities. This will give this group more choice about where they live and close the shortfall in funding. The Department of Social Security will transfer resources to local authorities for their new responsibilities. Subject to Parliamentary approval these changes will come into effect in April 2002. Guidance on this change will say that councils will be required to offer the option of direct payments to anyone who meets the prescribed conditions.

A Person-Centred Approach to Planning

4.17 A person-centred approach to planning means that planning should start with the individual (not with services), and take account of their wishes and aspirations. Person-centred planning is a mechanism for reflecting the needs and preferences of a person with a learning disability and covers such issues as housing, education, employment and leisure.

4.18 Care management is the main way individuals link with services. The type and extent of care management can vary markedly between council areas. This can result in duplicated assessments and care plans for some people with learning disabilities, while others receive insufficient attention. Some people receiving publicly funded services have problems accessing the care management they need. This confusing and inconsistent situation is unacceptable.

PRIORITIES FOR PERSON-CENTRED PLANNING

4.19 The Government will issue further guidance later this year to help local councils develop a person-centred approach and put people with learning disabilities and their families at the centre of the process of planning services for and with them. We expect Learning Disability Partnership Boards to use this guidance to agree a local framework by April 2002. It will take time to develop a person-centred approach to planning for everyone who needs services. Local areas may wish to develop their own priorities, paying particular

Alan is in his 50s and now lives in his own terraced house. He wasn't happy living in a hostel nor in his own flat with support from a key worker. He met someone who was getting a direct payment and decided '– *yes that's for me! I like the idea of employing my own personal assistants who I could ask to do what I wanted when I wanted.*' His social worker put him in touch with the local independent direct payments support agency. They helped him apply for a direct payment, advertise for personal assistants and prepare job descriptions and contracts. They arranged training about direct payments and employment. Alan said '*Without the training I wouldn't have been able to cope with a direct payment.*' Now he gives talks to social workers and people with learning disabilities about how to get a direct payment.

attention to those individuals who are poorly served. However the Government also has some specific priorities. These include:

By 2003:

- People still living in long-stay hospitals;
- Young people moving from children's to adult services.

By 2004 we expect to see significant progress in the following areas:

- People using large day centres;
- People living in the family home with carers aged over 70;
- People living on NHS residential campuses.

Susan, who is in her early 20s, is severely disabled. She makes her views known through her actions, verbal responses, facial expressions and moods. Susan's circle of support realised she was unhappy with her existing services and put together a package of money to enable her to live independently. Direct payments are part of the package. The circle formed itself into a user-controlled trust fund, which manages the direct payment. Susan's expressions and views guide how the money is spent, so she is in control of the use of the money. Direct payments mean Susan can live in her own house with her own rota of support workers. She is relaxed, confident and content with a full social life and is very much part of the community.

CARE MANAGEMENT

4.20 Care management will continue to be the formal mechanism for linking individuals with public services. Its systems must be responsive to person-centred planning, and have the capacity to deliver the kinds of individualised services likely to emerge from the process. It must link effectively with other plans including:

- vocational plans (led by Connexions for young people);
- health action plans (led by an identified health professional);
- housing plans, (including a joint housing/community care assessment);
- communications plans, (where the person has communications difficulties).

4.21 Development of a person-centred approach requires real changes in organisational culture and practice. Achieving these changes should be a priority for Partnership Boards.

4.22 Given the importance of person-centred planning as a tool for achieving change, we will make supporting its implementation one of the priorities for the Learning Disability Development Fund and the Implementation Support Team. Its development and the responses of the services will be monitored, along with the extent to which person-centred services emerge as a consequence.

FAIR ACCESS TO CARE

4.23 Later in 2001 the Government will be issuing the Fair Access to Care (FACS) guidance. This will set out how eligibility for adult social care services should be determined, and following implementation from April 2002, should lead to a more consistent and fairer access to care services. The guidance will also cover procedures for reviewing adult service users' needs and continuing eligibility for support. At the same time, the Government will publish general principles of assessment to update previous 1990/1991 guidance.

4.24 In implementing this guidance councils will need to take a corporate approach, with eligibility criteria agreed across all council departments and with health and other local agencies. Councils and local health bodies will be specifically asked to develop joint eligibility criteria for adult social care and continuing health care. Partnership Boards will need to ensure that all systems are compatible with this guidance.

4.25 Person-centred frameworks will need to be fully compatible with the locally agreed joint eligibility criteria which councils and local health bodies will be asked to develop following the Fair Access to Care guidance.

INDIVIDUAL CO-ORDINATION

4.26 By July 2002 all people with learning disabilities who make substantial and long-term use of publicly funded services should have a named individual to act as their service co-ordinator. The co-ordinator will be responsible for ensuring effective organisation and monitoring of services by all relevant agencies and will be the first point of contact for people with learning disabilities and their families.

Involvement In Policy Development and Decision Making

4.27 People with learning disabilities should be fully involved in the decision making processes that affect their lives. This applies to decisions on day to day matters such as choice of activities, operational matters such as staff selection and strategic matters such as changes to eligibility criteria. It is no longer acceptable for organisations to view people with learning disabilities as passive recipients of services; they must instead be seen as active partners. Further advice will be issued in 2001 to help local agencies involve people with learning disabilities in decision making.

4.28 At national level, we have begun to involve people with learning disabilities in policy development. The Service Users Advisory Group played an important role in developing the new strategy. During 2001 the Group will develop into a more nationally representative forum linking with local groups of learning disabled people. The National Forum for People with Learning Disabilities will contribute to monitoring the impact of *Valuing People*.

4.29 *Making Decisions* (published October 1999) set out the Government's proposals to reform the law in order to improve and clarify the decision making process for those people unable to make decisions for themselves. The proposals include: definition of capacity; factors to be taken into account in assessing a person's best interest and the introduction of general authority to act reasonably which will regulate day-to-day decisions. *Making Decisions* also sets out proposals to introduce Continuing Powers of Attorney to replace Enduring Powers of Attorney, and a modernised court which will deal with all areas of decision making for adults without capacity.

> "People First has learnt a lot by being part of this Strategy Group and we hope that we can work together more in the future. **I am proud of being included in this group**.
>
> It means a lot to me to work together with such a good team of people who are all committed to supporting people with learning difficulties in their hard struggle to live independent lives. (Carol)

Communication and Equipment

4.30 The Government expects organisations working with learning disabled people to develop communication policies and produce and disseminate information in accessible formats. For those with severe disabilities this may require individual communication techniques and effective use of new technology.

4.31 People with learning disabilities may need specialist equipment because they also have a physical disability or sensory impairment. Assistive technology can increase their control, choice and independence through improving cognitive and social functioning. It can also enable people with learning disabilities to make good use of education, training and employment opportunities. From April 2001 councils with social services responsibilities and the NHS will receive additional funding to improve and expand community equipment services. By 2004 the Government expects health and social services to integrate their community equipment services, and increase by 50% the number of people benefiting from them.

CHAPTER 5

SUPPORTING CARERS

Government Objective: To increase the help and support carers receive from all local agencies in order to fulfil their family and caring roles effectively.

This Chapter focuses on the rights of carers. Carers need to be confident that public services will provide reliable support for their family members with learning disabilities, and that our proposals for improving services will bring them benefits. The support and commitment of carers is critical in enabling people with learning disabilities to achieve independence, choice and inclusion.

Problems and Challenges

5.1 Caring for a family member with a learning disability is a lifelong commitment, which continues even when the person is living away from the family home. Carers make a vital contribution to the lives of people with learning disabilities, often providing most of the support they need. They are a crucial resource for ensuring that people with learning disabilities can live in the community. We have no precise data on numbers, but it is estimated that some 60% of adults with learning disabilities live with their families. Statutory agencies do not always properly recognise the extent of carers' contribution or its value.

5.2 Carers face many problems and challenges. They need:

- More and better information;
- Better assessment of their own needs;
- Improved access to support services such as day services and short break services (respite care) particularly for those with more severe disabilities;
- To be treated as valued partners by local agencies, not as barriers to their son's or daughter's greater independence.

5.3 The challenge is to ensure that carers:

- receive the right support to help them in their caring role;
- obtain relevant information about services;
- know who to approach for advice and help;
- are respected and treated as individuals in their own right;
- make their voices heard at national and local level.

What More Needs To Be Done

KEY ACTIONS – CARERS

- Carers of people with learning disabilities to benefit from all mainstream carers initiatives.
- Implementation of Carers and Disabled Children Act 2000.
- In partnership with Mencap the Government will provide £250,000 per annum for the next three years to develop a National Learning Disability Information Centre and Help Line.
- New guidance on exclusions from services.
- Local councils to pay particular attention to identifying and supporting carers aged over 70 and carers from minority ethnic communities.
- Carers and carer organisations to be represented on Learning Disability Task Force.

National Carers Strategy

5.4 The Government is determined to improve support for carers. *Caring about Carers: the Report of the National Carers Strategy* sets out our general approach. Social security benefits are being increased to help carers. From April 2001 a package of extra support worth £500 million over the next three years will help some 300,000 carers. We are increasing the carer premium in income related benefits by 70% (from £14.15 to £24.40). We are also raising the earnings limit (now £50 per week) in the Invalid Care Allowance (ICA) to the level of Lower Earnings Limit (currently £67 per week). Subject to a suitable legislative opportunity we will extend the opportunity to claim ICA to people aged 65 and over and the entitlement to ICA for up to 8 weeks after the death of the disabled person will also help carers.

5.5 The Government expects carers of people with learning disabilities to benefit from all mainstream carer initiatives. This requires effective targeting at local and national levels. Carers must be able to obtain information, advice and help easily from local agencies, especially local councils with social services responsibilities and must be given a single point of contact.

Implementation of the Carers and Disabled Children Act 2000

5.6 The Carers and Disabled Children Act 2000 comes into force in April 2001. It extends a carer's right to an assessment, already provided for in the Carers and Recognition and Services Act 1995, to carers where the person cared for has refused an assessment or has refused community care services, and gives local councils the power to offer carers services to support them in their caring role and to help them maintain their own health and well being. The Department of Health is issuing guidance to local councils on implementing the legislation together with a leaflet *The Carers Guide to a Carer's Assessment* to be made available to all carers. The Government is committed to ensuring that these new rights become a reality. We shall consult on a new Performance Indicator to monitor how many people with learning disabilities are receiving breaks services (respite care).

Excluding People from Services

5.7 Excluding people with learning disabilities from services if they are found to be difficult to handle or present with challenging behaviour represents a major cause of stress for carers, who may be left unsupported to cope with their son or daughter at home. This practice is unacceptable and families must not be left to cope unaided. No service should be withdrawn on these grounds without identifying alternative options and putting a suitable alternative service in place where possible. Decisions to exclude a person with learning disabilities from a service should always be referred to the Learning Disability Partnership Board, which will be responsible for the provision of alternative services in such cases, provided the person meets the eligibility criteria. This issue will be addressed in the guidance to be issued on implementing *Valuing People*.

Tameside: Flexible Respite Services

Three years ago the council identified money within the learning disability budget to develop an alternative option to the building based respite service. A flexible service has now been developed to support people in their own homes or in accessing community services and provide a break for carers. People access it for between 1 or 2 hours and 10 hours a week, which has opened up many opportunities for people to go to community facilities with individual support. Last year the council used money from the Carers Grant and the Promoting Independence Grant to expand the service. It now provides 340–350 hours a month to around 36 people. The independent sector provides the service: about 90% is delivered by the same provider who runs the building based respite care service.

Information for Carers

5.8 Carers need more and better information provided in ways that are easily accessible. The most effective information exchange is often between carers, who share experiences and solutions. These networks also need reliable information from others. Many organisations provide telephone and written advice, but there is currently no national Information Centre or Help Line for people needing help on learning disability issues.

5.9 In order to fill this gap, the Department of Health is providing £750,000 over the next 3 years to enable Mencap to work with other key interests to establish a National Learning Disability Information Centre and telephone help and advice line. The Centre will provide help to all who need it, including people with learning disabilities and professionals, but we expect it to have a particularly important role for carers. Services to be provided will include:

- Advice on all aspects of learning disability and the services and help people with learning disabilities need;
- Links and collaboration with the Contact a Family Information Centre for Children (see paragraph 3.12);
- Links with other databases and websites, including the National Electronic Library for Health, the Social Care Institute of Excellence, and NHS Direct on line;
- Putting people in touch with local support groups.

The Carers Grant: Meeting the Needs of Older Carers and Carers from Minority Ethnic Communities

5.10 *Family Matters, Counting Families In* published alongside *Valuing People* identifies three groups of carers who face additional pressures: older carers (those aged 70 or over), carers from minority ethnic communities and carers whose sons or daughters are going through transition from school to adult life. Chapter 3 looks at transition, and we discuss below the other two priority groups. Both face additional difficulties in carrying out their caring role effectively.

5.11 It is estimated that a third of people with learning disabilities living in the family home are living with a carer aged 70 or over. Many are sole carers with reduced support. In many cases the learning disabled person also takes on a caring role, but this is not generally recognised and they are often not properly supported. There is some evidence to suggest that up to 25% of people with learning disabilities do not become known to statutory agencies until later in life, when the parent becomes too frail to continue caring for their adult son or daughter. Lack of planning for the future creates anxiety and stress for the parent and the learning disabled person. This group is one of the priority groups for developing a person-centred approach to planning (see paragraph 4.19). We propose to introduce a Performance Indicator: % of carers aged 70 or over for whom a plan has been agreed. This will be monitored as part of the arrangements for monitoring the White Paper.

5.12 Difficulties facing carers from minority ethnic communities include insensitivity to issues of culture and language and false assumptions about communities wishing to provide care within their own family environment or putting up barriers against statutory agencies. All services for carers should be responsive to the needs of people from minority ethnic communities.

5.13 The Carers Grant provides funds to help ensure that substantial and regular carers, who will include lifelong carers, get a break from caring when they need it. Analysis of the Grant's first year of operation (1999/2000) shows that at least 10% of the total grant of £20 million was spent on breaks for carers of adults with learning disabilities. Over the next 3 years the amount available for all carers will be £70 million/£85 million/£100 million.

5.14 The Department of Health will shortly issue new guidance for the Carers Grant 2001/02 which will encourage local councils to identify older carers and carers from minority ethnic communities.

5.15 The Department of Health will monitor the impact of its new guidelines as part of the process of monitoring the Grant. People living with carers aged 70 or over will also be an early priority for the introduction of person-centred planning.

Carers as Partners

5.16 It is essential that the voices of carers are clearly heard in policy development and implementation at both national and local levels. Carers should be treated as full partners by all agencies involved. The Government will ensure that carers are represented on the Learning Disability Task Force. We will also ensure that this group of carers contributes to the Department of Health's existing arrangements for discussing policy and practice issues with the generic national carers' organisations. We expect this to be mirrored at local level so that carers participate in debates about local policy development.

5.17 Carers have training needs and can also be a training resource. Local councils should offer them training opportunities so that they develop their skills. Professional staff can learn a great deal from their experience and expertise. The Government will require local agencies to ensure that carers and their organisations are fully involved in the development of local action plans for implementing the White Paper.

CHAPTER 6

IMPROVING HEALTH FOR PEOPLE WITH LEARNING DISABILITIES

Government Objective: To enable people with learning disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary.

This chapter shows how the Government's commitment in the NHS Plan to a person-centred health service which challenges discrimination on all grounds will improve health care for people with learning disabilities. Good health is an essential prerequisite for achieving independence, choice and inclusion.

Problems and challenges

6.1 Most people with learning disabilities have greater health needs than the rest of the population. They are more likely to experience mental illness and are more prone to chronic health problems, epilepsy, and physical and sensory disabilities. An increasing number of young people with severe and profound disabilities have complex health needs. Poor oral health may lead to chronic dental disease. As life expectancy increases age-related diseases such as stroke, heart disease, chronic respiratory disease and cancer are likely to be of particular concern. There is an above average death rate among younger people with learning disabilities.

6.2 Surveys have highlighted shortfalls in primary care and hospital provision. *Facing the Facts*, for example, found inconsistencies in the provision of health care in different parts of the country. When people with learning disabilities approached health care providers for assessment or treatment they often found difficulties in gaining access to the help they needed. The health needs of people with learning disabilities may not be recognised by doctors and care staff who have no experience of working with people who have difficulties in communication. Health outcomes for people with learning disabilities fall short when compared with outcomes for the non-disabled population. We know that:

- Few people with learning disabilities access health screening services with uptake rates for breast and cervical screening being especially poor.
- Research has highlighted inadequate diagnosis and treatment of specific medical conditions, including heart disease, hypothyroidism and osteoporosis.
- Studies of the management of people with challenging behaviour has shown an over-dependence on the use of psychotropic drugs with poor outcomes as a consequence.
- Doctors and care staff can fail to recognise the potential health complications of many of the conditions that cause learning disability.

6.3 Because mainstream health services have been slow in developing the capacity and skills to meet the needs of people with learning disabilities, some NHS specialist learning disability services have sought to provide all encompassing services on their own. As a result the wider NHS has failed to consider the needs of people with learning disabilities. This is the most important issue which the NHS needs to address for people with learning disabilities.

What More Needs To Be Done

KEY ACTIONS – HEALTH

- Action to reduce health inequalities: explore feasibility of establishing a confidential inquiry into mortality among people with learning disabilities.
- Action to challenge discrimination against people with learning disabilities from minority ethnic communities.
- Health facilitators identified for people with learning disabilities by Spring 2003.
- All people with a learning disability to be registered with a GP by June 2004.
- All people with a learning disability to have a Health Action Plan by June 2005.
- NHS to ensure that all mainstream hospital services are accessible to people with learning disabilities.
- Development of local specialist services for people with severe challenging behaviour to be a priority for the capital element of the Learning Disability Development Fund.
- Mental Health NSF will bring new benefits to people with learning disabilities.
- New role for specialist learning disability services, making most effective use of their expertise.

Reducing Health Inequalities

6.4 The NHS Plan made clear that inequalities in health cannot be tackled without dealing with the fundamental causes – including poverty, low educational attainment, unemployment, discrimination and social exclusion. These factors affect many people with learning disabilities, and their high morbidity and mortality rates show the importance of addressing their needs. The Government has launched a comprehensive plan to tackle health inequalities and work is taking place across Government to tackle the root causes.

6.5 The Government has announced that local health inequalities targets will be reinforced by the creation of national health inequalities targets, to be delivered by a combination of specific health policies and broader Government policies. Health policies such as improved access to services, smoking cessation, healthy diet and exercise will be particularly important for narrowing the gap between the health of learning disabled people and the population as a whole. In addition, health authorities should take account of the needs of learning disabled people in planning services and making them accessible to all.

6.6 Those who live and work with people with learning disabilities are well placed to encourage healthier life styles. Providers of support in social care settings have a responsibility for ensuring that an individual's general health needs are met, by developing links with health professionals, promoting family and staff competence in basic health issues and implementing health promotion initiatives.

6.7 The Government will ensure that policies on health inequality make explicit reference to people with learning disabilities. Health Action Zones, for example, should ensure that the needs of people with learning disabilities are being addressed within their areas when undertaking work to meet the needs of vulnerable people. Successful innovative learning disability work being led by HAZs should be identified and highlighted so that this can be mainstreamed and replicated elsewhere. Health Improvement Plans (HimPs) will provide a means of addressing the health needs of people with learning disabilities so that they do not experience avoidable illness and premature death.

6.8 Evidence of avoidable illness and premature death amongst people with learning disabilities is a major cause of concern for the Government. We will explore the feasibility of establishing a confidential inquiry into mortality among people with learning disabilities. This will help us take steps to reduce the number of avoidable deaths.

6.9 The Government will explore the possibility of developing performance indicators to compare the health status of the learning disabilities population with that of the general population. We shall consult on performance indicators later this year.

People with learning disabilities from minority ethnic communities

6.10 People with learning disabilities from minority ethnic communities are at particular risk of discrimination in gaining access to appropriate health care. Problems arise if professionals are not aware of cultural or language issues or only use English language based assessment tools. The NHS Plan recognises that ethnic minorities can face discrimination in gaining access to health services and confirms the Government's commitment to tackling the problem. Achieving this will be helped by the new statutory duty to promote race equality, in the Race Relations (Amendment) Act 2000. From 2 April 2001 listed public bodies, including central and local Government, the NHS and NHS Trusts, for example, will be obliged to work towards the elimination of unlawful racial discrimination and to promote good relations between persons of different racial groups. Staff who understand the values and concerns of minority ethnic communities and who can communicate effectively with them have an important role to play in ensuring that minority ethnic communities can access the health care they need.

Meeting Health Needs

6.11 For most people, GPs, practice nurses and other members of primary care teams provide the main contact with the NHS. In future, we expect this to be the same for people with learning disabilities. Building on the guidance on good practice in primary care given in *Once A Day*, the primary care team will play a key role in providing health care for people with learning disabilities and in ensuring that people with learning disabilities can access the full range of health services to meet both their ordinary health needs and their additional health requirements through referral to specialist services. Primary care teams also have a key role in supporting and improving the health of carers.

Primary health care in Liverpool

'Speaking up' in public to doctors and nurses at a Primary Care Group Board was a new experience for self-advocates from the Toxteth and Granby Resource Centre, Liverpool. Some of the things they said were:

'We would like the same checks as everyone else'

'We want – you to explain and listen to us and not just talk to our carers; leaflets about health with pictures and get to know us as people and ask our point of view.

The result was an agreement to review primary care provision across the area.'

Health Facilitators

6.12 As the first point of contact, primary care is the place where many important decisions are made. But for many people with learning disabilities their encounter with the primary care team may be frustrating and difficult. In order to overcome these barriers staff from the local community learning disability team in each area will need to take on the role of health facilitators to support people with learning disabilities to access the health care they need from primary care and other NHS services. This role might be taken up by any community learning disability team member, but learning disability nurses will be well placed to fulfil this role.

6.13 Health facilitators will help general practitioners and others in the primary care team to identify their patients with learning disabilities, in collaboration with colleagues from social services, education and health. Their task will be to facilitate, to advocate and to ensure that people with learning disabilities gain full access to the health care they need, whether from primary or secondary NHS services. The role of the health facilitators should embrace mental as well as physical needs. The health facilitator role will be vital in helping people with learning disabilities navigate their way around the health service.

6.14 All people with learning disabilities should be registered with a general practitioner. We expect that all general practices, with support from the health facilitator and in partnership with specialist learning disability services, will have identified all people with a learning disability registered with the practice by June 2004. Progress in achieving this objective will be monitored by the Department of Health.

Health Action Plans

6.15 The Government expects each individual with a learning disability to be offered a personal Health Action Plan (HAP). Responsibility for ensuring completion of the HAP will rest with the health facilitator in partnership with primary care nurses and general practitioners. The HAP will form part of the person-centred plan. The HAP is an action plan and will include details of the need for health interventions, oral health and dental care, fitness and mobility, continence, vision, hearing, nutrition and emotional needs as well as details of medication taken, side effects, and records of any screening tests.

6.16 Health Action Plans will be offered and reviewed at the following stages of peoples' lives:

- Transition from secondary education with a process for ongoing referral;
- Leaving home to move into a residential service;
- Moving home from one provider to another;
- Moving to an out of area placement;
- Changes in health status, for example as a result of a period of out-patient care or in-patient treatment;
- On retirement;
- When planning transition for those living with older family carers.

Anna has Down's syndrome. She uses a wheelchair and cannot communicate verbally. Her support team had difficulty in involving her in planning as she was lethargic, passive and difficult to motivate. A health care check revealed that she had undiagnosed thyroid problems, diabetes and hypertension. After treatment Anna became more involved, used her wheelchair less, and volunteered to help in a children's day centre.

6.17 The Government expects all Learning Disability Partnership Boards to have agreed a framework for the introduction of Health Action Plans and to have ensured that there are clearly identified health facilitators for all people with learning disability by June 2003. All people with learning disabilities should have a HAP by June 2005.

6.18 Primary Care Trusts in their commissioning role should ensure that general health care for people with learning disabilities is built into existing priorities. Partnership Boards need to work with the Primary Care Trusts to ensure that there is an integrated plan for supporting the primary and general health care services to work with people with learning disabilities, with clarity about expectations upon both general practice and general hospitals.

Secondary health care

6.19 Mainstream secondary health services must also be accessible for people with learning disabilities. There must be no discrimination. Support will be needed to help people with learning disabilities admitted to a general hospital for medical or surgical treatment to help them to understand and co-operate in their treatment. The NHS will ensure that all its procedures comply with the Disability Discrimination Act and that its staff recruitment and training practices are also fully compliant. Whenever possible NHS resources should be used to provide the appropriate health care support to enable people to live in their own home.

6.20 Health facilitators will have primary responsibility for facilitating access to secondary health care. But by 2002 a Patient Advocacy and Liaison Service (PALS) will be established in every NHS Trust. Individuals will then have an identifiable person they can turn to if they have a problem or need information while they are using hospital and other NHS services. Within the 130 or more NHS Trusts providing specialist health care for people with learning disabilities, PALS will have an especially important role for ensuring that people with learning disabilities can access the full range of NHS provision. PALS will complement the work of the health facilitator.

Consent to Treatment

6.21 The Government is committed to having good consent to treatment practice in place in all health settings. This is of particular importance in general hospitals where staff may be unfamiliar with seeking consent from people who have learning disabilities. The

Government has introduced changes to ensure that clearer guidance on consent issues is available and accessible.

National Service Frameworks (NSFs) and the National Cancer Plan

6.22 National Service Frameworks have already been published for mental health and coronary heart disease. NSF's for older people and for diabetes and for long term health conditions (including epilepsy) will follow. The National Cancer Plan which is now being implemented makes specific reference to the needs of people with learning disabilities. They will all apply equally to people with learning disabilities as to other patients and people with learning disabilities should benefit from all these initiatives.

THE NSF FOR MENTAL HEALTH – PEOPLE WITH LEARNING DISABILITIES

6.23 Most psychiatric disorders are more common amongst people with learning disabilities than in the general population. As for their other health needs, people with learning disabilities should be enabled to access general psychiatric services whenever possible. This will require mainstream mental health services to become more responsive, and specialist learning disability services to provide facilitation and support.

6.24 The NSF for Mental Health applies to all adults of working age. A person with a learning disability who has a mental illness should therefore expect to be able to access services and be treated in the same way as anyone else. The NSF for Mental Health seeks to integrate CPA (the Care Programme Approach) and care management. This should lead to a seamless service for people with learning disabilities who have mental health needs.

6.25 The Government will take steps to ensure that:

- Mental health promotion materials and information about services are provided in an accessible format for people with learning disabilities, including those from minority ethnic communities.
- Strategies for improving access to education, housing and employment which enhance and promote mental wellbeing will include people with learning disabilities and mental health problems.

- Clear local protocols are in place for collaboration between specialist learning disability services and specialist mental health services.
- For people with learning disabilities and mental health problems the Health Action Plan will equate with the Care Plan. Care co-ordinators should have expertise in both mental health and learning disabilities. There will be close collaboration between psychiatrists in the relevant specialities.
- Specialist staff from the learning disability service will if necessary provide support to crisis resolution/home treatment services or other alternatives to in-patient admission whenever possible.
- Each local service has access to an acute assessment and treatment resource for the small number of individuals with significant learning disabilities and mental health problems who cannot appropriately be admitted to general psychiatric services, even with specialist support.
- If admission to an assessment and treatment resource is unavoidable, specialist staff will help the patient understand and co-operate with treatment.

Tertiary Specialist Services

6.26 Referral to a tertiary specialist health service should be a rare event. However, there may be a small number of people who have complex health needs that cannot be met locally. For example, people who present very severe behavioural challenges may have needs for support and treatment which cannot be met within the skills and resources available locally. In the first instance the NHS provider should always work in partnership with the local authority to provide intensive support to sustain local provision. If individualised packages of housing and support are commissioned, they should be sited as close to a person's home area as possible. To facilitate this, we have made development of specialist services for people with severe challenging behaviour a priority for the use of the capital element of the Learning Disability Development Fund based on advice in the Mansell Committee Report.

Specialist Learning Disability Services

6.27 It is essential that sufficient good quality multi-disciplinary specialist services are available to meet the needs of people with learning disabilities. Locally based specialist community learning disability services are key components of the modern NHS. Over 130 NHS Trusts in England provide specialist services for people with learning disabilities. Through these NHS Trusts people with learning disabilities have access to a range of learning disability specialists including learning disability nurses, occupational therapists, physiotherapists, psychiatrists, speech and language therapists and clinical psychologists, working in a multi-disciplinary way in close collaboration with social workers and care managers. Other NHS professionals such as dieticians, psychotherapists and creative therapists, chiropodists, opticians, audiologists and pharmacists also have specialist roles.

6.28 The Government believes that professional staff employed in locally based specialist services provide vital support for people with learning disabilities. But their role must change. Staff may continue to work within specialist clinical directorates, but their tasks will need to be refocused to give greater emphasis to their role in providing high quality specialist expertise. They will also take on a key supplementary role in supporting people to access mainstream services.

6.29 Specialist services should be planned and delivered with a focus on the whole person, ensuring continuity of provision and appropriate partnership between different agencies and professions. To support these aims, services will need to demonstrate that they are listening carefully to the views and experiences of people with learning disabilities and their families, which should also play a critical part in the education and training of paid staff.

6.30 In their specialist role staff should recognise the importance of enhancing the competence of local services to enable service users to remain in their usual surroundings and save the often high costs (both personal and financial) of specialist placements out of area. Specialist staff will need to give more time to facilitating the work of others in mainstream services to developing the capacity of services to support those with complex needs to service design and less to direct interventions. Partnership Boards will review the role of specialist learning disability services to bring them into line with the new vision outlined here.

6.31 In addition to their clinical and therapeutic roles specialist staff should take on the following complementary tasks:

- a health promotion role; working closely with the local health promotion team;
- a health facilitation role; working with primary care teams, community health professionals and staff involved in delivering secondary health care;
- a teaching role; to enable a wide range of staff, including those who work in social services and the independent sector, to become more familiar with how to support people with learning disabilities to have their health needs met;
- A service development role; contributing their knowledge of health issues to planning processes.

Intensive Health Care Support

6.32 A proportion of people with learning disabilities will require intensive health care support through specialist community services, including learning disability teams and/or challenging behaviour teams, over a prolonged period of time – because of their complex disability or the challenges they place on services. Such people have the same entitlements to independence, choice, inclusion and civil rights as all others. The aim should be to provide them with ordinary housing and support services, in the least restrictive environment possible, with opportunities to lead full and purposeful lives.

6.33 Many people with such complex needs are currently living in community services as NHS in-patients. This is only appropriate where people require continuous medical supervision. A need for nursing supervision is not a sufficient reason for NHS in-patient care. Localities with large numbers of people living in such NHS accommodation should use person-centred planning and pooled budgets to design more appropriate locally based housing and support and so reduce the number of long term NHS in-patient beds to more appropriate levels. Forthcoming guidance on continuing care from the Department of Health will support this approach.

CHAPTER 7

HOUSING, FULFILLING LIVES AND EMPLOYMENT

This chapter sets out the Government's programme for reform in three areas which are of central importance in the lives of all people with learning disabilities: housing, living a fulfilling life, and employment. Bringing about change in all these areas will be essential in order to achieve greater independence, choice and inclusion for people with learning disabilities.

HOUSING

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

Problems and Challenges

7.1 Most people with learning disabilities live with their families. Often they leave the family home only as the result of a crisis such as the illness or death of the carer. Planning ahead to move to more independent living is not always possible as the appropriate housing, care and support options may not be available. With growing numbers of people living with older carers, the Government wishes to see better forward planning by local councils so that carers do not face continuing uncertainty in old age and their sons and daughters gain greater independence in a planned way.

7.2 People with learning disabilities can live successfully in different types of housing, from individual self-contained properties, housing networks, group homes, and shared accommodation schemes, through to village and other forms of intentional community. They can cope with the full range of tenures, including home ownership.

David inherited the tenancy of a housing association bungalow following his mother's death. He has a support package from a care provider and had some intensive support from the Community Team for Learning Disabilities to improve his cooking and domestic skills. His brother and sister-in-law live nearby and provide emotional and practical support. He is now coping well.

Expanding the range and choice of housing, care and support services is key to giving individuals more choice and control over their lives.

7.3 Few areas offer a full range of options. Obstacles include:

- A culture of professionals deciding what is good for individuals, and the traditional "take what you are given" attitude in public provision of housing;
- A conservatism in developing housing options for people with learning disabilities, with authorities replicating current provision rather than taking opportunities to broaden the range of housing available.

7.4 We now know more about outcomes associated with living in different types of accommodation. Research commissioned by the Department of Health examined the differences in cost and benefits between dispersed housing, NHS residential campuses, and village communities.[11] It found dispersed housing and village communities had strengths and weaknesses: dispersed housing was associated with greater personal choice, greater participation in community activities, wider personal relationships, and better qualified and more senior staff; village communities were associated with better activity planning, more routine day activities, better access to health checks, and less likelihood of exposure to crime or verbal abuse. There were many areas where no significant difference was found, including cost. Living in NHS residential campuses produced significantly poorer outcomes.

7.5 Various studies showed that housing design on its own does not guarantee positive outcomes. Factors such as management style and staff training are at least as important. In view of this, the Government wishes to encourage development of a range of housing options and, thus, provide real choice to people with learning disabilities and their families. No housing solution should be routinely disregarded as a matter of deliberate policy. The role of public services is to facilitate choice, not frustrate it.

7.6 Widening the housing, care and support options available creates the potential for choice, but individuals also need accessible information in order to make choices. Many people with learning disabilities will need advice and support to do this.

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[11] The Quality and Costs of Residential Support for People with Learning Disabilities, Summary & Implications (Hester Adrian Research Centre, University of Manchester, 1999

What More Needs To Be Done

KEY ACTIONS – HOUSING

- Housing and social services to work together to expand housing, care and support options: Department of Health and Department of the Environment, Transport and the Regions to issue new joint guidance in 2001.
- Legislation to introduce new duty on local housing authorities to provide advice and information.
- Learning Disability Partnership Boards to develop local housing strategies for people with learning disabilities.
- Learning Disability Development Fund will prioritise "supported living" approaches for people living with older carers.
- Enabling people living in the remaining long-stay hospitals to move to more appropriate accommodation by 2004 will be a priority for the Learning Disability Development Fund.

Expanding Choice in Housing, Care and Support Services

7.7 The Housing Green Paper (April 2000) set out the Government's agenda for improving the quality and choice of housing available to all. Its proposals, such as more open housing access and choice based lettings procedures, apply as much to people with learning disabilities as to other people. We are also removing other obstacles and barriers to expanding housing, care and support options by putting in place new policies and tools to create the environment and the imperative for local action.

7.8 Local housing authorities have a key role to play through their work to develop and implement local housing strategies and by providing housing advice and improving access to housing. However, they can only succeed in expanding the housing choices available to people with learning disabilities by working in partnership with social services, health and other local agencies.

Options and Choices – Barnet

Housing and social services work together and benefit from this joint working. Social services keep an up to date list of priority cases for housing and accommodation needs. An annual quota for nominations for housing association or council lettings was jointly managed with the housing department agreeing eligibility for housing. By 1999 this had changed the range of services from one which was predominantly registered residential care to one where more than a hundred people had their own tenancy and were receiving housing benefit.

7.9 In order to strengthen such partnerships, the Department of Health and the Department of the Environment, Transport and the Regions will shortly issue a joint circular and detailed guidance on commissioning the range of housing, care and support services required to expand housing choice. This will include consideration of ways to develop new joint performance indicators for social services and housing authorities.

7.10 In England there are over 4 million existing homes in the social rented sector alone. These, together with private sector housing, are potential resources that can be drawn on to open up housing, care and support options for people with learning disabilities. The Government is also making available over £10 billion of housing capital resources over the next three years to be drawn upon to finance remodelling of existing housing or new development.

7.11 The Government expects local councils to give people with learning disabilities a genuine opportunity to choose between housing, care and support options that include:

- **Supported living:** this approach is concerned with designing services round the particular needs and wishes of individuals and is less likely to result in housing and support that is designed around congregate living. Department of Health research has shown that supported living is associated with people having greater overall choice and a wider range of community activities.
- **Small scale ordinary housing:** Department of Health research has shown that small scale ordinary housing is likely to lead to better outcomes across a range of factors than is large housing or hostel provision.
- **Village and intentional communities:** These comprise houses and some shared facilities on one or more sites. Department of Health research shows such communities were associated with better activity planning, more routine day activities and better access to health checks. A study commissioned as part of the White Paper's development found 3,000 people living in 73 village and intentional communities. This study and *Facing the Facts* also indicated that some local authorities are reluctant to support people with learning disabilities who wish to live, or whose families make arrangements for them to live, in a village or intentional community.

7.12 The Government will issue statutory guidance to local councils to ensure they do not rule out any of these options when considering the future housing, care and support needs of people with learning disabilities and their families.

Supporting People

7.13 *Supporting People* is a new policy and funding framework for support services that will be implemented in April 2003. It will bring together resources from several existing programmes into a new grant to local authorities, which can be applied more flexibly to fund support services for people with learning disabilities and for other vulnerable people wherever they live. Local social services and housing authorities, working with other partners including the NHS, will be expected to establish joint arrangements for deciding how to apply the new grant and to integrate the planning and commissioning of support services with the planning and commissioning of housing, care, and health services.

Housing Advice and Assistance

7.14 Legislation to enable local authorities to introduce choice based letting systems for access to social housing is currently before Parliament. The provisions include a new duty on local housing authorities to provide assistance to people, including those with learning disabilities, who need help when applying for and obtaining social housing. Local authorities will have flexibility as to how this is provided, and how far they integrate it with their wider advice and advocacy services for people with learning disabilities.

Local Housing Strategies

7.15 Learning Disability Partnership Boards will be expected to ensure that they set out plans for the provision of information, advice and advocacy services covering the different aspects of individuals' needs, including housing, as part of the Learning Disability Joint Investment Plan (JIP). This requires the participation of housing authorities in the development of the Learning Disability JIP, and in the planning and development of services. Likewise, social services and the NHS need to be involved in developing the local housing strategy and Housing Investment Programmes. At operational level, links need to be made between local housing authorities' housing advice services and local arrangements for accessing housing, and wider person-centred planning processes for people with learning disabilities. Joint Investment Plans provide an opportunity for all stakeholders to review the housing care and support options available in their area and develop plans for how to expand choice for individuals.

People Living with Older Carers

7.16 The Government recognises that there is particular concern about the position of people with learning disabilities living with older carers aged 70 and over. They and their families need to be able to plan for the future in good time. We have therefore decided to make promoting supported living for this group of people with learning disabilities one of the priorities both the revenue and capital elements of the Learning Disability Development Fund.

The NHS as Housing Provider

7.17 For almost 30 years, successive Governments have been committed to the reprovision of long-stay hospital accommodation in order to enable people to live in community-based housing. However, there remain over 1500 people living in old long-stay hospitals. In some areas, the long-stay hospitals have been partly replaced by NHS residential campuses often on former hospital sites or in NHS homes in the community. There are about 1500 people, outside the hospitals, who remain as patients under the care of a consultant in the NHS. Research has raised significant concerns about the quality of life enjoyed by people living in NHS residential campuses developed as a result of the contraction or closure of NHS hospitals.

7.18 While people with learning disabilities, like other people, may need to be admitted to hospital on a short-term basis, we do not believe it is right for them to live in NHS hospital accommodation on a long-term basis. The Government will enable all people currently living in long-stay hospitals to move into more appropriate accommodation by April 2004. Learning Disability Partnership Boards should therefore work together to agree and implement alternative housing, care and support plans for such people in order to achieve closure of those hospitals by this date. This will be a priority for the revenue element of the Learning Disability Development Fund.

7.19 In the case of residential campuses and retained beds, Partnership Boards should agree a timetable for extending person-centred planning (to commence by October 2002) to all people currently living there. This will inform discussions with the person and their family to decide whether alternative community-based housing, care and support options would be in their best interests. Where they are, these alternatives should be made available. Where people wish to remain in NHS residential campuses, Partnership Boards will be expected to monitor and improve the quality of care they receive.

FULFILLING LIVES

Government Objective: To enable people with learning disabilities to lead full and purposeful lives within their community and to develop a range of friendships, activities and relationships.

Problems and Challenges

7.20 At present many people with learning disabilities do not take part in community activities or participate in wider social networks with non-disabled people. Few have friends apart from those paid to be with them, their close family, or other people with learning disabilities with whom they live. Being part of the local community benefits everyone. This chapter sets out the action the Government will take to help promote social inclusion for people with learning disabilities.

KEY ACTIONS – FULFILLING LIVES

- Five year programme to modernise day services by 2006 – priority for the Learning Disability Development Fund.
- Learning and Skills Council to ensure equal access to education.
- Action to outlaw discrimination against people with learning disabilities on public transport.
- Leisure plans to incorporate the needs of people with learning disabilities.
- New initiatives to improve services for parents with a learning disability
- Improved disability awareness training for Department of Social Security staff administering Disability Living Allowance.

Modernising Day Services

7.21 For decades, services for people with learning disabilities have been heavily reliant on large, often institutional, day centres. These have provided much needed respite for families, but they have made a limited contribution to promoting social inclusion or independence for people with learning disabilities. People with learning disabilities attending them have not had opportunities to develop individual interests or the skills and experience they need in order to move into employment.

7.22 Local councils currently spend over £300 million a year on day services of which more than 80% goes on over 60,000 day centre places that often focus on large, group activities. The most severely disabled people often receive the poorest service and the particular cultural needs of people from minority ethnic communities are too often not addressed.

7.23 Some local councils have done much to modernise their day services, but overall progress has been too slow. The barriers standing in the way of change include:

- Difficulties in releasing resources tied up in buildings and staff;
- Slow development of links with other services (including supported employment) and support in the wider community;
- Tension between providing respite for families and fulfilling opportunities for the person;
- Slow progress in introducing person-centred approaches to planning.

7.24 The Government wishes to see a greater emphasis on individualised and flexible services which will:

- Support people in developing their capacity to do what they want;
- Help people develop social skills and the capacity to form friendships and relationships with a wider range of people;
- Enable people to develop skills and enhance their employability;
- Help communities welcome people with learning disabilities.

7.25 These problems will be addressed through a five year programme to support local councils in modernising their day services. Our aim will be to ensure that the resources currently committed to day centres are focused on providing people with learning disabilities with new opportunities to lead full and purposeful lives. Securing the active involvement of people with learning disabilities and their families in redesigning services will be essential to the success of the programme. The Government recognises that, for many families, day centres have provided essential respite from the day to day demands of caring. The services that replace them must result in improvements for both users and their families. The needs of people with profound or complex disabilities will be carefully considered as part of the modernisation programme.

Sawston and Bottisham, Cambridgeshire

A group of people with learning disabilities won the bid to keep the vending machines in the local college filled. Another group bid to win the contract to keep the village tidy. A strong partnership with the Village College in Sawston provided a base and opportunities to participate in a range of courses. A local charity funded a job coach, so people had opportunities for individualised employment. This meant that people did not have to be bused into Cambridge to a large day centre.

7.26 Modernising day services will involve developing and strengthening links with local supported employment schemes, and with providers of further and community education and training for disabled people. The Government recognises the need to strengthen these relationships further at national level.

7.27 Day services should be modernised by 2006. Learning Disability Partnership Boards will be required to draw up modernisation programmes by 2002 for achieving this. Plans will address the future role of existing large day centres. The introduction of person-centred planning for people using day centres will be a key element for achieving this. People using them should be an early priority for person-centred planning.

7.28 Modernising day centres will be one of the priority areas for the Learning Disability Development Fund, in order to provide bridging finance to support change. The Implementation Support Team will give early priority to supporting day service modernisation.

Education and Lifelong Learning

7.29 Many people with learning disabilities make use of further education provision, Local Education Authority adult and community education and adult work-based training opportunities to develop and extend their skills. They need to have the same access as other people to opportunities for education and lifelong learning.

7.30 We recognise the importance of meeting the learning needs of people with learning disabilities through a person-centred approach. Young people in particular should not be sent to further education colleges because there is a lack of suitable provision either in updated training facilities or in supported employment. The Learning and Skills Act 2000 gives the Learning and Skills Council (LSC) specific responsibility to have regard to the needs of young people and adults with learning disabilities when securing post-16 education and training. The LSC is required to:

- Make arrangements to ensure that young people and adults with learning disabilities have access to provision which meets their needs and, where appropriate, to additional support;
- Build equality of opportunity into its policies, programmes and actions, working closely with key equality organisations including the Disability Rights Commission;
- Have regard to the needs of learners with learning difficulties when providing work experience.

The Department for Education and Employment will be working with Skill, the National Bureau for Students with Disabilities, to prepare a statement of good practice on the practical steps institutions should take to enable students to gain access to suitable places and successful work experience there.

7.31 In addition, the Government has announced that £172 million in the post-16 sector (Further Education, Higher Education, Adult Education and the Youth Service) will be used over the period 2002/03 to 2003/04 to improve accessibility for disabled students and adult learners in England. The new Adult Basic Skills Strategy Unit, based in the Department for Education and Employment, will oversee literacy and numeracy developments at national and regional level and act as a catalyst to initiate action by others to improve people's basic skills. The Unit is funding a £1.5 million project to develop ways of improving literacy and numeracy among people with learning difficulties and/or disabilities.

7.32 The Learning And Skills Act 2000 also established Local Learning Partnerships which will have a key role to promote learning and ensure it meets the needs of local communities. These Partnerships will ensure:

- effective consultative mechanisms are in place so that the views of people with learning disabilities are heard by providers and the LSC;
- the content of and access to local learning provision meet the needs of people with learning disabilities.

7.33 The Special Educational Needs and Disability Bill currently before Parliament will remove the current exemption of education from disability rights legislation and give people with disabilities new rights in Local Education Authority (LEA) adult and community education, further education, higher education institutions and LEA youth service provision. It aims to ensure that disabled students, including those with learning disabilities, are not treated less favourably than non-disabled students. Post-16 institutions will have to make reasonable adjustments to their premises to ensure that disabled students are not put at a substantial disadvantage to their peers. The Bill will make it unlawful for institutions to discriminate against disabled people not only in the way they carry out their main business – the provision of education – but also in arranging admissions and providing wider services, such as accommodation, welfare services, and careers advice.

Transport

7.34 Access to transport is essential to enable people with learning disabilities to lead full and purposeful lives. However, they currently face many obstacles using public or private transport. Transport staff and operators may not understand their needs and people may lack the necessary support and training to become independent travellers.

7.35 The Department of the Environment, Transport and the Regions (DETR) is committed to working closely with people with learning disabilities and the transport industries to identify and meet the transport needs of people with disabilities. Government measures to improve access to transport for disabled people already taken or under way include:

- Implementation of the transport provisions in the Disability Discrimination Act;
- Development of disability training packages by the transport industry (supported by DETR);
- Greater emphasis on meeting the transport needs of disabled people, including those with learning disabilities, through Local Transport Plans;
- Increased focus on learning disability in the membership and agenda of DETR's Disabled Persons Transport Advisory Committee.

7.36 DETR will consult on proposals for legislation to outlaw discrimination against disabled people, including those with learning disabilities, on public transport and will monitor the effectiveness of local authority responses to meeting the needs of disabled people in the Local Transport Plans.

Heart'n'Soul – a national touring company of 10 people with learning disabilities and 4 professional musicians-was founded in 1986. It is based in the Albany Theatre London. The company has forged a name for itself on the international stage with performances. They run the Beautiful Octopus Club – a night club run and organised by people with learning disabilities. It has toured with 10 full scale musical productions and produced *Breaking the Rules*, its own half-hour television programme for BBC2.

Leisure and Relationships

7.37 People with learning disabilities often do not take part in ordinary leisure activities. Leisure is rarely built into individual or community care plans. It tends to be seen as an optional extra, generally coming well down the list of agencies' priorities when decisions are being made about resources. Enabling people to use a wider range of leisure opportunities can make a significant contribution to improving quality of life, can help to tackle social exclusion, and encourage healthy lifestyles.

7.38 The Government expects local councils to ensure that their local cultural strategies and service plans encompass the needs of people with learning disabilities. This will include a review of physical access to leisure resources and ways to find out about them. Leisure will be an integral part of person-centred planning.

7.39 People with learning disabilities are often socially isolated. Helping people sustain friendships is consistently shown as being one of the greatest challenges faced by learning disability services. Good services will help people with learning disabilities develop opportunities to form relationships, including ones of a physical and sexual nature. It is important that people can receive accessible sex education and information about relationships and contraception.

Parents with a Learning Disability

7.40 The number of people with learning disabilities who are forming relationships and having children has steadily increased over the last 20 years. Parents with learning disabilities are amongst the most socially and economically disadvantaged groups. They are more likely than other parents to make heavy demands on child welfare services and have their children looked after by the local authority. People with learning disabilities can be good parents and provide their children with a good start in life, but may require considerable help to do so. This requires children and adult social services teams to work closely together to develop a common approach. Social services departments have a duty to safeguard the welfare of children, and in some circumstances a parent with learning disabilities will not be able to meet their child's needs. However, we believe this should not be the result of agencies not arranging for appropriate and timely support.

7.41 Support for disabled parents, including those with learning disabilities, is patchy and underdeveloped, as confirmed in the Social Services Inspectorate inspection *A Jigsaw of Services*[12]. There are tensions and even conflicts within social services departments between those whose focus is the welfare of the child and those concerned with the parent.

7.42 The Government's Framework for the Assessment of Children In Need and their Families is intended for use with all children in need and their families. Further work is needed to help staff use the Assessment Framework when working with parents with learning disabilities and ensure that assessments result in appropriate services being provided to the child and their family. The Department of Health will commission the development of training materials to

[12] Department of Health, (2000) (CI (2000) 6) Social Services Inspectorate Inspection: A Jigsaw of Services: Inspection of services to support disabled adults in their parenting role

assist in this process. Parents with learning disabilities will be a priority for follow-up work on the Assessment Framework. We shall also ensure that their needs and those of their children are addressed in future Quality Protects initiatives. The Department of Health will work with Sure Start and the National Parenting Institute to ensure that the needs of parents with learning disabilities are recognised within the Government's wider initiatives to improve parenting and family support.

7.43 At local level, it will be the responsibility of the Director of Social Services, as part of his/her responsibilities for ensuring quality under the social care Quality Framework to ensure effective partnership working for parents with learning disabilities between children's and adult's teams. Partnership Boards should ensure that services are available to support parents with a learning disability.

Social Security Benefits

7.44 For many learning disabled people, the social security system represents their main source of income. Only a small proportion are in paid employment and they are likely to be receiving benefits as well. The main benefits that learning disabled people receive are Income Support, Severe Disablement Allowance (SDA) and the Disability Living Allowance (DLA). They make up a significant proportion of the caseload for SDA (nearly a fifth) and DLA (10%).

7.45 A high proportion of decisions on DLA (Disability Living Allowance) are currently subject to successful challenge on appeal – around 46% for all cases and higher for cases involving some learning disabilities. The Government recognises the importance of ensuring consistency in decisions on entitlement. The Department of Social Security is developing a training programme for delivery to all staff, designed to lead to improvements in the quality of service provided to disabled people and their carers.

7.46 The Government is aware of concerns that attempting work or training will affect entitlement to DLA. Entitlement is assessed on a person's need for help with personal care and/or difficulty in getting round. People in work (see also paragraph 7.64) can receive DLA and evidence suggests that for many disabled people who work, this benefit provides important support. Indeed, some disabled people would not be able to work without the additional help and support provided by DLA.

7.47 Benefit decision makers are encouraged not to assume that starting work inevitably means that the severity of disabilities has reduced. Hard and fast rules are inappropriate, since some disabled people may require more support after starting work. The Department of Social Security has issued new guidance on this matter to benefit decision makers and is committed to keeping it under review. This should ensure that disabled people starting work do not lose their DLA without strong and sufficient reason. Complaints have reduced significantly since the guidance was improved.

7.48 The benefits system needs to keep pace with changes in society and the economy generally. The Government will shortly be introducing some changes to improve support for people with long-term sickness or disabilities, who rely on social security benefits:

- From April 2001, young people disabled before the age of 20, many of whom will have learning disabilities, will be able to qualify for Incapacity Benefit, without having to satisfy the normal contribution conditions. This age limit is extended to 25 for young people in education or work-based training immediately before the age of 20. From April 2002, these young people will get up to £27.60 a week extra from Incapacity Benefit (2001 benefit rates).
- A new premium in the income-related benefits will deliver, from April 2001, increased incomes for adults under 60 with severe disabilities and the greatest care needs who are on the lowest incomes. The Disability Income Guarantee will ensure an income of at least £142.00 a week for a single person and £186.60 for a couple. A new enhanced disability tax credit will be introduced to deliver equivalent increases within Working Families Tax Credit and Disabled Persons Tax Credit.

7.49 The Department of Social Security has a programme of work to help disabled people access benefits, including material for people who have difficulty using standard products. These are mainly targeted on clients who are visually impaired. It has also concluded that the best way to provide benefit information to people with learning disabilities and their carers is on a one-to-one basis. However the Department of Social Security plans to consult further about the most effective ways of communicating with people with learning disabilities and their carers to identify whether specially designed material would be effective.

MOVING INTO EMPLOYMENT

Government Objective: To enable more people with learning disabilities to participate in all forms of employment, wherever possible in paid work, and to make a valued contribution to the world of work.

7.50 The Government believes that employment is an important route to social inclusion and that all those who wish to work should have the opportunities and support to do so. Our Welfare to Work agenda is designed to increase employment opportunities for those who can work while retaining support for those who are unable to work. We will ensure that people with learning disabilities benefit from this major programme of reform.

Problems and Challenges

7.51 Disabled people are amongst those in our society with the lowest employment rates. It is likely that less than 10% of people with learning disabilities are in employment. Paid employment will not be a realistic option for all those with learning disabilities, but real jobs with real wages are a major aspiration for many people.

7.52 The reasons for this exclusion from the labour market are complex, but they include:

- Low expectations on the part of many agencies and professionals of what people with learning disabilities can achieve. This has meant that many learning disabled young people have not received training and preparation for employment. Services working with adults with learning disabilities have not seen helping them find work as a priority;
- The interaction between social security benefit rules and employment can result in disincentives to work for some learning disabled people;
- Difficulties in progressing from supported employment schemes (where these exist) into mainstream employment.

7.53 The Government is committed to helping more people with learning disabilities develop the skills they need to move into the labour market. Employment has the potential to improve people's financial situation, open up another source of friends and social contact and increase people's self-esteem.

What More Needs To Be Done

KEY ACTIONS – MOVING INTO EMPLOYMENT

- New Government target for increasing numbers of people with learning disabilities in work.
- New Workstep Programme will benefit people with learning disabilities.
- Joint Department of Health/Department for Education and Employment scoping study into links between supported employment and day services.
- Job Brokers under the New Deal for Disabled People will have skills in working with people with learning disabilities.
- Disabled people starting work will not lose Disability Living Allowance unfairly.
- Learning Disability Partnership Boards to develop local employment strategies.
- Better employment opportunities in public services for people with learning disabilities.

New Targets and Incentives

7.54 The Government's overall aim is to increase the number of people with learning disabilities in employment and to work towards their achieving parity with other disabled people in the workforce. Our target for this group is to increase the employment rate of people with learning disabilities and reduce the difference between their employment rates and the overall employment rate of disabled people. The challenge now is to ensure that our programmes and policies reach as many people with learning disabilities as possible and are delivered in ways which are responsive to their needs. The Government will work with the Employers Forum on Disability and the local Employer Networks to ensure that employers are engaged in this process.

7.55 The Government has taken a number of important steps to improve the incentives for moving into employment, including introduction of the minimum wage and the Disabled Person's Tax Credit which will help to achieve our target. We recognise that the interaction between benefit rules and income from employment can result in

Steven's Story

After Steven left school he went to an Adult Training Centre every day. By the age of 26 he felt ready to look for work. A trial work placement in a local garage was arranged. The owner realised Steven could locate and assemble parts into organised pre-assembly kits efficiently and accurately. Steven has now developed into a skilled and valued member of staff. 10 years later he is still working there on the assembly line with complex parts and production techniques.

disincentives for disabled people. Various measures have been introduced to address this, including:

- The improved Incapacity Benefit linking rule allows people to re-qualify for benefits if they move into work or employment training, but fall ill again and return to benefit within a year (two years if they move on to Disabled Persons Tax Credit);
- The higher earnings disregards in the Independent Living Fund for those of their clients who wish to work;
- From April 2001, the earnings disregard in income-related benefits will rise from £15 to £20 a week for disabled people and other special groups including carers.

Workstep: Reforming the Supported Employment Programme

7.56 Supported employment is provided by a variety of agencies including the voluntary sector, local authorities (usually via social services departments), and health authorities and through the Government's Supported Employment Programme. Many using supported employment are people with learning disabilities and in one form or another supported employment has traditionally been the main route to employment for people with learning disabilities.

7.57 A recent report by the Policy Consortium for Supported Employment takes stock of current provision and concludes that there is scope for considerable development in this sector. The report identifies barriers to the expansion of supported employment and proposes possible ways of tackling them.

7.58 The Government's Supported Employment Programme is operated by the Employment Service. Over 22,000 disabled people are employed at a cost of over £155 million including over 10,000 people employed by Remploy and over 12,000 people employed through Supported Employment Programmes (SEP) run by local authorities and voluntary bodies. Some 40% of those on SEP have learning disabilities – the highest single category of disability.

7.59 The Government is modernising the programme. From April 2001 it will be renamed Workstep and it will have greater focus on developing disabled people and helping them move into mainstream employment where they wish to do so and with longer term support available where needed. The aim for progression will be 10% a year for existing supported employees and 30% over two years for new supported employees. This figure may be adjusted once we have more information on which to base it. The evaluation of the programme will look at its impact on people with learning disabilities.

Links between Supported Employment and Day Services

7.60 The Government recognises that we need to look more closely at the interface between the full range of pre-vocational, employment and supported employment provision, including Department for Education and Employment's Workstep, and day services provided by local councils and the health service. The Department for Education and Employment and the Department of Health will establish a joint working group to explore this issue further, in partnership with local authorities and the voluntary sector. The two Departments will also jointly fund a scoping study to look at these issues in more depth. The outcome from this work will help the Learning Disability Partnership Boards in drawing up their plans to modernise day services.

The Working Age Agency

7.61 From summer 2001, the services currently delivered by the Employment Service and Benefits Agency will be brought together in the new Working Age Agency. This will allow for delivery of a more integrated and efficient service. It will be important that frontline staff in the new Agency have the right skills and training to work with people with learning disabilities. An appropriate training programme will be developed.

New Deal for Disabled People (NDDP)

7.62 The New Deal for Disabled People- the joint initiative between the Department of Social Security and the Department for Education and Employment – has been testing a range of approaches to find out how best to help disabled people who want to work. By the end of December 2000 the NDDP pilots had helped over 6,000 disabled people into work. NDDP will be extended nationally from July 2001, building on experience in the pilot phase. The development of a network of job brokers to offer work focused help to disabled people will be a central feature.

James's Story

James started working at Leeds United last season, a club for which he holds a season ticket. This is his first paid job, which means he can spend money on his other hobby- music. Before he had to save for weeks to buy CDs. When he started working, he received full training on which chemicals to use when cleaning and how to handle them. The training was tailor made so that he could recognise the different bottles easily. It was easiest for him to remember the pictures on the bottles and their colours. In the past people might say horrible things to James, which easily undermined his confidence. But he says that since he's been working it's really boosted his confidence. He's good at this job and so now has more responsibility overseeing different areas of work. He's made lots of friends since he started working, feels a sense of belonging and loves his job.

7.63 The Department for Education and Employment will ensure that the new job brokers have the skills needed to work with people with learning disabilities. Organisations bidding to be job brokers will need to have the right capacity and competences. Arrangements will be set up for sharing good practice and ensuring on-going strong performance by job brokers in this area. All organisations and individuals who work with disabled people must provide the support and advice they need to make appropriate decisions and be sensitive to the needs of people with learning disabilities. We will be looking to see what additional training and advice needs to be put in place.

The Disability Living Allowance (DLA)

7.64 As mentioned in paragraphs 7.46 and 7.47 this benefit provides important support for many disabled people who work. Disabled people in work can receive DLA and benefit decision makers are encouraged not to assume that starting work inevitably means that the severity of disabilities has reduced.

Local Employment Strategies

7.65 Local councils have been asked to have Joint Investment Plans for Welfare to Work for Disabled People in place by April 2001. This is an important tool for improving the range of local employment opportunities. In many areas, preparatory work for the Welfare to Work Joint Investment Plans has done a good deal to strengthen relationships between local councils and the Employment Service in order to increase employment opportunities for disabled people. The Government intends to build on these emerging links. Local Employment Services will be members of the Learning Disability Partnership Boards, and will play an active part in developing local employment strategies. These will include local targets for the employment of people with learning disabilities. Partnership Boards will also be expected to identify employment champions.

Better Employment Opportunities in the Public Sector

7.66 Central Government, local government and the NHS together form one of the largest employment groups in the world. A small minority within the public sector employ people with learning disabilities, but currently very few are employed in real jobs in either central or local government or the NHS.

7.67 The Government is committed to a dramatic improvement in diversity with the Civil Service, including the employment of disabled people. We will seek to improve our employment of people with learning disabilities as part of this process.

7.68 The Department of Health is committed to widening opportunities for employing disabled people, including those with learning disabilities, in the NHS. Local councils will be setting targets for the employment of socially excluded people, including people with learning disabilities, as part of Local Public Service Agreements.

CHAPTER 8

QUALITY SERVICES

8.1 The Government is committed to raising standards and improving quality in services for people with learning disabilities. Good quality services that promote independence, choice and inclusion will lead to good outcomes for people with learning disabilities. This chapter covers quality, workforce training and planning, resources and people with additional needs. The last topic covers services for people with profound and complex disabilities, people suffering from the autistic spectrum disorder; people with challenging behaviour, and people developing conditions associated with old age. These groups have additional and complex needs and achieving good quality services for them requires greater skill and effective co-ordination

QUALITY

Government Objective: To ensure that all agencies commission and provide high quality, evidence-based and continuously improving services which promote both good outcomes and best value.

Problems and Challenges

8.2 Quality assurance in learning disability services is currently underdeveloped. Few places have achieved a holistic approach that systematically draws on all sources of information and research, including feedback from users. Complaint procedures are often inaccessible. People from minority ethnic communities are too often at the margins of services and funding, and people with learning disabilities do not always receive adequate protection from abuse and exploitation. The challenge for agencies working in the learning disability field will be to:

- develop a better approach to measuring quality, which emphasises improved outcomes as informed by the best quality research;

- work in partnership with other agencies in developing benchmarks for measuring performance;
- enable people with learning disabilities to lead lives safe from harm and abuse;
- put the needs and wishes of the person using the service at the centre of their quality assurance systems.

What More Needs To Be Done

KEY ACTIONS – QUALITY

- National Minimum Standards for residential care for people with learning disabilities.
- Social Care Institute of Excellence to be leading source of expertise in learning disability informed by high quality research evidence base.
- Local quality assurance frameworks to be in place by April 2002.
- Department of Health guidance issued on user surveys in 2001.
- Local councils to collect information about incidents of abuse.
- DH guidance on physical interventions with people with learning disabilities in 2001.
- Measures to assist vulnerable or intimidated witnesses give evidence in court.

Care Standards Act 2000

8.3 The Care Standards Act 2000 introduces major changes to registration and inspection. It establishes a new regulatory framework for social care which will improve protection and raise standards for people with learning disabilities who use care services. The National Care Standards Commission (NCSC), which will come into operation from April 2002, will be responsible for ensuring that all regulated care services, including those managed by local councils, are provided to national minimum standards laid down by the Secretary of State. The Department of Health will be consulting on draft regulations and national minimum standards for care homes, adult placements and domiciliary services.

The Social Care Institute of Excellence (SCIE)

8.4 The Government is setting up the Social Care Institute of Excellence which will contribute to improvements in learning disability services by promoting evidence based practice to address the current variation in quality. The Department of Health will ensure that SCIE is properly equipped to become a leading voice in learning disability. SCIE will consult people with learning disabilities and their carers about guidelines on what works and produce their work in an accessible format.

Local Quality Frameworks

8.5 The new Quality Framework for Social Care – set out in *A Quality Strategy for Social Care* – and clinical governance in the NHS – set out in *A First Class Service* – together provide a means of promoting high quality services for people with learning disabilities. As part of their responsibilities under the Quality Framework, we expect Directors of Social Services to ensure that their local quality systems recognise and address the needs of people with learning disabilities. Given the importance of close integrated working for learning disability services, the Learning Disability Partnership Board will need to ensure the development of an integrated quality framework that applies across all agencies. This should make people with learning disabilities its central focus with their voices clearly heard and services clearly accountable to them.

8.6 An inter-agency quality assurance framework should be in place by April 2002.

User Surveys and Complaints Procedures

8.7 The Government expects people with learning disabilities and their carers to be fully involved in planning, monitoring and reviewing services; and also in evaluating the quality of the services they receive, as required under the new Quality Framework for Social Care. Local councils need to have a clearer picture of the experience of all users and carers who receive social care services, including hard to reach groups such as people with learning disabilities. The Department of Health will be issuing guidance in September 2001 to help local authorities improve the way they use and carry out surveys.

8.8 The Government believes that complaints procedures should be more accessible to service users and their carers. The Department of Health is currently considering ways of improving social services complaints procedures, including their accessibility. The NHS Plan commits the Government to reforming the NHS complaints procedures; the intention is to consult on proposals later this year.

Minority Ethnic Communities

8.9 The Government has identified many ways in which services and support to people with learning disabilities from minority ethnic communities are failing to meet the needs of individuals and their families. There are a small number of innovative initiatives across the country. These are not widespread and the Government expects all agencies to improve their practice to fulfil the objectives of the NHS Plan and legal obligations set out in the Race Relations (Amendment) Act 2000. Learning Disability Partnership Boards, which will largely be drawn from bodies which are subject to the new duty to promote race equality in the performance of their functions, should ensure that local services are culturally competent and can meet all the cultural needs of their communities.

Imran's Story

Imran lives with his family, whose concerns for his welfare made them reluctant to introduce him to activities outside the home. Since becoming involved in a community-based group for Asian people with disabilities, he has grown in confidence and independent living skills. His family has developed more trust in what he can gain from an outside environment. Imran now has financial independence through his skills as an entertainer. He is often asked to perform at local and city-wide events and is a popular member of his community.

Protecting Vulnerable Adults

8.10 People with learning disabilities are entitled to at least the same level of support and protection from abuse and harm as other citizens. This needs to be provided in a way which respects their own choices and decisions. Good quality services for people with learning disabilities must support them to lead lives safe from harm and abuse, whilst enabling them to lead fulfilling lives. The Department of Health's No Secrets guidance sets out a framework for the protection of all vulnerable adults that will provide important safeguards for people with learning disabilities. Local councils with social services responsibilities should take the lead in developing local policies and procedures for the protection of vulnerable adults within an inter-agency framework, which may be supported by the establishment of a multi-agency management committee.

8.11 Local councils will need to ensure that learning disability services are represented on local adult protection management committees, and that information about incidents of abuse of people with learning disabilities is gathered and recorded.

Vulnerable Witnesses

8.12 Although measures are in place to assist child witnesses, many adult victims and witnesses find the criminal justice process daunting and stressful. Some witnesses are not always regarded as capable of giving evidence and so can be denied access to justice. This can include people with learning disabilities.

8.13 In June 1998 the Government published the report *Speaking up for Justice*, which made 78 recommendations to assist vulnerable or intimidated witnesses, including children, give evidence in court and so improve their access to justice. Those recommendations requiring legislation were included in the Youth Justice and Criminal Evidence Act 1999 and will enable the court to order one or more of a range of measures to assist the witness in court. These include:

- screens round the witness box to prevent the witness viewing the defendant;
- giving evidence by live TV link;
- assistance with communication;
- video-recorded evidence in chief;
- use of an intermediary;
- video-recorded pre-trial cross-examination;
- clearing the public gallery in sex offence cases and cases involving witness intimidation.

8.14 The 1999 Act also amends the law on competency. This provides that as a general rule, all people, whatever their age, are competent to act as witnesses unless they cannot understand questions asked of them in court or cannot answer them in a way that can be understood, with, if necessary the assistance of any of the special measures above. The legislation also makes clear that those who are competent to give evidence but who are not allowed to give evidence on oath may give evidence unsworn. The Government is aiming to implement the majority of the special measures in the Crown Court by Spring 2002.

Physical Interventions

8.15 Many organisations and individuals are concerned about the inappropriate use of physical interventions with adults and children with learning disabilities. The Department of Health will be issuing guidance clarifying policy on the appropriate use of physical interventions later in 2001.

People with learning disabilities in prison

8.16 Prisoners with learning disabilities present a wide range of issues. The Prison Service seeks to identify their individual needs for education and health care within the framework of addressing their sentence requirements. Prison establishments have to balance the resources needed to deliver this level of care with the many other demands of prisoner management.

Resources and Best Value

8.17 The Government's aim is to ensure that people with learning disabilities gain fair access to, and maximum benefit from, all available resources, whether in mainstream services or specialist provision for people with learning disabilities. In order to achieve this, decisions about resource allocation need to be evidence-based and take account of the likely increase in demand for services from people with learning disabilities.

8.18 We know that expenditure on and costs of services for people with learning disabilities vary significantly from one authority to another. The scale of these variations is difficult to justify, and we believe that there is scope for the money currently devoted to learning disability services to be used more effectively. The application of Best Value principles will achieve better value for money. Many councils have chosen learning disability as an area for Best Value Reviews. To be most effective, such reviews will need to look at services from a whole systems perspective, rather than considering particular services, such as day services in isolation. They should be person-centred in their approach. Advice on designing such reviews will be available in 2001.

WORKFORCE TRAINING AND PLANNING

Government Objective: To ensure that social and health care staff working with people with learning disabilities are appropriately skilled, trained and qualified; and to promote a better understanding of the needs of people with learning disabilities amongst the wider workforce

Problems and Challenges

8.19 Implementing the Government's proposals will require a new focus on the skills and training of the social care and health workforce. While the data are not reliable, there may be as many as 83,000 people in the learning disability workforce (33,000 in local councils, 30,000 in the voluntary and independent sectors, 20,000 in the NHS). The problems for national Government, local agencies and individuals are:

- An estimated 75% of staff are unqualified;
- Difficulties in recruitment and retention of professional and care staff;
- Low status among the workforce;
- Few recognised accredited training qualifications;
- Little attention to workforce planning;
- Variable involvement of service users and carers in training or planning.

8.20 We need to be confident that people in this field are equipped to work in the new ways required by the new strategy. The challenge is to ensure that in future people working or dealing with people with learning disabilities are:

- Better trained and qualified with a commitment to lifelong learning;
- Skilled at working in partnership with users and carers;
- Confident in working in multi-professional teams, and across agency boundaries;
- Culturally competent;
- Part of a local workforce and services which represent their communities;
- Well led and managed.

8.21 People with learning disabilities come into contact with a wide range of other professionals in their daily lives: staff in social security offices, the Employment Service and housing agencies; teachers and lecturers; police; GPs and other staff in the NHS. All these groups would benefit from a wider understanding of the needs of people with learning disabilities so as to overcome any lingering prejudice and enable people to make use of services on an equal basis with other citizens. This is demanding but must be more than window dressing if the provisions of the Disability Discrimination Act are to be met.

What More Needs To Be Done

KEY ACTIONS – WORKFORCE

- Health and Social Care Workforce Strategies to provide new opportunities for learning disability staff.
- Learning Disability Awards Framework introduced in April 2001.
- Learning Disability Development Fund to support range of leadership initiatives.
- Local Workforce Planning and Training Plans.

Health and Social Care Workforce Strategies

8.22 The Government has set in train major changes to lifelong learning and training. The Learning and Skills Council with its Local Learning Partnerships are expected to promote opportunities for education and lifelong learning, which will help develop a knowledge based approach in the workforce. The Department for Education and Employment's scheme to establish Individual Learning Accounts (ILAs) will help individuals meet the costs of training. The Government has set out general workforce strategies for health and social care which offer new opportunities for the learning disability field. The new Quality Framework for Social Care recognised the need for a new focus on workforce training and development. The NHS Plan promises all staff receiving dedicated vocational training – including those working in the learning disability field – a £150 individual learning account to 'top up' the contribution from the Department for Education and Employment scheme.

8.23 The Training Organisation Personal Social Services (TOPSS) National Training Strategy (endorsed by Government) contains specific proposals about learning disability. In 2001/2002 £2 million is being provided for TOPSS to support implementation of the Training Strategy. TOPSS will use the funds to roll out training based on the new Induction Standards for social care staff. TOPSS Regional Forums will administer this funding.

8.24 In each area the new NHS Workforce Confederations will involve all service providers- health, social care, independent and voluntary. TOPSS Regional Training Forums should work together with the Confederations to maximise the impact of training for staff in all sectors. The Confederations will have increased capacity to consider local workforce demands in learning disability. The Government will ensure that the work of each Confederation takes full account of the proposals set out here.

Learning Disability Awards Framework (LDAF)

8.25 The Government recognises that the levels of skills, training and qualification in the learning disability workforce need to be raised. We are therefore introducing from April 2001 a new Learning Disability Awards Framework, within the existing qualifications structures, to provide a recognised route to qualification and career progression for care workers in learning disability services. By April 2002 all new entrants to learning disability services will be registered for the new awards. The Framework is based on two new vocational qualifications:

- A level 2 Certificate in working with people with learning disabilities;
- A level 3 Advanced Certificate in working with people with learning disabilities.

Government Targets

From April 2002 all new entrants to learning disability care services should be registered for qualification on LDAF.

By 2005 50% of front line staff should have achieved at least NVQ level 2.

In Bristol Social Services and Health we already provide a structured programme of training on issues such as ‘Protecting Vulnerable Adults’ and ‘Working with Challenging Behaviour’. LDAF is what we’ve been waiting for – a framework which will give staff a nationally recognised qualification for all the learning they have done. Because of the new Awards, staff will be motivated to think more about their own development, and there will be close links with the NVQ level 3, which will all help towards creating a better qualified workforce. This will benefit the people who use our services – which is really what the whole thing is about!

Bristol Social Services and Health

8.26 The new qualifications provide a comprehensive summary of learning outcomes, mapped against occupational standards. The new Framework will enable staff and employers to plan career paths and provide a route for people to progress to higher education and professional qualifications.

8.27 In partnership with TOPSS we have set some ambitious targets for rollout of the Framework. These will be monitored through data collected from the awarding bodies, National Open College Network and City and Guilds Affinity.

8.28 The next phase of the work on LDAF is in hand to bring levels 4 and 5 into the Framework. The General Social Care Council comes into operation in October 2001. The Department will explore with the Council how the Learning Disability Awards Framework can be linked to registration requirements for the learning disability sector.

Involving Users and Carers

"I want staff who treat you well, who know how to treat you properly"

8.29 The best way to achieve this is to promote the involvement of people with learning disabilities and their family carers in training and development activities. Staff and managers at all levels in organisations need to have an opportunity to hear directly from people with learning disabilities about their expectations. Some authorities have already begun to enable service users to play an effective role in the design and delivery of training to both managers and front-line staff.

Wendy's Job

Wendy has a job teaching health care staff. '*Teaching Doctors about Disability is very powerful and I enjoy it, but am exhausted afterwards. Getting the job in the first place was very difficult, I was lucky I had the right support, but it was really, really hard and I had to do a lot of preparation before I started!*'

Leadership

8.30 Effective leadership is essential for achieving the changes required. The Government will use the Learning Disability Development Fund to support a range of initiatives aimed at enhancing professional and managerial leadership in learning disability services. As part of the programme of work to implement this White Paper, we will also:

- Further develop the leadership capacity of people with learning disabilities and carers;
- Work in partnership with elected local councillors who have an important role to play in promoting positive acceptance of people with learning disabilities by the wider community;
- Recognise the valuable role to be played by academic leadership in creating and developing appropriate learning systems, stimulating investment in applied research and teaching and encouraging a new generation of leaders.

Local Workforce Plans

8.31 Learning Disability Partnership Boards will be required to develop a workforce and training plan. These should cover how service users and carers are being involved in training and workforce matters, the content and quality of health professional training, resourcing training and development needs across all organisations in the field including the independent sector and proposals for dealing with any shortfall in staffing.

People with Additional and Complex Needs

8.32 Good quality services will ensure that people with additional and complex needs are appropriately cared for so that their needs are well managed and they lead fulfilling lives. This includes people who:

- have severe and profound disabilities (including those with sensory impairments);
- have epilepsy;
- have an autistic spectrum disorder and also a learning disability;
- present with behaviour that challenges their carers and service providers;
- develop conditions associated with old age.

Margaret's Life

Margaret lived almost all her life in largish homes with people she didn't particularly enjoy being with. She acquired neither language nor formal signing, but was very well able to make her wishes known. She lost contact with her family once her mother died, but acquired a long-term personal advocate who gave her links with the outside world and helped her do some of the things she enjoyed: meals out, long walks, her own personal holiday. This was the one person who was "there for her", and the advocate was with her during her last days and when she died.

People with severe and profound disabilities

8.33 People with severe and profound learning disabilities often have other associated health problems such as physical disabilities, sensory impairments and epilepsy. They will almost always require a greater level of health care support than is usually available from a primary health care team. Members of the specialist learning disability service should provide additional support to the primary health care team to help them manage the complex health needs of those with multiple disabilities. In addition they may need access to a range of medical, nursing and other health services including physiotherapy, occupational therapy, speech and language therapy and orthopaedic services. Those who are technology dependent will require substantial additional support. The numbers of children who are technology dependent are relatively small, but an increasing number are surviving into adulthood.

8.34 People with profound and complex disabilities may have difficulty communicating their needs and wishes. They may need the support of someone who knows them well such as a family member, an advocate or a supporter. Nevertheless, it is important to enable people with profound and complex needs to exercise as much control as possible over their own lives.

People with epilepsy

8.35 The rate of 'active' epilepsy for people with mild or moderate learning disabilities is 5% compared to a normal rate of 0.5% in the general population. We may expect to find 30% of people with severe learning disabilities at risk of developing epilepsy, rising to 50% among those with profound learning disabilities. The condition originates in childhood for the majority. For people with Down's syndrome the onset of seizures in middle age may be associated with the onset of dementia.

8.36 Modern diagnostic investigations include referral to a specialist with expertise in epilepsy for detailed examination. People with severe and profound disabilities may have difficulties in co-operating with the investigations and specialist neurological clinics may be reluctant to accept such referrals. All people with learning disabilities are entitled to have access to specialist clinics, including tertiary services. Adequate and appropriate facilitation must be available to enable this to happen. Good support of the person with epilepsy involves careful and sympathetic understanding, effective monitoring of medication and support of daily routines to minimise the impact of factors that may provoke seizures.

People with learning disabilities and autistic spectrum disorders

8.37 Many people with severe and profound learning disabilities have autistic behaviours, even if not formally recognised. It is important that all services for people with learning disabilities have the skills to recognise and make adequate provision locally for them although the majority will not need autism specific services. The presence of an autistic disorder is normally first recognised in early childhood. The diagnosis depends on a full and competent assessment from a child and adolescent psychiatric, paediatric or learning disability service that specialises in this area. A number of new diagnostic instruments have recently been introduced and are currently being evaluated.

8.38 Many parents face lengthy waiting times for early diagnosis of autistic spectrum disorders. This often reflects the high workload of child development centres and Child and Adolescent Mental Health services and a lack of skilled expertise in diagnosing autistic spectrum disorders. This is in part being addressed by a joint initiative by the Department of Health and Royal College of Psychiatrists to develop a training programme for paediatricians with special expertise in mental health disorders.

8.39 The Department of Health has asked the Medical Research Council to obtain a clear and comprehensive picture of current knowledge about the incidence, prevalence and causes of autism and the strength of the evidence which underpins that knowledge. The Medical Research Council will submit a report to the Department of Health in autumn 2001. This will be circulated more widely to a range of policy-makers, patients, interest groups, the research community and the public.

8.40 Recent research suggests that family based early intervention for children with autistic spectrum disorders may result in improvements in skill and behaviour. Early intervention helps a significant number to overcome their disability sufficiently to attend mainstream schools. However, throughout their lives the majority of people with autistic spectrum disorders require educational, social, psychological and therapeutic interventions. Real choice is often limited by what is available rather than what might best suit the individual, and referral to residential services far from home is not uncommon. The Government will continue to work with the relevant professional bodies and other experts on autism to consider how screening, diagnosis and early intervention can be improved.

8.41 Although we focus on the needs of those individuals with autism who have learning disabilities, some general principles apply. Children with autism are children first and their needs as children should be the main focus. Whether or not they have learning disabilities in addition to their autism, they should therefore benefit from our proposals for improving services for disabled children.

8.42 Adults with autism need a range of living and working environments. Those who require intensive treatment and support are often unable to access local services and are referred to residential services far from home. While this may suit some individuals, others may prefer to live in their local community, take part in a local day service, find a job or seek supported employment. Person-centred planning should make it possible for individuals to be able to exercise their choice in how their housing and support is provided.

People with learning disabilities who have challenging behaviour

8.43 Commissioning and providing services for people who present significant challenges is one of the major issues facing learning disability services. The presence of challenging behaviour does not make an individual the responsibility of the NHS, although the NHS is responsible for commissioning and providing appropriate health input including intensive support from health professionals. The report of the Mansell Committee (Department of Health 1993) provided guidance on this and stressed that services should be commissioned on an individualised basis and should seek to promote inclusive lifestyles.

8.44 Challenging behaviours are best thought of as being a way in which people respond and try to gain control over difficult situations. Sometimes the challenging behaviour may be triggered by pain and a full medical assessment should always be undertaken. Psychotropic medication may be very effective when there is an underlying psychiatric disorder but there is concern that too often this medication is used as an alternative to adequate staffing. Modern behavioural approaches can result in significant short and medium term reductions in the severity of the behaviour. Learning Disability Partnership Boards should ensure that local services develop the competencies needed to provide treatment and support within the local area. To facilitate this, we have made developing specialist services for people with severe challenging behaviour and/or autism one of the priorities for the capital element of the Learning Disability Development Fund.

Older people with learning disabilities

8.45 Many people with learning disabilities now in their 50s and 60s were not expected to outlive their parents. Improved medical and social care now means they are living longer. Life expectancy is influenced by the severity of the learning disability. Those with severe and profound disabilities tend to die younger. As with the rest of the population women survive longer than men. Many of those now entering old age have spent most of their lives in long-stay hospitals and are likely to be adjusting to a new life in a home of their own, in supported living or in a small group home. A small number have continued to be in the care of the NHS in continuing care provision.

8.45 There are some people with learning disabilities over the age of 75, who have shown significant physical and mental deterioration with age, who have high dependency needs and who make considerable demands on health and social services. Their difficulties as older people overshadow any problems associated with their learning disability and their needs are practically identical to those of the elderly population as a whole. Person-centred plans for these individuals should be developed in the context of services for elderly people.

8.46 There are other older people with learning disabilities who are more mentally alert and have aspirations more typical of younger people. They may be misplaced in older peoples' homes living alongside much older and more incapacitated people. 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. They should be enabled to be as actively engaged as possible.

8.47 Those who develop Alzheimer's disease have very special needs. About a third of those with Down's syndrome may be expected to show clinical evidence of dementia, but others without Down's syndrome may also develop dementia. In Down's syndrome the onset of dementia may be from 35 years of age or earlier and their health often deteriorates quite rapidly. Providing good quality support for these individuals is a major challenge. The Government will expect learning disability services to work with the specialist mental health services to ensure that, between them, appropriate supports are provided for younger people with learning disabilities suffering from dementia.

8.48 The NSF for Older People will set out a framework that applies to services for all people over 65 years of age. But for people with learning disabilities the ageing process may begin much earlier. This means that planning for the needs of "older people" with learning disabilities may need to include a more extended population, perhaps taking account of those aged from 50 years upwards. Developing the person-centred approach to planning services described in Chapter 4 will enable local agencies to address the needs of older people with learning disabilities. Local Partnership Boards will ensure that there is co-ordination between learning disability services and older people's services so that people can access the services which are most appropriate to their needs.

PART THREE:

DELIVERING CHANGE

CHAPTER 9

PARTNERSHIP WORKING

Government Objective: To promote holistic services for people with learning disabilities through effective partnership working between all relevant local agencies in the commissioning and delivery of services.

9.1 This objective aims to promote:

- **Rights:** local Partnership Boards will need to ensure the availability of service options to meet people's assessed needs and wishes;
- **Independence:** agencies responsible for mainstream housing, education, employment and leisure will be fully included in local planning and commissioning;
- **Choice:** greater integration between agencies will open up wider service options for all people;
- **Inclusion:** people with learning disabilities and their families will be given the opportunity to be involved in local partnerships.

This objective is concerned with services for adults, with partnership for children services continuing to be addressed through Children Services Plans.

Problems and Challenges

9.2 Effective partnerships are key to achieving social inclusion for people with learning disabilities. Learning disability services have traditionally shown innovative approaches to partnership working. However, these are not widespread for reasons including:

- A lack of agreement about values and service objectives;
- An inability or unwillingness to agree on financial arrangements;
- Low priority being given to joint working within organisations.

9.3 In many places, people with learning disabilities and their families continue to be passed between organisations and professionals with insufficient clarity about where responsibility rests for ensuring effective service provision. Community learning disability teams were forerunners in partnership working, but they have not consolidated their position.

9.4 People with learning disabilities and their families need to have confidence that all organisations are working together to achieve integrated service planning and commissioning, and that they can gain access to their choice of services through one clear access route.

What More Needs To Be Done

KEY ACTIONS: PARTNERSHIP WORKING

- Learning Disability Partnership Boards to be established by October 2001.
- National support to partnership working to be provided through the Learning Disability Development Fund, Implementation Support Team and the production of good practice advice.
- Partnership Boards to agree plans for the use of Health Act flexibilities in the updated Joint Investment Plan (JIP).
- Further Department of Health guidance on partnership working and future role of community learning disability teams.

Partnership Boards

9.5 The Government intends to build on existing inter-agency planning structures to establish Learning Disability Partnership Boards in all local authority areas by October 2001. Partnership Boards will be responsible for those elements of the Government's proposals which relate to services for adults with learning disabilities. Services for disabled children will continue to be addressed through children services planning structures. The Partnership Board will operate within the overall framework provided by Local Strategic Partnerships (LSPs).

9.6 The development of Local Strategic Partnerships (LSPs) offers a framework for local partnership working, bringing together public, private, community and voluntary sectors in order to provide effective co-ordination. These arrangements aim to simplify and expand the scope of partnerships concerned with community well-being. Many areas already have a strategic partnership on which an LSP can build. Our proposals for partnership working in learning disability will fit within the overall umbrella offered by LSPs. Close links between Learning Disability Partnership Boards and LSPs will ensure a common direction and help to address wider issues, such as access to other local services, including transport.

9.7 Learning Disability Partnership Boards will not be statutory bodies. They will be responsible for:

- Developing and implementing the Joint Investment Plan for delivering the Government's objectives;
- Overseeing the inter-agency planning and commissioning of comprehensive, integrated and inclusive services that provide a genuine choice of service options to people in their local community;
- Ensuring that people are not denied their right to a local service because of a lack of competence or capacity amongst service providers;
- The use of Health Act flexibilities;
- Ensuring arrangements are in place to achieve a smooth transition to adult life for learning disabled young people.

9.8 Learning Disability Partnership Boards should particularly ensure that:

- people with learning disabilities and carers are able to make a real contribution to the Board's work;
- the cultural diversity of the local community is reflected in its membership;
- local independent providers and the voluntary sector are fully engaged.

9.9 It will be the responsibility of the chief executive of the local council to ensure that the Partnership Board is in place. Membership should include senior representatives from social services, health bodies (health authorities, Primary Care Trusts (PCTs)), education, housing, community development, leisure, independent providers, and the employment service. Representatives of people with learning disabilities and carers must be enabled to take part as full members. Minority ethnic representation will be important in view of the Government's commitment that their needs should not be overlooked.

9.10 The Learning Disability Development Fund and Implementation Support Team will make partnership development an early priority. The Department of Health will issue further guidance on partnership working in 2001.

Health Act Flexibilities

9.11 The new flexibilities introduced by the Health Act 1999 (see glossary) already provide opportunities to improve partnership working. They also provide the framework within which Learning Disability Partnership Boards will be required to operate. The NHS Plan makes clear that the Government expects the partnership flexibilities to be used in all parts of the country. Some localities are making early use of these flexibilities in the learning disability field, and we believe that wider use of these flexibilities will benefit people with learning disabilities and their families.

9.12 The Government expects all agencies involved in the Partnership Boards to show in their updated JIPs that they have fully considered how to use the Health Act flexibilities to underpin effective partnership working.

9.13 Joint Investment Plans will be evaluated and monitored to ensure effective partnership working. Evidence of failings in partnership arrangements will be taken into account in determining the allocation of the new Learning Disability Development Fund. Where there is evidence that services for people with learning disabilities are failing, partnership working is unsatisfactory and the Health Act flexibilities not being properly used, the Government will consider use of the new powers of intervention contained in the Health and Social Care Bill, which will enable the Department to direct the use of the partnership arrangements.

9.14 The Government places emphasis on the importance of promoting choice and achieving inclusion for people with learning disabilities through close partnership between health and social services and a wide range of other agencies including employment, education, housing and the and voluntary and independent sectors. In this context, it is likely that the leadership of the local partnership will rest with the local council, making use of one or more of lead commissioning, joint commissioning and pooled budgets.

Cumbria County Council, Morecambe Bay Health Authority, and North Cumbria Health Authority have agreed to commit £20 million to a pooled fund for learning disabilities. The intention is to enable an integrated strategy to be delivered, providing a consistent and high quality service, which can respond to the needs of individuals. The Partnership Arrangement has been established on the basis of broad participation from users, carers, providers – statutory and independent. It has clear performance measures based on priorities identified through the consultation process – including improving respite care, day care and activities, and reducing the size of accommodation units. Lack of co-terminosity has not been a barrier to development. A project manager has been appointed who is focusing on where integrated provision would enable the strategy to be fulfilled.

9.15 However, where effective partnerships are not established with local council leadership, the Government will consider using its intervention powers to require the development of a Care Trust. There may also be particular local circumstances which make the creation of a Care Trust an appropriate way to achieve local integration of services.

The Role of Primary Care Trusts (PCTs)

9.16 Primary Care Trusts (PCTs) will be key players in the Learning Disability Partnership Boards. As PCTs become more firmly established and develop their commissioning responsibilities, they will be the lead health body for learning disability services. They will need to develop skills and knowledge in commissioning learning disability health services. Partnership Boards will not constrain the freedom of emerging PCTs, but will enable them to enhance the effectiveness of their overall contribution to improving health outcomes for people with learning disabilities.

Integrated Professional Working

9.17 Professional structures need to ensure that people with learning disabilities and their families have easy access to services from all agencies. To achieve this, Partnership Boards should review the role and function of community learning disability teams in order to ensure that:

- All professional staff become accountable for the outcome of their work to the local partnership arrangements – whilst ensuring the retention of appropriate professional accountabilities and support;
- All professional staff become a resource for the local implementation of the White Paper and to help achieve social inclusion for people with learning disabilities;
- Organisational structures encourage and promote inclusive working with staff from the fields of housing, education, primary care, employment and leisure.

9.18 The Department of Health guidance on partnership working will provide further advice on the future role of community teams.

CHAPTER 10

MAKING CHANGE HAPPEN

10.1 Delivering the Government's ambitious plans for people with learning disabilities will take time, as real change always does. Improving the lives of people with learning disabilities is a complex process which requires a fundamental shift in attitude on the part of a range of public services and the wider local community. This will not be easy. It needs real leadership at both national and local levels, supported by a long-term implementation programme with dedicated resources and on-going action to monitor delivery. This chapter sets out how the Government intends to approach this challenging task.

10.2 The Department of Health in partnership with the Department for Education and Employment, the Department of the Environment, Transport and the Regions and the Department of Social Security will issue further guidance on what is expected of local agencies in order to implement the new strategy.

National Action

Learning Disability Task Force

10.3 The Government will set up a national Learning Disability Task Force to take forward the implementation. The role of the Task Force will be to monitor and support implementation by acting as a champion for change and improvement at local level. Drawing on the knowledge and experience of members, the Task Force will also offer advice to Government on the continuing development of learning disability policy. It will focus on the adult elements of the Government's proposals, and its membership will be drawn from a wide range of interests, including minority ethnic communities. The Children's Task Force will continue to have the lead on disabled children's issues and we will ensure that effective links are in place between the two.

10.4 People with learning disabilities and carers will be full members of the Task Force. We will ensure that effective links are in place between the Task Force and the National Forum for People with Learning Disabilities.

Learning Disability Development Fund

10.5 To support implementation of the new proposals for adults, the Government will create a new Learning Disability Development Fund of up to £50 million per annum, of which up to £30 million will be revenue funding and £20 million capital. This will be introduced in April 2002 and will be targeted on the Government's priorities.

10.6 The revenue element of the Development Fund will be created from that element of the current old long-stay adjustment within general health allocations which is released as former long-stay patients die. We will conduct a census of old long-stay patients through the NHS regional offices later in 2001 in order to determine the final size of the Development Fund. We will announce this in good time before April 2002.

10.7 The Development Fund will be used to support our priorities for service change. Priorities for the use of revenue funding will be:

- Modernising day centres;
- Completing the reprovision of the remaining long-stay hospitals to enable people to move to more appropriate accommodation by April 2004;
- Developing supported living approaches for people with learning disabilities living with older carers;
- Promoting the further development of advocacy;
- Supporting the wider introduction of person-centred planning;
- Enhancing leadership in learning disability services.

10.8 Priorities for the use of the capital will be:

- enabling local providers to develop specialist services for people with severe challenging behaviour;
- developing integrated health and social services facilities for children and young people with severe disabilities and complex needs;
- developing supported living approaches for people with learning disabilities living with older carers.

10.9 Learning Disability Partnership Boards will be required to submit updated Joint Investment Plans (JlPs) to the Department of Health by January 2002, setting out their plans for implementing the White Paper. Updated JIPs should include bids against the capital element of the Learning Disability Development Fund. Decisions about the allocation of the Learning Disability Development Fund will require the social care and health regions of the Department of Health to be satisfied that the JlPs are acceptable and that in particular they provide evidence of satisfactory partnership arrangements.

10.10 The Learning Disability Development Fund will be made available subject to the condition that the resources may only be used where they are deployed as part of pooled funds under the Health Act flexibilities. This will enable the Learning Disability Development Fund to support the implementation of all aspects of *Valuing People*. Learning Disability Partnership Boards will be required to show how they will make use of the Health Act flexibilities to enhance partnership working and this will be taken into account in decisions about the allocation of the Development Fund.

Implementation Support Team

10.11 We believe that a strong national lead which provides effective support to local action will be vital in delivering the vision set out in *Valuing People*. The Government will therefore set up a national Implementation Support Team during 2001. The team will be led by a Director with a Development Worker based in each of the eight Department of Health regions and will be charged with promoting good practice and sharing practical experience across the country.

Implementation Support Fund

10.12 The Government will set up an Implementation Support Fund of £2.3 million a year for 3 years from April 2001 to provide central support for key aspects of the new strategy. (This includes £300,000 for increasing volunteering opportunities for citizen advocates.) Priorities for the Fund include:

- Development and expansion of advocacy services;
- Establishment of a National Learning Disability Information Centre and Helpline in partnership with Mencap;

- Funding a number of development projects on key priorities, including person-centred planning, partnership working and a scoping study of the interface between employment and day services;
- Extension of the Learning Disability Awards Framework.

Improving the Information Base

10.13 National data on learning disability issues are currently underdeveloped. The Government intends to take steps to improve the situation. During 2001/02, the Department of Health will commission a national survey of people with learning disabilities in contact with social services in order to improve our knowledge and provide a stronger baseline against which to evaluate the impact of *Valuing People*.

10.14 The Department of Health will also be undertaking a project to improve its own data collection in the learning disability field by establishing which activities and services should be the subject of regular statistical returns. For disabled children, the children in need census is already improving the knowledge base, and the forthcoming Integrated Children's System will set out the minimum data requirements for collecting information about individual children and families, including disabled children.

Research

10.15 Research has an important role to play. Findings from research contribute towards fostering an evidence based approach to service delivery. The Department of Health will be funding a £2 million research initiative *People with Learning Disabilities: Services, Inclusion and Partnerships* starting in 2001/02 and lasting for four years. The areas we wish to study are:

- Service delivery in health and social care and its effectiveness to identify elements of good practice, implementation and sustainability;
- Social inclusion, including access to good health care, and the factors which create disability barriers in people's lives;
- Organisation development to show how staff performance in learning disability services can be supported to achieve better services.

10.16 The aim of this initiative is to generate a knowledge base to inform the implementation of our proposals. We expect to fund 6–10 studies. The initiative will be overseen by a reference group and its findings disseminated to complement the *Valuing People* implementation programme.

10.17 There is already a considerable amount of research activity on learning disability in the NHS. Over 130 separate research projects, as listed on the National Research Register (NRR), have recently been completed. About £3 million is being spent on 50 current studies. Topics being researched include the health needs of people with learning disabilities in the community. Among those recently completed were a study of women with learning difficulties and their experiences of cervical smear tests and research on the impact of training for carers, on the mental health of people with learning disabilities.

10.18 The NHS Information Authority will develop a National Electronic Library for Learning Disability. In 2001/2002 the Authority will be putting more resources into the pilot project.

Inspection

10.19 We shall ensure that the Social Services Inspectorate (SSI) and the Commission for Health Improvement (CHI) give attention to learning disability services within their national work programmes. During 2001/02, there will be a national inspection by SSI of learning disability services in order to assess how well placed local councils will be to implement the new strategy. Findings from the inspection will be used to inform the work and priorities of the Implementation Support Team.

Local Action

10.20 Learning Disability Partnership Boards will be accountable for implementing the proposals in *Valuing People* at local level. Boards will be expected to appoint a senior officer who will have lead responsibility for taking this forward.

10.21 Health and local authorities have already been asked to have learning disability Joint Investment Plans (JlPs) in place by April 2001. Guidance on the development of the learning disability JIP foreshadowed some of the key themes in the new strategy. The Government has therefore decided to build on the JlPs as the basis for local implementation of its proposals. Learning Disability

Partnership Boards will be required to develop local action plans as supplements to the JIP and to submit the updated JIP to the regional offices of the Department of Health by 31 January 2002. The JlPs will then be jointly evaluated by Department of Health social care and NHS regional offices.

10.22 As part of overall guidance on implementation, the Department of Health will issue guidance on the contents of the updated Joint Investment Plan (JIP). It will be essential that the JIP is agreed by all agencies represented on the Learning Disability Partnership Board. The Government will expect people with learning disabilities, carers and the local voluntary and independent sectors to be fully involved in this process.

Delivery Plan

10.23 Set out below are the key actions which will be taken by the Government and by local agencies to implement the new strategy. This needs to be at least a five year implementation programme. Although we are clearer now about the early milestones, the Learning Disability Task Force will revisit this plan on a regular basis to roll it forward for future years.

Spring 2001

- Recruitment of Implementation Support Team begins
- Funding for Citizen Advocacy Network and Self-Advocacy work comes on stream
- Work begins in partnership with Mencap to develop National Information Centre
- Regional office census of former old long-stay patients carried out
- Guidance on person-centred planning commissioned
- Guidance on Physical Interventions issued
- All new entrants to learning disability care services should be registered on LDAF

Summer 2001

- Learning Disability Task Force established
- Issue guidance on implementation
- Issue joint DH/DETR guidance on housing for people with learning disabilities
- DH/DfEE study into interface between day services and supported employment commissioned and DH/DfEE joint working group set up
- Work under way to establish National Learning Disability Users Forum

Autumn 2001

- Implementation Support Team up and running
- Guidance on direct payments issued
- Good practice materials on learning disabled people and decision making issued
- Good practice materials on partnership issued
- Learning Disability Partnership Boards in place
- Issue guidance on person-centred planning

Winter 2001/02

- Learning Disability Partnership Boards submit updated JIP to the Department of Health which is to act as local action plan
- Complete analysis of JIPs and notify decisions about Learning Disability Development Fund

Spring 2002

- Introduction of new Learning Disability Development Fund
- Agree local framework for person-centred planning and begin implementation
- Inter-agency framework for quality assurance to be agreed
- Plans for closing remaining long-stay hospital units agreed

Winter 2002/03

- Day service modernisation programme agreed
- JIP updated
- Agree Housing Strategy
- Agree Employment Strategy

Summer 2003

- All Learning Disability Partnership Boards to have agreed framework for Health Action Plans
- Health facilitators identified.

Winter 2003

- Person-centred planning for people in long-stay hospitals completed.
- Full range of employment and support service options in place

Targets post March 2004

- Programme to enable people still living in long-stay hospitals to move into more appropriate accommodation by April 2004
- 50% of front line staff to have achieved at least NVQ level 2 – 2005
- All people with a learning disability to be in receipt of a HAP by June 2005
- Modernisation of day centres completed by 2006

Monitoring Delivery

10.24 Delivering the changes set out in *Valuing People* involves a complex range of agencies, including at least four Government departments and a wide range of local agencies. The large number of stakeholders involved makes it particularly important that the Government takes a comprehensive approach to monitoring implementation. We will ensure that existing performance assessment mechanisms across health, social services, education, employment and housing enable us to monitor implementation of the key initiatives. Best Value and the performance assessment arrangements for social services are likely to make a particularly important contribution, given the lead role that local councils have in taking forward our proposals.

10.25 We have reviewed the existing data and performance indicators which are already in place on learning disability services, and are proposing new performance indicators for use as part of the further development of JIPs. These are set out at Annex A in support of the Government's objectives for learning disability services. We intend to replace the existing national performance indicators within the social services Performance Assessment Framework with new outcome-focused indicators. We shall consult Local Government Association, Association of Directors of Social Services and the NHS Confederation on more detailed proposals.

Conclusion

10.26 We do not underestimate the difficulties involved in delivering our ambitious new vision for people with learning disabilities. The principles of rights, independence, choice and inclusion we put forward are challenging and have far reaching implications for all those agencies – public, independent and voluntary – who work with people with learning disabilities. Enabling people with learning disabilities to have their voices heard and have wider opportunities for a fulfilling life as part of the local community is central to our message. Delivering this involves new ways of working in more effective partnerships. But getting it right for people with learning disabilities will show what can be achieved with and for one of the most vulnerable and socially excluded groups in our society.

ANNEXES

ANNEX A

OBJECTIVES AND SUB-OBJECTIVES, TARGETS AND PERFORMANCE INDICATORS

Objective 1: Disabled children and young people

To ensure that disabled children gain maximum life chance benefits from educational opportunities, health care and social care, while living with their families or other appropriate settings in the community where their assessed needs are adequately met and reviewed.

BY:

Sub-objective 1.1

Ensuring early identification of disabled children to enable them to access appropriate and timely intervention and support

Sub-objective 1.2

Ensuring that parents and disabled children receive reliable, comprehensive and culturally appropriate information about services on a multi-agency basis from the statutory and voluntary sectors.

Sub-objective 1.3

Increasing the number of disabled children in receipt of a range of family support services and the number of hours provided.

Sub-objective 1.4

Maximising the number of children with disabilities/special educational needs who receive good quality co-ordinated care and education in inclusive settings in their own communities.

Sub-objective 1.5

Ensuring that disabled children receive appropriate health care throughout childhood so as to enable them to participate fully in education, family and community life.

Sub-objective 1.6

Increasing the number of disabled children who use inclusive play, leisure and cultural services including holiday play schemes, after schools clubs and pre-school provision with appropriate support if necessary.

Performance against this objective and associated sub-objectives will be measured through the Quality Protects programme

The above sub-objectives build on existing Government Objectives for Children's Social Services and will be finalised in the autumn Quality Protects circular

Objective 2: Transition into adult life

As young people with learning disabilities move into adulthood, to ensure continuity of care and support for the young person and their family, and to provide equality of opportunity in order to enable as many disabled young people as possible to participate in education, training or employment.

BY:

Sub-objective 2.1

Ensuring that each Connexions partnership provides a full service to learning disabled young people by identifying them, deploying sufficient staff with the right competencies and co-ordinating the delivery of appropriate supports and opportunities.

The Connexions Unit headline target for young people at risk (including people with learning disabilities) is: participation and achievement over time to converge with those in the population in the same age group

Sub-objective 2.2

Ensuring effective links are in place within and between children's and adult's services in both health and social services.

Objective 3: More choice and control

To enable people with learning disabilities to have as much choice and control as possible over their lives through advocacy and a person-centred approach to planning the services they need.

BY:

Sub-objective 3.1

Promoting the rights of people with learning disabilities

Sub-objective 3.2

Enabling advocacy to be available for people with learning disabilities who want or need it.

Proposed Performance Indicator and PAF Indicator: The amount spent by each council on advocacy expressed as the amount per head of people with learning disabilities known to the council

Sub-objective 3.3

Making direct payments available to all those people with learning disabilities who request them and who meet the requirements of the scheme.

Proposed Performance Indicator: % of people with learning disabilities receiving community based services who are receiving direct payments

Sub-objective 3.4

Developing locally agreed protocols and procedures to ensure services are based upon a person-centred approach.

Sub-objective 3.5

Ensuring that people with learning disabilities are fully and actively involved in all decisions affecting their lives.

Objective 4: Supporting carers

To increase the help and support carers receive from all local agencies in order to fulfil their family and caring roles effectively.

BY:

Sub-objective 4.1

Assessing the needs of carers and putting in place the services required.

Proposed Performance Indicator: % of adults with learning disabilities receiving community based services who are receiving short term breaks

Sub-objective 4.2

Establishing a complete picture of the number of older carers (ie those aged 70 and over) in the local area in order to plan services in partnership with them.

Proposed Performance Indicator: % of carers aged 70 or over for whom a plan has been agreed

Sub-objective 4.3

Providing services and support that meet the needs of carers from minority ethnic communities.

Sub-objective 4.4

Making sure that all agencies work in partnership with carers, recognising that carers themselves have needs which must be considered.

Objective 5: Good health

To enable people with learning disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary.

BY:

Sub-objective 5.1

Reducing the health inequalities experienced by people with learning disabilities.

Sub-objective 5.2

Enabling mainstream NHS services, with support from specialist learning disability staff, to meet the general and specialist health needs of people with learning disabilities.

Sub-objective 5.3

Promoting the development of NHS specialised learning disability services which are evidence based and delivered with a focus on the whole person.

The Department of Health will develop performance indicators to compare the health status of people with learning disabilities with that of the general population and will consult on these.

Objective 6: Housing

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

BY:

Sub-objective 6.1

Increasing the range and choice of housing open to people with learning disabilities in order to enable them to live as independently as possible.

PAF PERFORMANCE INDICATOR: B14 Unit Cost of residential and nursing care for adults with learning disabilities

Sub-objective 6.2

Ensuring people with learning disabilities and their families obtain advice and information about housing from the appropriate authorities.

Sub-objective 6.3

Enabling all people currently in NHS long-stay hospitals to move into more appropriate accommodation and reviewing the quality of outcomes for people living in NHS residential campuses.

Target: Enabling the people currently living in NHS long-stay hospitals to move to more appropriate accommodation by April 2004

Objective 7: Fulfilling lives

To enable people with learning disabilities to lead full and purposeful lives within their community and to develop a range of friendships, activities and relationships.

BY:

Sub-objective 7.1

Modernising day services to enable people to exercise real choice over how they spend their days

Proposed Performance Indicators:

- **Gross expenditure on day care as a percentage of expenditure on all non-residential services**
- **Ratio of expenditure on day and domiciliary services for people with learning disabilities to expenditure on residential provision for people with learning disabilities**

Sub-objective 7.2

Enabling people with learning disabilities to have access to a wide range of opportunities for education and lifelong learning in order to promote greater independence and maximise employment opportunities.

The Learning Skills Council (LSC) will set targets as part of its equal opportunities strategy

Sub-objective 7.3

Enabling people with learning disabilities to make full use of transport and access mainstream community and leisure services.

Sub-objective 7.4

Supporting parents with learning disabilities in order to help them, wherever possible, ensure their children gain maximum life chance benefits.

Sub-Objective 7.5

Making sure that people with learning disabilities receive the social security benefits to which they are entitled.

Objective 8: Moving into employment

To enable more people with learning disabilities to participate in all forms of employment, wherever possible in paid work and to make a valued contribution to the world of work.

BY:

Sub-objective 8.1

Ensuring that more people with learning disabilities find appropriate employment, including supported employment, which makes the most of their talents and potential.

Proposed National Target: Increase the employment rate of people with learning disabilities and reduce the difference between their employment rates and the overall employment rate of disabled people

Proposed Performance Indicator: number of people with learning disabilities in work as a proportion of those with learning disabilities known to the council

Sub-objective 8.2

Making sure that people with learning disabilities are actively helped to access employment related advice and guidance through mainstream and specialist advisory services.

Sub-objective 8.3

Ensuring that public services provide a lead in the employment of people with learning disabilities.

Objective 9: Quality

To ensure that all agencies commission and provide high quality, evidence based, and continuously improving services which promote both good outcomes and best value.

BY:

Sub-objective 9.1

Demonstrating that people with learning disabilities and their families are increasingly satisfied with services provided.

Sub-objective 9.2

Ensuring that the needs of people with learning disabilities from minority ethnic communities are recognised and addressed through the provision of appropriate services.

Proposed Performance Indicator: the proportion of people with learning disabilities from minority ethnic communities who are receiving services divided by the proportion of all people in the local population from minority ethnic communities

Sub-objective 9.3

Ensuring that local quality assurance frameworks for social care and health meet the needs of people with learning disabilities.

Sub-objective 9.4

Ensuring people with learning disabilities receive best value from publicly funded services.

Proposed Performance Indicator: Number of people with learning disabilities known to the local council per head of general population

Sub-objective 9.5

Ensuring that local adult protection policies and procedures (including those for protecting vulnerable victims and witnesses of crime) are in place and fully complied with.

Objective 10: Workforce and planning

To ensure that social and health care staff working with people with learning disabilities are appropriately skilled, trained and qualified; and to promote a better understanding of the needs of people with learning disabilities amongst the wider workforce.

BY:

Sub-objective 10.1

Introducing the new national framework for training, competencies, qualifications and skill levels in the learning disability workforce.

Targets

- **From 2002 all new entrants to learning disability care services to be registered with Learning Disability Awards Framework**
- **By 2005 50% of front line staff to have achieved at least NVQ Level 2**

- **Proposed Performance Indicator: Percentage of staff working in learning disability services achieving at least NVQ Level 2**

Sub-objective 10.2

Promoting awareness among the wider workforce (in areas such as housing, the wider NHS, transport and the Department of Social Security) of the skills, attitudes and knowledge needed to work with people with learning disabilities in a positive and respectful manner.

Sub-objective 10.3

Ensuring that local workforce plans are developed.

Objective 11: Partnership working

To promote holistic services for people with learning disabilities through effective partnership working between all relevant local agencies in the commissioning and delivery of services.

BY:

Sub-objective 11.1

Establishing local Learning Disability Partnership Boards to take responsibility for local delivery of the White Paper, led by the local council and with the active participation of all key stakeholders.

Target Date: October 2001

Sub-Objective 11.2

Making effective use of the Health Act flexibilities.

Sub-objective 11.3

Promoting effective partnership working by staff from all relevant disciplines and agencies.

The Department of Health will be consulting further with the Local Government Association, the Association of Directors of Social Services and the NHS Confederation on the proposed indicators and consequential changes to the PAF Indicators. The agreed set of indicators will then be used to assess performance in the supplements to JIPs required by January 2002.

The Department of Health will be commissioning a national survey of people with learning disabilities in order to improve knowledge about the lives of people with learning disabilities and their families. It is anticipated that fieldwork would begin towards the end of 2001/2002.

ANNEX B

GLOSSARY

Childcare Development Partnerships – *aim is to establish good quality affordable childcare in all communities. From 2001 all will be required to identify and train a special educational needs (SEN) co-ordinator.*

Children's Fund – *£450 million Government programme targeted at preventive work with vulnerable children (primarily in the 6 to 13 age group). Strong emphasis on voluntary sector delivery.*

Connexions Service – *brings together into a single strategy across Government policies for young people aged between 13 and 19. Provides advice and support, gives particular attention to those at greatest risk of not making a successful transition to further leering and adulthood.*

Direct payments – *cash payments service users can receive from social services departments to purchase for themselves services to meet their assessed needs. The only service they cannot be used for is permanent residential care.*

Disability Rights Commission – *set up following recommendations from the Disability Rights Task Force and the Disability Rights Commission Act 1999 to work towards the elimination of discrimination against disabled people. Came into operation April 2000.*

Health Act flexibilities – *provisions in the Health Act 1999 enabling local authorities to work more closely with health authorities to provide improved services.*

Intentional community – *services operated by independent sector organisation comprising houses and some shared facilities on one or more sites and based on philosophical or religious belief.*

Joint Investment Plans (JIPs) – *plans produced jointly by local authorities, health authorities, and other local stakeholders for the integrated provision of services for a range of client groups.*

Learning and Skills Council – *set up under the Learning and Skill Act 2000. Has overall responsibility for post-16 education below higher education.*

Learning Disability Advisory Group – *set up in 1998 to advise Ministers on issues affecting people with a learning disability. Members include professionals, NHS and LA representatives, voluntary organisations, researchers, service users, and parents.*

NHS residential campus – *service operated by an NHS Trust comprising housing, some of which will be clustered on one site, together with some shared central facilities and developed as a direct result of the closure of NHS hospitals.*

NHS Plan – *contains proposals for ensuring that health services more fully meet the needs of patients.*

Old long-stay patients – *patients with a learning disability who were admitted to hospital prior to 1 January 1970 and who were still receiving care on 1 April 1996.*

Quality Protects – *Government programme designed to improve children's social services.*

Reprovisioning – *developing alternative settings for services currently or formerly provided in long-stay hospitals, large hostels, day centres etc.*

Sure Start – *Government programme aimed at promoting the physical, intellectual, and social well-being of pre-school children.*

Village communities – *service operated by independent sector organisation comprising houses clustered on one site together with some shared central facilities.*

ANNEX C

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The six working groups listed in Annex D considered papers prepared by their members on a range of subjects.

ANNEX D

ADVISORY GROUPS AND WORKING GROUPS

Learning Disability Advisory Group

Ann Gross, Disability Branch, Department of Health (Chair)

Colin Beacock – Royal College of Nursing
Norma Brier – Norwood Ravenswood
Maurice Brook – Rescare
James Churchill – Association for Residential Care
Jean Collins – Values into Action
Yvonne Cox – NHS Confederation
Ian Davey – Association of Directors of Social Services
Eric Emerson – Institute for Health Research (Lancaster University)
Rob Greig – Community Care Development Centre
John Harris – British Institute of Learning Disabilities
Fred Heddell – Mencap
Sheila Hollins – St George's Hospital Medical School
Mary Lindsey – Royal College of Psychiatrists
Joan Maughan* – National Development Team
Bill Robbins – Association of Directors of Social Services
Noel Towe – Local Government Association
Jan Webb – Success in Shared Care
Chris Wells – Department for Education and Employment

* replaced Simon Whitehead

Department of Health officials:
  Catherine Baines – Disability Branch
  Alistair Brechin – Disability Branch
  Sue Carmichael – Nursing Division
  Elaine Cooper – Disability Branch
  David Ellis – Inspector, Disability Branch
  Patricia Parris – Disability Branch
  Oliver Russell – Senior Policy Adviser (Medical), Disability Branch

Services Users Advisory Group*

Change:
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Mary Byrne
Andrew Gayle
Justine March
Jean Sapsford
Richard West

Mencap:
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James Calvert
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People First:
Michael Brookstein
Michelle Chinery
Andrew Lee
Carol Lee
Raymond Johnston
John Watson

Speaking Up Cambridge
Eve Rank-Petruzziello

Supporters
Tim Gunning
John Herzov
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Penny Mendonca

* Representatives from the Service Users Advisory Group are also full members of the Learning Disability Advisory Group

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Catherine Baines – Department of Health (Joint Chair)
Peter Smith – Department of Health (Joint Chair)
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Zoe Wentworth – Department of Health
Simon Whitehead – National Development Team

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Francis Ward – TOPSS England

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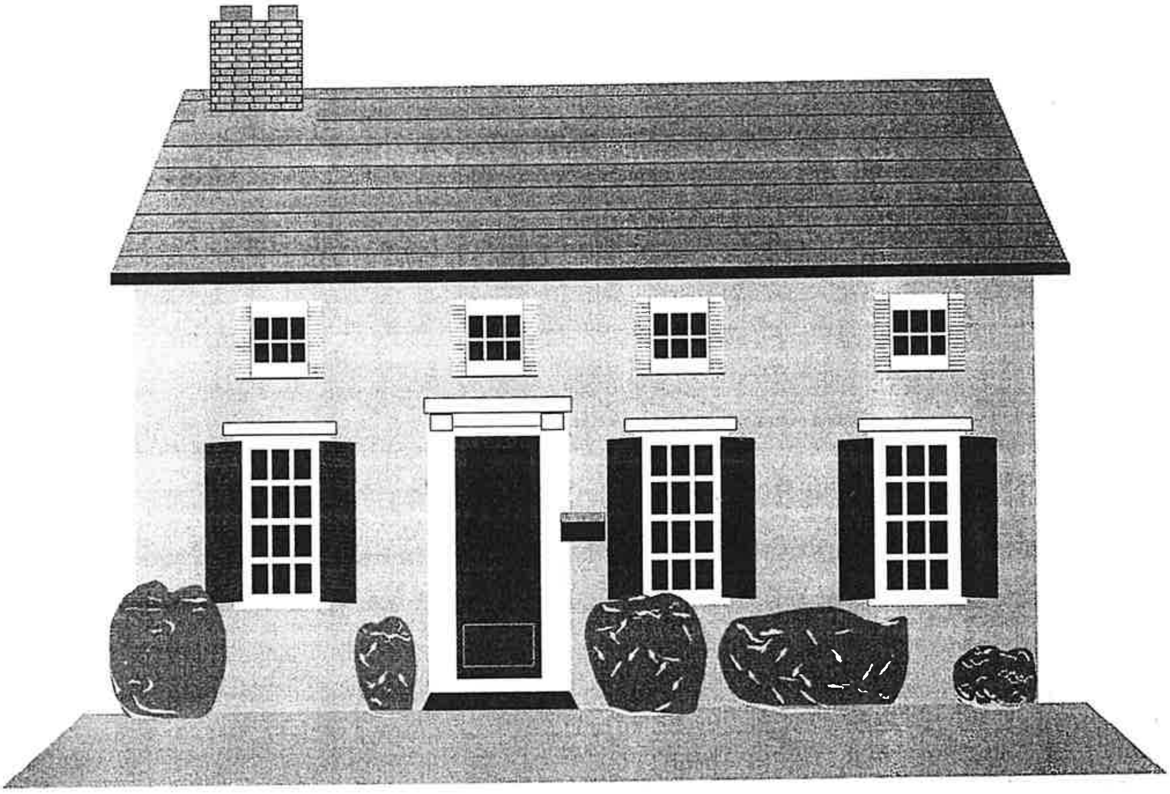
Bill Robbins – Association of Directors of Social Services
Wendy Wallace – Department of Health
Jan Webb – Success in Shared Care

Supported Living

An evaluation of three schemes in Northern Ireland for people with learning disabilities



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Contents

Acknowledgements

Our grateful thanks to the tenants, staff, relatives and all others who answered our queries. This study was funded in part by South & East Belfast HSS Trust.

Acknowledgements

Our grateful thanks to the tenants, staff, relatives and all others who answered our queries. This study was funded in part by South & East Belfast HSS Trust.

Executive Summary

Supported living is no longer a novel concept for people with learning disabilities. It is well established in North America and is increasing used in Britain. There is strong empirical evidence that it delivers better outcomes for tenants than other forms of residential options (Simons, 1998).

It has been defined as follows. *"Supported living is primarily about enabling people with learning disabilities to be actively engaged citizens through:*

- *Supporting them to live in their own homes (owned or rented by them)*
- *Enabling them to participate in their communities (for example through working if they wish) (*Simons and Watson, 1999: *p.41).*

The key features of the supported living approach (as distinct from residential or group homes) can be summarised as follows.

- The person with learning disabilities has a tenancy agreement with a housing provider.
- The house is not registered with the local authority or Health and Social Services Board.
- No more than three people share the same living unit.
- Funding for support staff can come from housing payments and social security payments.

To date there have been no studies in N. Ireland of supported living options. An evaluation of existing schemes would help to identify their strengths and weaknesses. It would also inform the development of similar schemes elsewhere as this model is attracting interest from both housing and social service agencies.

Three supported living services

Triangle Housing Association are directly involved in the management of three schemes for a total of 36 tenants with learning disabilities with a fourth scheme coming on stream in Ballymoney in 2001.

Two schemes have been operative from 1992 based in Ballymena (Tower Court) and in Ballycastle (Kiln's Court). Both these developments consist of a mix of single and two-person housing in the grounds of a registered home for more dependent people with learning disabilities.

A further scheme was opened in 1998 in association with South and East Belfast HSS Trust for seven tenants with learning disabilities and additional needs. This consists of five purpose-built bungalows arranged in a small cul-de-sac at the entrance to Belvoir Park Housing Estate.

The Trust had been actively involved in developing supported living arrangements as an alternative to hostel accommodation, largely for more able people with learning disabilities. They instigated the Gray's Park scheme with a view to extending and testing the supported living model to people with more complex needs. Another development with Triangle Housing is currently being planned (Sandown).

Further details of the schemes are given in Part 2 of the report.

Evaluation Process

The aims of the evaluation were common to all three schemes, namely:

- ☐ To develop a shared vision of what supported living means for people with a learning disability who are tenants in the supported housing provided by S&E Belfast Trust and/orTriangle Housing Association.
- ☐ To obtain the reactions of various stake-holders – tenants, staff, managers, relatives, professional workers and friends of tenants – involved with the three housing schemes. This is in terms of what is going well and what needs to be improved.
- ☐ To develop action plans for improving the schemes.
- ☐ To identify lessons that will assist in improving supported housing schemes both locally and elsewhere in N. Ireland and beyond.

Information about Gray's Park Court was collected in 1999 and again in 2000 so that changes could be monitored. Comparisons are also made among the three schemes and with data reported by Emerson et al (1999) for 63 tenants in six schemes in Britain which were judged as exemplars of good practice.

Part 3 of the report provides detailed information on the evaluation process.

Gray's Park Court

All the evidence gathered suggests that Gray's Park Court continues to achieve many of the objectives that were set for the project at outset, namely:

- To provide ordinary inclusive housing for individuals assessed as requiring 24 hour support due to their level of cognitive impairment and additional physical and/or mental health disorders

- To provide 24 hour, person centred support which enables tenants to live safely in their own home and at the same time improve their overall quality of life and contribution to the local community.
- To develop a model of joint working that effectively and efficiently mobilises resources for each tenant.
- Many of the aspirations contained in the Vision statement developed by the stake-holders at the first review gathering (see p. 20) are being fulfilled.

The issues that require to be addressed appear to result from the development of a new model of service delivery that is still unfolding.

Concerns about the physical care of the tenants appear to have been satisfactorily addressed alongside with managing the risks of living more independently.

The social inclusion of the tenants into the wider community is still tenuous but slowly improving.

The current difficulties in staffing may not be speedily resolved but they do require urgent attention. Good staff have been attracted and nurtured in the past and hopefully will be again but changes in staffing arrangements may need to be made in response to the changing labour market.

The tensions between a supporting housing model in a clustered residential setting will probably need to be continuously managed, explained and even agonised over. Compromises, inconsistencies and disagreements among stake-holders will probably have to be tolerated for some time to come.

Further details of the evaluation of Gray's Park Court are given in Part 4.

Tower Court and Kiln's Court

Overall, the comments from tenants, staff and relatives confirm that many elements of the vision statement (p. 32) for these two Courts are being realised. Tenants are broadly happy living in the Courts; most feel safe living there; they are given choices in their lives and they have changed for the better since moving there. They appreciate the help of staff and the sleep-over arrangements provide extra security of them. Contact with relatives is good but there appears to less contact with the wider community than the tenants would like.

The main issues that needed addressing in addition to community linkages were improvements to the houses and the location; greater opportunities for tenants to become more self-reliant and increasing staffing levels along with having dedicated staff who supported the tenants.

More details are given in Part 5.

Comparison of the Courts

The tenants in the Tower Court and Kiln's Court schemes tend to be more competent than those at Gray's Park Court with fewer behavioural and mental health problems and fewer have epilepsy. However the Gray's Park Court tenants more closely resemble those in supported living arrangements in Britain which suggests that supported living is a feasible option for more dependent tenants with challenging behaviours, mental health problems and epilepsy.

Overall, the tenants in supported living appear to have more choices open to them and to enjoy better quality of life experiences. Sizeable proportions will have had health checks carried out although not to the same extent as reported in Britain. There were concerns about the risks that tenants might experience and in some instances these appear to be higher than those reported in Britain.

Over the course of one year there were few significant changes in the Gray's Park Court tenants with the exception of a reduction in stereotypical behaviours. However there were indications of improvements in their socialisation skills and a decline in their number and time skills. They also tended to be less lethargic and to have had fewer stressful life events.

Part 6 describes the results on which these conclusions are based.

Costs

The costs of the three schemes in N. Ireland fall into the lower range of costs reported for the British schemes and yet they appear to be serving a comparable tenant group and producing similar outcomes.

In two of the schemes the costs are met entirely by housing monies and social security payments while in Gray's Park Court, the HSS Trust contributes 20% of the costs. This contrasts sharply with the British schemes which were funded mainly by health and local authorities.

Further details are given in Part 6.

Conclusions and recommendations

Experience in N. Ireland confirms the advantages of supported living arrangements that have been reported internationally.

Supported living has been done at remarkably low cost to Health and Social Services bodies. This has resulted from partnerships with Housing Associations and the use of social security payments; housing benefits and the Independent Living Fund.

Although supported living may not suit everyone, it does meet with the approval of tenants and relatives who have experienced it. It also seems to be the preferred option when people with learning disabilities and their families were consulted on future living options[1].

Hence HSS Trusts and Boards in N. Ireland should urgently develop plans to extend the number of supported living placements they can offer to people being resettled from Muckamore Abbey Hospital; people living with family carers who are no longer able or available to care for them; and people in existing residential homes and hostels who want to move on.

The roles and conditions of staff in supported living services needs to be reviewed and payments made commensurate with the demands of the job.

The clustered living arrangements used in these three schemes may be a pragmatic response to supporting more dependent people but it does bring inherent tensions. It is neither the best or only option but rather one of several possibilities.

Supported living per se does not result in greater social inclusion. Rather these schemes need to integrate with a range of initiatives in employment, advocacy and befriending.

In Britain, policy directives have been placed on housing bodies, health and social services to extend supported living options. This has not happened in N. Ireland.

New equality and rights legislation may make supported living an essential means of providing housing and support to a client group who are not ill, who do not require nursing care and who are not elderly.

These conclusions and recommendations are amplified in Part 7.

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[1] *McConkey, R. and Barr, O. (2000) Future housing and support needs of people with learning disabilities and their families. Ballymena: NHSSB & NI Housing Executive.*

1. Supported Living – A New Approach to Housing and Support

In Northern Ireland, most adult persons with a learning disability live with their families. Those who live away from their families; mostly reside in nursing or residential homes with only a very small proportion having their own houses or tenancies (McConkey and Barr, 2000). For example a census of residential accommodation In the Northern Health and Social Services Board area in October 1999 found that only 8% of persons were living in their own homes or in small registered homes (see Figure 1).

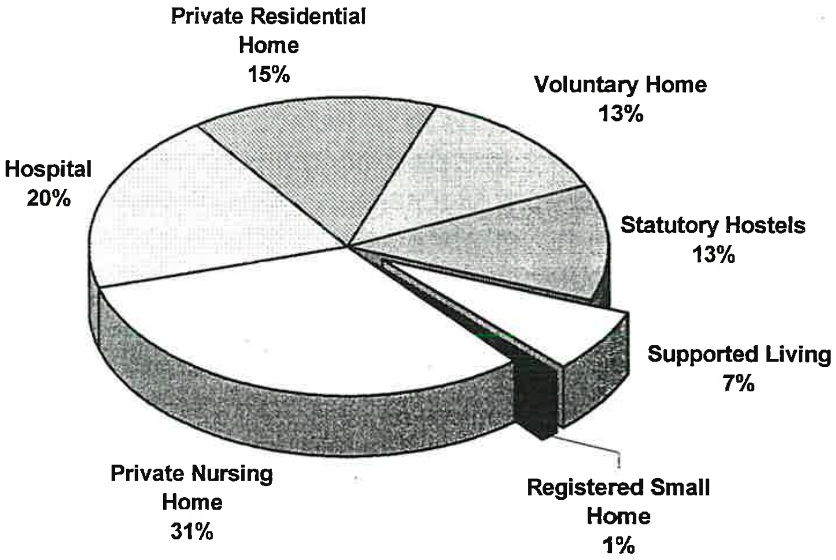

Figure 1: The proportion of places in different forms of residential accommodation in NHSSB – October 1999. (N=512 places)

The pattern is similar in England and Wales. Emerson and Hatton (2000) undertook an analysis of the 1997 Census of residential accommodation. This suggested that only 13% of adults lived in homes with less than 5 persons; 38% were in homes with between 5-9 persons and nearly half (49%) lived in settings with 10 people or more. Likewise in hospital resettlement programmes, very few people (4%) were found to be living independently (Cambridge et al, 1996)

In the United States, the 1996 census of people in residential services showed a rather different picture. Just over half (51%) lived in one to six person settings with 14% in facilities for 7 to 15 persons. A further 21%

lived in residential or nursing homes for 16 or more persons and the remainder in state institutions (Braddock, 1999).

Supported Living

The concept of supported living which emanated from the United States comes closest to the norm for our society, namely people being supported to live in their own homes; usually in rented accommodation to which they have the tenancy. A tenant may live alone or with one or two friends or as a married couple. Visiting staff come to the house to assist the tenant(s) in designated ways. This may be for a few hours a week or for a number of hours each day. Variations on this model include offering free accommodation for students (or others) within a block of flats if they provide support for other neighbouring tenants with learning disabilities (Simons and Watson, 1999).

Proponents of this model argue that it is built around four principles – person-centred planning; individualised support; bridge building into community networks and change in existing service systems (Kinsella, 1993). It is not a single model and it certainly is more than de-registering homes and giving people their own tenancy.

Simons and Watson (1999) define it as follows:

> *"Supported living is primarily about enabling people with learning disabilities to be actively engaged citizens through:*
> - *Supporting them to live in their own homes (owned or rented by them)*
> - *Enabling them to participate in their communities (for example through working if they wish (p.41)*

However these authors recognise that there are many different kinds of arrangements for different circumstances and with different kinds of strengths and weaknesses. In many ways, supported living is better view as a way of thinking about housing and support services rather than a set of instructions to be followed (Kinsella, 1993).

Nevertheless the key features of the supported living approach (as distinct from residential or group homes) can be summarised as follows.

- The person with learning disabilities has a tenancy agreement with a housing provider.
- The house is not registered with local authority or Health and Social Services Board.
- No more than three people share the same living unit.

- Funding for support staff can come from housing payments and social security payments.

Although the evaluation of supported living services has been sparse internationally, there are indications that this model of services has distinct advantages. Emerson et al (1999) identified the following as advantages of supported living over group homes and residential campuses:

- people are more likely to have tenancy agreements;
- they tend to deliver more intensive staffing;
- there are better internal procedures for allocating staff support on the basis of the needs of tenants;
- evidence of greater tenant's choice (especially over where and with whom they live.
- better social integration and access to leisure and recreational activities
- more contact with relatives

The disadvantages compared to other models were found to be:

- fewer hours of scheduled activity;
- more likelihood of having their home vandalised;
- poorer implementation of habilitative procedures such as individual plans; key-workers and reviews.

Simons and Watson (1999) concluded from their review of housing options that

> *"supported living can claim to be a practical as well as a principled option, one that has a legitimate claim to be a key part in any commissioning strategy" (p. 47).*

Supported Living in N. Ireland

To date there have been no studies in N. Ireland of supported living options. An evaluation of existing schemes would help to identify their strengths and weaknesses. It would also inform the development of similar schemes elsewhere as this model is attracting interest from both housing and social service agencies.

2. Three Supported Housing Schemes

In N. Ireland, one of the leading providers of supported living arrangements for people with learning disabilities has been Triangle Housing Association. They are directly involved in the management of three schemes for a total of 36 tenants with learning disabilities with a fourth scheme coming on stream in Ballymoney in 2001.

Two schemes have been operative from 1992 based in Ballymena (Tower Court) and in Ballycastle (Kiln's Court). Both these developments consist of a mix of single and two-person housing in the grounds of a registered home for more dependent people with learning disabilities.

A further scheme was opened in 1998 in association with South and East Belfast HSS Trust for seven tenants with learning disabilities and additional needs. This consists of five purpose-built bungalows arranged in a small cul-de-sac at the entrance to Belvoir Park Housing Estate.

The Trust had been actively involved in developing supported living arrangements as an alternative to hostel accommodation, largely for more able people with learning disabilities. They instigated the Gray's Park scheme with a view to extending and testing the supported living model to people with more complex needs. Another development with Triangle Housing is currently being planned (Sandown).

In this section a description is given of the three established schemes.

Tower Court - Ballymena

Tower court was opened in 1992 with six new flats added in 2000. It presently has 18 tenants (15 at the time of the evaluation). It consists of 10 single person units and four, two person houses in the grounds of Tower House (a registered residential home for 13 people with learning disabilities) with another house for one person off the site but close by. The development is reasonably close to the centre of Ballymena.

The staff sleep-in room is located in one of the two person houses.

There is an establishment of 7 full-time staff and 3 part-time staff; each working 20 hours. In addition there is an on-site manager. This provides a total of 356 hours per week plus another 63 hours of sleep-in cover. Generally three staff are available at evenings and weekends.

Kiln's Court - Ballycastle

Kiln's Court was opened in 1992 . There are 11 tenants living there; four in single person houses and seven in two person houses (the staff sleep-in room is accommodated in one of these houses).

The houses are in the grounds of a registered residential home for 10 people with learning disabilities. The development is on the outskirts of Ballycastle.

There is an establishment of 6 full-time staff plus a fulltime manager on site. This provides a total of 259 hours plus 63 hours of sleep-in cover. Generally two staff are available at evenings and weekends.

Common features and procedures in these two Courts

Tenants

There are four eligibility criteria for tenancy in the courts:

1. the person is assessed as having a learning disability;
2. they are aged 18 years and over;
3. they are assessed as requiring clustered accommodation and requiring personal support;
4. they are able to integrate successfully with the other tenants.

Referrals can come from the person directly; their family carer and from the Community Learning Disability Team. Under the new Housing Executive procedures, their names are added to the waiting list held under the Common Selection Scheme. These are prioritised in order of need.

The tenants have come from their family home or they have been resettled from hospital or residential homes. Some tenants have moved on to more independent living arrangements both with and without support.

Each person has his or her own tenancy with Triangle Housing. This also applies to those who share a house. None of these properties are registered with the local health and social services board.

All tenants are enrolled with a local day centre or they attend work placements organised by the Triangle's supported employment scheme. Some also attend College courses. A few are in part-time paid employment. However each tenant spends one day per week at home for shopping, medical appointments, household chores etc.

Funding

The capital costs of the houses were borne by housing grants from the Department of the Environment to Triangle Housing and this is recouped in part through rentals paid to Housing Association. Triangle cover the costs of redecoration and carpeting for new tenants and provide the white goods.

Revenue funding comes from a number of sources with variations across tenants: Housing Benefits; Special Needs Management Allowance (from Dept. of Social Development); Income Support, Severe Disablement Allowance and Disabled Living Allowance (Care component). No additional monies are paid by health and social services. Hence none of tenants have a care manager although all have a named social worker.(see p.17)

In addition low or medium mobility allowances are paid to tenants. In each of the Courts, one tenant has purchased his or her own car through mobility allowances. The other tenants have agreed to pool their monies and they have the use of a fleet car that is based at each Court. A log is kept of the mileage used by each tenant so that equitable use is monitored.

All monies are handled on an individual tenant basis; both income and expenditure. Tenants are supported by staff in doing this.

Staffing

The main role of staff is to provide personal care support for tenants in cooking meals, household chores, personal care needs, shopping and managing their budget.

In each court, staff are available 24 hours a day. One staff provides sleep-in cover from 10.00 pm to 7.00 am. Staff work a mix of long shifts (10.00 am to 10.00 am following day including sleep-over) or split shifts depending on needs of tenants.

The staff team is pooled with the residential home and every two months, staff rotate working in the Courts with working in the home.

All the houses are connected to the staff sleep-in room by an intercom system plus staff carry a bleep so that they can be easily contacted when they are on-site.

In each Court, the manager holds a nursing qualification and some support workers have social work and psychology qualifications. All the support workers have completed NVQs in Social Care at level 2 and some at Level 3. In addition, visiting support and supervision is provided daily by

Triangle's Support Services Manager (Margaret Cameron). Also 24 hour management back-up is provided through an on-call system.

Gray's Park Court – Belvoir, Belfast

This scheme opened in 1998 and consists of five, two-bedded bungalows in a cul-de-sac on the edge of the Belvoir Housing Estate built by Triangle Housing Association. Two people share in two bungalows while the other three have single occupants. (However the spare bedroom in one house is used as a staff sleep-in room cum office).

Over the past two years there have been changes to the way the scheme is managed and these are described below. The first part describes arrangements at the scheme's inception.

Tenants

Tenants were invited to apply for a place at the scheme and they were given trial visits and overnight stays before their tenancy was confirmed. Of the five original tenants, one had been previously resident in Muckamore Abbey; three in community hostels run by S&E Belfast Trust and one had lived at home with his parents.

Each person has their own tenancy with Triangle Housing. This also applies to those who share a house (see later).

All tenants are enrolled with a local day centre or they attend work placements or College courses. They are transported by Trust buses.

However each person spends one day per week at home for shopping, medical appointments, household chores etc.

Staffing

Staff are available 24 hours a day. One staff provides sleep-in cover from 10.30 pm to 7.30 am. Two staff are then rota'd from 7.30 am to 10.30 pm with three at busy times and weekends.

There was an establishment of nine staff; initially five on a full-time basis and four part-time. (Later this became seven fulltime staff in order to have fewer people involved with the tenants.) Two were employed by Triangle Housing both as Housing Support workers and as Person Care Assistants and a further four as personal care assistants. Three are employed by the Trust as Care Support Workers. However all staff are managed by the Trust through their supported living service. A total of 364 staff hours per week is funded (including 56 hours for sleep-in cover).

Personal Care support is provided to tenants for cooking meals, household chores and personal care needs.

All the bungalows are connected to the staff room by an intercom system. One bungalow is equipped with a computerised controlled system to open doors, switch on electrical appliances and lights.

Funding

The capital costs of the houses were borne by housing grants from the Department of the Environment to Triangle Housing and this is recouped in part through rentals paid to Housing Association. The Trust covered some of the costs of furnishings and other physical aspects of the houses. In addition community care grants of £1,300 were obtained from social security for the furnishings.

Funding comes from a number of sources with variations across tenants: Independent Living Fund; Housing Benefits; Special Needs Management Allowance (from Dept. of Environment); Income Support, Severe Disablement Allowance; Disabled Living Allowance (Care component) and Personal Support Care monies from S&E Belfast HSS Trust (see p.51). These total to nearly £750 per person per week for four tenants. In addition medium or higher rate mobility allowances are paid to tenants. Management costs incurred by the two agencies are *not* costed to the scheme.

One tenant has purchased his own car through mobility allowances. Use is made of taxis or staff cars for shopping and social events.

All monies are handled on an individual tenant basis; both income and expenditure by the Housing Support staff. They are also responsible for any maintenance issues.

Changes up to May 2000

Two tenants moved in to share a house with two existing tenants. Previously they had been living in a hostel managed by S&E Belfast Trust and were considered 'friends' of the existing tenants.

Video cameras were installed in one bungalow with TV monitors in the staff sleep-in room so that staff could monitor the night-time movements of one tenant.

An advocacy scheme begun by South and East Belfast Trust (PAL) to provide an independent advocate for those clients considered to be the most vulnerable, became involved with the tenants at Gray's Park Court.

Changes from June 2000

Two staff provide sleep-in cover.

All staff are now employees of Triangle Housing but managed by South and East Belfast Trust as part of their supported living service.

Staff are employed as either housing support workers or personal care assistants although for historical reasons two staff still combine these roles.

The basic salary of support workers has been increased and a three-point scale introduced.

3. The Evaluation Process

The evaluation of the supported living scheme at Gray's Park was commissioned in 1998 by South & East Belfast HSS Trust and Triangle Housing Association. This was intended to be prospective study over the course of 18 months so that changes in the scheme and in the tenants might be monitored.

At the completion of this evaluation it was decided to extend the evaluation to other schemes provided by Triangle Housing Association. This would help to identify the differences between the tenants at Gray's Park Court and those in other schemes and also to confirm if the same issues that arose in Gray's Park were common to other supported living schemes.

However the aims of the evaluation were common to all three schemes, namely:

- ☐ To develop a shared vision of what supported living means for people with a learning disability who are tenants in the supported housing provided by S&E Belfast Trust and/orTriangle Housing Association.
- ☐ To obtain the reactions of various stake-holders – tenants, staff, managers, relatives, professional workers and friends of tenants – involved with the three housing schemes. This is in terms of what is going well and what needs to be improved.
- ☐ To develop action plans for improving the schemes.
- ☐ To identify lessons that will assist in improving supported housing schemes both locally and elsewhere in N. Ireland and beyond.

Evaluation Process

A broadly similar process was used for the evaluation of the three schemes although this was more detailed with the evaluation of Gray's Park Court than with the other two courts.

The approach used aimed to engage the participation of all stake-holders; to empower them to make their views known; to enable them to listen to views of others and to encourage them to find their own solutions to the issues that require to be addressed. This developmental approach to evaluation contrasts with the more usual 'inspectorial' approaches that have dominated to date (Dunne et al, 1996).

The main steps involved in the evaluation were:

- ☐ The evaluation process was first discussed with the senior managers of S&E Belfast Trust and Triangle Housing Association. This helped to scope the main issues to be addressed during the evaluation and to plan a meeting of all the stake-holders.
- ☐ A meeting for the stake-holders – tenants, staff, family members and Trust personnel – was held at the outset to inform them about the evaluation. This was facilitated by Roy McConkey. Through work in small groups and then as a large group, a vision-statement was created for the court (see later). Decisions were also made about the people who should be approached to give their opinion about the Courts.
- ☐ In the case of Gray's Park Court a steering group[2] with representatives from the main stake-holders was also formed following the first meeting. They provided advice and guidance on the information to be gathered; the identification of key issues for action and the planning of subsequent stake-holder meetings.
- ☐ Research staff devised structured interview schedules and self-completion questionnaires which covered the various elements of the Vision that stake-holders held for the Courts. In addition standardised assessment tools were identified for measuring certain client characteristics and service outcomes. These were completed by key-workers in conjunction with their tenants if possible.
- ☐ Research staff undertook individual interviews with the tenants and relatives in Gray's Park Court and telephone interviews were conducted with relatives of the tenants in the other two courts. Questionnaires were completed anonymously by staff in the Courts; professionals workers in health and social services; befrienders and employers of certain tenants.
- ☐ A draft report of the findings from this information gathering was prepared for senior managers and the Steering Group for Gray's Park. Factual corrections and changes in emphasis were then made and a shortened version of the report prepared for distribution to the stake-holders.
- ☐ A second meeting of stake-holders was then held. Proposed action plans for dealing with the issues raised were developed at this meeting with the participants. These were then incorporated into the final report that was submitted to the commissioners of the evaluation.

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[2] *Initially this consisted of: : Gillian Ferguson (tenant); Gary Leebody (tenant); Louise Patterson (tenant); Alan Patterson (family); Suzanne Thompson (staff); Karen Cove (staff); Ian Williamson (staff); Pauline Black (professional); Tony McQuillan (housing executive). They joined members from the management group: Winnie Hughes, Maureen Hunter, Helen Boyd and Maurice O'Kane (S&E Belfast Trust) and Chris Alexander Triangle Housing).*

Information Gathered

The evaluation yielded two main types of information. For each supported living scheme detailed qualitative information was obtained using interviews and self-completion questionnaires from a range of stake-holders.

Quantitative information was also obtained about each tenant using a variety of rating scales and checklists covering Health Issues; Challenging Behaviours; Adaptive Behaviours; Mental Health Screen; Risks, Choices and Lifestyle.

In addition the evaluators visited the Courts on various occasions and at different times and observed tenant activities and interactions with staff.

In summary, the following information was obtained:

Gray's Park Court

Information was gathered at two time points: 1999 and 2000.

1999:

- Individual interviews were conducted with five of the six tenants; with four of the five relatives and the two sets of managers of the project.
- Written questionnaires were sent to all staff working at Gray's Park Court, day centre staff and professional workers in the Trust and befrienders linked with each client. These could be completed anonymously. However the response from all but the staff was poor.

2000:

- Information was obtained through interviews with six of the seven tenants; with three of the five family carers and with four senior managers.
- In addition written questionnaires were completed by staff (5); service personnel who know the tenants (4) and a friend of a tenant (1). However the response to written questionnaires was again disappointing.

Tower Court and Kiln's Court

For the purposes of the evaluation these two schemes were treated together,

- Interviews were conducted with 25 of the 26 tenants; one person declined to participate.

- Questionnaires were returned from five of the 11 staff working at Tower Court and five of the seven staff at Kiln's Court.
- Seven questionnaires were returned from the 15 professionals whose names were supplied by Triangle staff as being in contact with some of the tenants in the two Courts.
- Nine telephone interviews were conducted with relatives of the tenants. Contact could not be made with the relatives of a further five tenants who had known relatives.
- Questionnaires were also received from two befrienders and two employers who had contact with tenants.
- Information was also obtained from senior managers at Triangle at meetings and through interviews.

Results of the Evaluation.

The findings are presented separately for Gray's Park Court and for the two other supported living schemes at Tower Court and Kiln's Court.

This begins by providing the vision that stake-holders had developed at their first meeting. The emphasis then is on providing details on what a consensus of respondents felt was 'going well'. Specific issues that require to be addressed are then summarised along with action plans that were proposed for dealing with these, either at the second stake-holder's meetings or by the Steering Group (in the case of Gray's Park Court) or the evaluator's discussions with the managers.

Part 6 of the report summarises the quantitative data and provides comparative information across the three schemes along with published data relating to 63 tenants of six supported living schemes in Great Britain.

The final section of the report identifies the main lessons about supported living that have wider applicability for service planners and managers in N. Ireland and beyond.

4. Evaluation of Gray's Park Court

Overview

This section presents the Vision statement for this scheme as developed by the stake-holders including tenants, staff, relatives, befrienders and Trust staff. The main features of the scheme that are perceived to be going well as summarised as are the issues that needed to be addressed; namely staff turn-over/absences' sleep-in cover; staff roles; the social inclusion of tenants; keeping true to the concept of supported housing; cost-benefits and tenants moving on.

The Vision for Gray's Park Court

The vision was developed at the first meeting of the stake-holders in November 1998. No changes were made when it was re-considered at the second gathering in June 2000.

Gray's Park Court is ..

- people living in their own homes; making choices
- comfortable homes
- homely atmosphere
- offers privacy and quietness
- people get on with each other
- people are safe and secure

- it encourages people to do things for themselves
- it nurtures self confidence/esteem
- assistance is available when required

- a meeting place
- go out to other places/people
- use local facilities
- builds friendships

- it's a unique place; the first of its kind
- different sources of money are used to fund the services
- assurance for the future
- families are involved

What is going well

The different people consulted were able to identify various achievements and aspects of the project that feel are going well. The opportunity to assess this at two points in time separated by about 12 months increases the reliability of these findings.

People with a range of complex needs continue to live there.

The seven tenants are individuals with diverse needs. One had been previously resident in Muckamore Abbey; five in community hostels run by S&E Belfast Trust and one had lived at home with his parents. Two people are wheel-chair users and two have a history of epilepsy. All the tenancies have been able to be maintained for upwards of two years and up to the date of the second evaluation no one had been admitted to a Specialist Hospital.

Tenants are broadly happy at Gray's Park Court

This was mentioned by all parties but notably the tenants themselves. They gave various reasons; the staff working there, the outings; the people they live with or beside; the space in the house and having Sky TV. One tenant said: *"it's far far better than (naming the hostel)."* Her close friend commented: *"I wasn't for the move but N. has surprised me and has settled well; a few ups and downs but that's life. I am pleased now."*

There are clear benefits to tenants of living at Gray's Park Court

The most commonly mentioned benefits were having your own house, independence; choice and having a more person-centred service. The level of funding to support the tenants is very much greater than the monies available for other forms of residential care, such as hostels.

The standard of houses and décor is good

All parties commented favourably this on. Tenant involvement in the decoration and choice of new furnishings was particularly valued. However mention was made of the houses being "too tidy" and not have a 'lived-in' look with the usual 'clutter' found in family homes.

Contact with family and friends

Contacts take place both at Gray's Park as well as in the family home. Relatives and friends feel they are able to drop-in at any time and they are made welcome by the staff. The tenants also invite friends for meals. The spare bedroom in two houses could be used for friends to stay over and this happened occasionally. This option is not available for tenants who share but none mentioned that they would like to invite friends to stay over.

Contact with staff

Last year comments were made about difficulties relatives and others had in contacting staff. These appear to have been largely resolved; with staff returning calls when messages are left on the answering machine. Staff are generally described as friendly and helpful.

Tenants are involved in various activities outside the home

All the tenants reported a range of activities in which they participated; including attendance at day centres; work placements; educational courses; attending special clubs; going to the cinema and bowling; having drinks and meals out, swimming and shopping. Two tenants now attend church regularly with church members calling to help with transporting the tenant. Each tenant spends a weekday at home when they do their shopping. The involvement of other agencies such as Orchardville Society's befriending scheme and Gateway Clubs has helped. Four tenants went to Spain on holiday in 1999 and three in 2000 with the Gateway Club.

Low level of risk

The issue of risk was given particular attention due to the needs of the tenants and the type of housing model provided for them. However the tenants and relatives felt that adequate systems were in place to guard against risks; i.e. 24 hour staffing; grouped housing in quiet location and the use of technology such as call systems. Certain individuals were thought to be more at risk than others primarily due to their tendency to wander or presence of epilepsy.

Health and safety issues in the home, such as falls or when crossing roads were the most common concerns mentioned but very few concerns were expressed of abuse from other tenants, staff and neighbours. Management undertook an investigation when it appeared that the dignity and rights of individual tenants were not being respected.

In the past 12 months there had been only a few instances when a tenant's well-being was threatened.

Tenants have improved since moving there

In 1999, relatives, staff and the tenants themselves were able to note ways in which the tenants had improved since coming to Gray's Park Court. Examples include:, feeling calmer, settled and relaxed; respecting other people's views; more independent; cooking meals and doing housekeeping chores ; less aggression; more assertive, more sociable; better sleep and eating patterns.

One year on, the picture was not so clear. The relatives felt their tenant had not changed or in one instance had deteriorated. Other professionals, staff and friends reported changes for certain people; namely, more relaxed, fewer seizures, making decisions and more independent.

Three tenants felt they had changed; all mentioning being able to talk to people:

> *"I'm a different personality: can talk to people more"*
> *"I'm an adult, know right and wrong. I'm a calmer person, not as often angry. More talkative and friendly"*

But two others felt they were little different. One commented:

> *"Changed a wee bit: I'm a bit older. I feel just the same – I'm able to do the same things."*

The two other tenants were not able to comment.

Joint Working between Triangle Housing Association and S&E Belfast Trust

A good working relationship has been established between both parties who share a common value-base. The Joint Management Group which has meet since the inception of the project has assisted the relationship and the Operational Group which meets quarterly deals with day-to-day issues. The responsibilities of the agencies are being redefined as the project unfolds. Both parties need to continue to work together in order to fund the scheme but their complementary expertise produces a better service for the tenants as well as providing another form of accountability.

Secured funding package for the housing scheme has been created

The scheme is funded by a combination of monies; Independent Living Fund; Housing Benefits; Special Needs Management Allowance (from Dept. of Environment), Severe Disablement Allowance; Disabled Living Allowance; Income support along with Personal Support Care monies and day services from S&E Belfast HSS Trust. (The latter also contribute managerial costs and they covered the costs before certain monies were secured). For four individuals this totals to nearly £850 per week (inclusive of day care but not managerial costs). In addition, certain tenants receive DLA mobiity allowances.

All these sources of income seem secure in the long-term with the only possible threat being a reduction to Housing Benefits under new Government proposals.

Systems for handling money are working well

Each tenant's finances is managed individually and all payments and bills etc are paid through their bank account. Book-keeping and auditing systems are working well. The Housing Support workers (employed by Triangle Housing) have particular responsibility for this. Managers are happy to supply relevant parties (e.g. relatives, advocates) with full details of individual tenant's income and expenditure if the tenant is agreeable.

An independent advocacy scheme has been established

S&E Belfast Trust have commissioned an advocacy service from Bryson House for the clients in their services who are deemed to be most vulnerable. Two paid advocates with experience of citizen rights have been appointed recently; they are involved with all the tenants at Gray's Park Court and they can by-pass operational managers and bring issues and concerns to the attention of the Trust's CEO or his officers. Already they have raised issues on behalf of particular tenants with management. This provides an additional safeguard for the tenants.

Conclusions:

All the evidence gathered suggests that Gray's Park Court continues to achieve many of the objectives that were set for the project at outset, namely:

- To provide ordinary inclusive housing for individuals assessed as requiring 24 hour support due to their level of cognitive impairment and additional physical and/or mental health disorders
- To provide 24 hour, person centred support which enables tenants to live safely in their own home and at the same time improve their overall quality of life and contribution to the local community.
- To develop a model of joint working that effectively and efficiently mobilises resources for each tenant.
- Many of the aspirations contained in the Vision statement developed by the stake-holders at the first review gathering (see earlier) are being fulfilled.

Issues to be addressed at Gray's Park Court

In this section, the issues identified in 1999 which stake-holders felt required attention are summarised along with others that had arisen in the 2000 consultations. Possible action steps are identified. These are based on recommendations offered by stake-holders; discussions held with managers and comments at the second stake-holder's meeting. (These are discussed more fully in Part 7 of this report.)

The dominant issue was staffing. Three aspects of this are identified along with other issues that have been raised.

Staff turn-over/absences

Since the project started, six staff have left (or will soon leave) and one has been on long-term sick leave. This is a much higher turn-over rate than in the other supported housing schemes provided by the Triangle Housing or S&E Belfast Trust.

This has impacted on tenants as they made many fewer positive comments about the staff compared to 12 months ago. Some mentioned particular staff members they missed. Others spoke of the staff being 'alright' and liking some staff better than others. Of the new staff they said, *"it takes a while for them to get used to my way of going"; "too many changes of staff – I'm not happy with that."*

Relatives too were concerned that 'good' staff had left and they felt the service was 'short-staffed'. Tenants were unable to go out to activities when staff are not available. This is further compounded if the staff cannot drive.

The staff also felt that the staff changes had unsettled the tenants and that it was harder to build up a spirit of team working. Working extra shifts and supervising agency staff has created extra stresses for staff, which in turn may increase the likelihood that they will leave.

Managers were also aware that staff shortages had impacted on the service; for example each tenant does not have a key-worker, reviews of person-centred plans may have slipped and there is less opportunities for staff supervision and mentoring.

The main response of management to date has been to try and fill vacancies as they arise and to engage agency staff. However they have had few suitable applicants for posts (a common experience in S& E Belfast) and police vetting takes time to come through. Hence the service has been short-staffed with frontline managers expending a lot of their time finding staff to cover shifts and having to work shifts themselves. The deployment of agency staff means that cover is provided but it is a costly option and it takes time for them to build up a trusted relationship with the tenants.

Favourable comments were made about the training opportunities on offer to staff. Indeed the scheme won a National Training Award for their work in this area. Managers feel that staff require more skills and knowledge to work in supported housing than traditional residential care settings. Ironically the training staff received makes them more employable elsewhere.

Sleep-in cover

In 1999, concerns were expressed by relatives and staff about only one member of staff being available through the night. These concerns are even more strongly present now with three tenants also expressing concerns about whether staff will be able to come to them if they needed help. Staff reported that they often had disturbed sleep and yet had to work a shift the next day. They appear to find the sleep-ins a particularly stressful part of the job.

The main proposal expressed at the review meeting in June 1999 was to have two staff sleeping in so that there would be a second person on hand to provide assistance if another emergency arose or if the staff member had to accompany a tenant to hospital.

Management noted that extra assistance could be speedily obtained by phone either from the hostel at 611 Ormeau Road or from the managers of the supported living service. Very few call-outs had been made over the past 12 months. Hence the extra costs of a second sleep-in staff could not be justified.

Separation of housing support and personal care in staff roles

The funding package provides two distinct forms of support for tenants, namely housing and personal care, and this is a crucial safeguard for them. However maintaining the distinction between personal care and housing support can be difficult for staff when they are on duty although they strive to do this. This is further compounded as some staff are contracted for both roles whereas others are contracted for one or other role. Moreover it is not possible for the same staff member to provide the personal care to individuals; they have to be shared across all tenants. Finally, staff shortages has meant that priority has had to be given to household duties rather than personal attention to tenants although this distinction is not always easily made in practice.

It would appear that this issue can only be addressed satisfactorily when a full staff team is in place with clearly defined roles for individual staff members; including agency staff when they are deployed.

Greater involvement of the tenants with the local community and more opportunities to develop friendships/relationships with others

Nearly all tenants expressed a wish to meet more people and to be out more. Relatives too had some concerns about people spending too much time on their own in their house.

Some progress has been made in that names of neighbours were mentioned and three tenants now attend church regularly with members of the church calling to accompany the tenants. Two tenants also attended a cookery class at a local College.

Three tenants seem to be happy attending the day centre. But four tenants do not particularly like attending the day centre; they had made this known 12 months ago. However two of them have been on work placements which they enjoyed. It has been suggested that tenants make application for a direct payment so that they could purchase their own day services. An other suggestion is that tenants be encouraged to develop more home-based hobbies so they have options other than watching TV.

Staff shortages has made it more difficult for people to go out on a one-to-one basis and to do the activities of their choice: This has even more effect on tenants who are wheelchair users as two staff are needed to accompany them and one needs to be a driver to use mobility car.

Suggestions made at the review meeting in 1999 about contacting community groups in the neighbourhood do not appear to have been taken up.

Although person-centred plans have been completed for all the tenants by a member of Trust staff seconded to do them, this exercise does not appear to have impacted on this dimension of tenant's lives.

Social inclusion remains the aim of the project but it is not readily or easily achieved for these tenants. Project managers and staff will need to work in partnership with other agencies, such as befriending, volunteer and employment schemes and continue to encourage family involvement.

Supported Housing

The tensions noted last year between providing a supported living service in a clustered residential environment appear to have become more accentuated over the year. To a large degree this has been triggered by staff shortages but contributing factors could be:

- The expectations of relatives differ from those of the managers; particularly around the amount of support and supervision their relative needs and receives, and balancing this with living more independently; tenants making decisions and some loneliness when living in your own house.
- The mixed messages given by management to staff regarding their role and priorities. For example, tenants being checked on every 15 minutes and the implications this has for their privacy and intrusions when other people are visiting.
- Staff reactions to the investigation carried out by management which appeared to have centred on this issue of respecting and responding to individuals but with limited resources to do this.
- The differential amounts of support and supervision required by the seven tenants; some require much more than others.
- Insufficient money being available to provide a supported housing model for people with more complex needs.
- None of the tenants are allowed to go away from the complex without being accompanied.

Because this is supported housing, the following decisions have been taken.

- No co-ordinator has been appointed for the 'site'. Instead front-line mangers visits daily and they can be readily contacted by phone;
- No tenant's meeting or committee has been encouraged but rather an individual advocacy scheme is in place;
- It is preferable for people to go out singly rather than as a group; although these form of outings can and do take place from time-to-time as the tenants wish.
- People may spend time alone in their own houses rather than being in the company of other tenants living nearby; although some do choose to visit one another.

Hence this tension between supervision and support of tenants is likely to continue and may never be completely resolved. This is discussed more fully in Part 7.

Moving on from Gray's Park Court

It may be that some people are not well placed in supported living settings. Their needs and aspirations could be better met in other forms of residential settings. This does not appear to be the wish of any of the tenants at present, with possibly one exception who spoke of having a house in another part of Belfast.

However it is an issue that has been raised by others about specific tenants (e.g." they miss the buzz of group living") and it will undoubtedly arise in the future. Consideration needs to be given to the following:

- Moving from Gray's Park Court must not be seen as a failure; otherwise undue pressure may be placed on tenants and staff to maintain an unsuitable placement.
- Still other forms of support may need to be developed by Trusts and Housing Associations; for example, adult placements (where a person lives with another family) or shared housing (living with chosen friend or friends). For certain people there can be a continuing role for residential and nursing home provision. Equally some people will never be happy wherever they live and it then becomes a case of choosing the least unsuitable option.
- If possible, tenants should have the opportunity of experiencing other forms of accommodation and support options before committing themselves to a move. However it seems clear that most of the tenants in Gray's Park Court do not want to go back to the settings from which they came; that is family home or hostels.

Cost-benefits with other forms of housing models

Several respondents commented on the high costs of the service. For tenants with higher dependency needs, these are estimated at around £45,000 per year (inclusive of day care). In Great Britain the average costs can exceed £50,000 for similar forms of service offering intensive support to tenants. Hence it may be that Gray's Park Court is under funded for the service it aspires to provide to tenants with high support needs. Recent changes in the upper limits payable under the Independent Living Fund, may mean that increased funding could be successfully sought.

These costs are nearly twice the cost of care in a residential home but the quality of life on offer would appear to be very much less than tenants experience at Gray's Park Court (Hatton and Emerson, 1996).

However by utilising other sources of funding the amount contributed by Health and Social services is proportionately reduced and to date the Trust has been able to fund this and other supported housing schemes in S&E Belfast through redeploying existing monies and has not needed new monies which lately have not been available.

Conclusions

The issues identified appear to result from the development of a new model of service delivery that is still unfolding.

Issues to do with the physical care of the tenants appear to have been satisfactorily addressed alongside with managing the risks of living more independently.

The social inclusion of the tenants into the wider community is still tenuous but slowly improving.

The current difficulties in staffing may not be speedily resolved but they do require urgent attention. Good staff have been attracted and nurtured in the past and hopefully will be again but changes in staffing arrangements may need to be made in response to the changing labour market.

The tensions between a supporting housing model in a clustered residential setting will probably need to be continuously managed, explained and even agonised over. Compromises, inconsistencies and disagreements among stake-holders will probably have to be tolerated for some time to come.

5. Evaluation of Tower Court and Kiln's Court

Overview

This section presents the Vision statement for these schemes as developed by the stake-holders including tenants, staff of Triangle Housing Association and Causeway HSS Trust staff. The main features of the two schemes that are perceived to be going well are summarised as are the issues that needed to be addressed; namely housing issues; fostering the tenants' development; staffing concern and contacts with the wider community.

Fuller details of the information gathered from the various groups consulted in the evaluation is available in another report[3].

The Vision for Tower Court and Kiln's Court

The vision was developed at the first meeting of the stake-holders in June 1999 (see overleaf). It was used as the basis for interviews with tenants and in obtaining information from support staff, relatives of tenants and other professionals and people with whom tenants had contact.

What is going well

Overall there was a high degree of satisfaction with the housing and support that tenants receive at Tower Court and Kiln's Court. This was expressed by tenants themselves and the staff working there, as well as professional workers, family, friends and employers. The following points were noted:

Most tenants are happy living there and would recommend the Courts to others

Of the 25 tenants interviewed, all but two mentioned at least one thing they liked about living in the Courts. One tenant commented: *"Having my own flat is great, I love it. I love the view from my room window"*. Another said: *"The staff are very good to me, they spoil me all the time"*.

When asked if they would recommend it to others again all but two said they would. Sample comments were: *"a happy, nice place to live"* which was *"like a home as you get your independence and freedom"*. "*You couldn't get better*" was another answer given while yet another tenant stated that *"anyone that came to live here would love it and would really enjoy it"*. *"It's much better than a residential house"* was another answer given.

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[3] *Tower Court And Kiln's Court: Supported Housing for Individuals with a Learning Disability. Triangle Housing Association, Ballymoney, December 2000*

Our Vision for the Courts

(Developed by representatives of tenants, staff, Trusts and Triangle Management)

Kiln's Court and Tower Court are places that provide people with a learning disability with a protected living environment. ***This means :***

- ☐ They are tenants first and foremost with all the rights and responsibilities of a tenancy.
- ☐ They have the support of staff including sleep-in staff at night-time.
- ☐ It is a safe place for them to live.
- ☐ It is a place that builds people's confidence.
- ☐ People are taught to look after themselves in doing things such as cooking and crossing busy roads.

The Courts are people's own homes. ***This means :***

- ☐ Tenants can live on their own if they wish to do so, or live with another person they choose to live with.
- ☐ They are encouraged to do things for themselves and become more independent.
- ☐ They are given choices.
- ☐ The tenant's privacy and dignity is respected.
- ☐ Tenant's individual needs are addressed.
- ☐ Their houses are kept clean and tidy.
- ☐ Their houses will be adapted to suit the needs and preferences of the tenants.
- ☐ There are activities and hobbies for them to do at home.

The Courts are a community within a larger community. ***This means :***

- ☐ Tenants are encouraged to lead ordinary lives through making use of community facilities. These should be based on the principle of equality of opportunities.
- ☐ They have opportunities to attend day centres and to get paid work.
- ☐ They have the opportunity to build a network of friends.
- ☐ They maintain contact with their relatives.
- ☐ In time people may wish to move into more dispersed housing that would not be associated with a residential facility.

The staff are highly thought of and provide valuable support to the tenants

The tenants have a very high opinion of the staff who support them in their homes, acknowledging the fact that they help them out, are very good to them and are as much their friend as their support workers. *"Making my meals"; helping me to dress; cleaning my house,* and *hovering"* were some of things that the tenants stated the staff helped them with.

Likewise all the relatives consulted though the staff were very good at their job. One lady stated *"the staff are very encouraging, and they are always on hand to help".* Another family member replied *"the staff are very helpful, they are so good and outgoing".*

Most people the tenants have changed for the better since moving there

Twenty-one of the 25 tenants interviewed felt they have changed in a positive way by being happier and more independent. However two people felt they were much the same and two felt less independent than previously.

Likewise all nine family members interviewed felt that their relatives have made great progress since coming to live in the Courts. One mother said, *"She has a better social life and it has done wonders to her independence".* Another family member explained that her relative *"wants to get back to Tower Court when she is away. It's like family to her".* Others commented that they are well looked after and far happier there. Five family members reported that their relatives have more independence, freedom and opportunities than they used to have. Only one family member felt that their relative would be happier living in *"his own private flat".*

Generally the tenants get on well with one another.

Twenty of the tenants reported few problems with their neighbours in the schemes. One lady said, "*I get on the best with them. I have no problems with the tenants, they are happy and friendly*". "*I like them all and get on with them but I keep myself to myself most of the time*" was another answer given by a tenant.

However other individuals felt that the other tenants can be *"noisy; sometimes cheeky, starting rows; telling tales on you and moody".*

The tenants have choices in their lives and opportunities to take part in a range of activities

All but a few residents felt they were given plenty of choices in their lives although two people on Guardianship orders did complain about choices being restricted. Some tenants complained about staff having too much control of their money.

Staff also confirmed that tenants had choices. For example, one commented: *choice is one of the key values of the organisation and is very much promoted".* However another staff member felt that tenants *"have very little say in what's happening in the Court".*

Contact with relatives is good.

All tenants but two reported regular contact with relatives and friends; most commonly by telephone but also through visits to them. All staff felt there was good contact with relatives although one person did comment: "*There is good contact but not often. We try to make the people feel welcome but the problem is that people still have the view that they don't belong here or that their relative's care is done by us, therefore they are not needed".*
The relatives who were contacted had no complaints about their contact.

The risks of living in separate houses are well managed and tenants generally feel safe.

The tenants generally had no worries about being in the house on their own as they knew staff were around if they were needed. *"If you need staff for anything at night or anytime you just buzz them and they come straight over"* was the answer given by nearly all the tenants.

The staff also perceived few risks for the tenants in heir home (see Part 6).

Conclusion

Overall, the comments from tenants, staff and relatives confirm that many elements of the vision statement for the two Courts are being realised. Nonetheless a number of tenants would prefer to live elsewhere; four with family members; three in their own houses in the community; another three to a new development planned in Ballymoney and two would like to move to the Courts in Ballymena. This is a reminder that it is not a case of providing people with homes for life, even if they are quite happy with the place they have at present.

Issues that need to be addressed

However the people consulted identified a number of issues that needed to be addressed. These were grouped into four areas; namely housing issues; tenant's development; staffing issues and contacts with the wider community. An issue was noted when at least two stake-holders from the

one group (e.g. tenants) mentioned it or when different stake-holders commented on it.

At the second gathering of stake-holders, the participants included tenants, staff, Triangle managers and a Trust representative. They first confirmed that the identified issues did need to be addressed. They then divided into two groups and brain-stormed various means by which these issues might be addressed. These proposed action plans are summarised below.

It was agreed that these proposals would be further discussed at tenant meetings and at staff meetings. Agreed action plans would then be drawn up and documented.

Housing Issues

The decoration of the houses needs improving

☐ Tenants were free to decorate their houses when and how they liked but they had to bear the cost of doing this.

☐ Tenants may need to be reminded of this and helped to budget for it.

☐ This point might need to be stressed in tenancy agreements.

Some tenants wanted telephones in their house

☐ Triangle management will check if all houses have points for telephone connection.

☐ These should be put in all future properties as it will also allow for connection to the Internet. This would be a natural follow-on to the development of the computer suite at Tower Hall.

☐ Tenants might wish to invest in a mobile phone – with prepaid call charges. These can be used primarily to receive calls.

Car parking facilities at Kiln's Court need improving

☐ People should park between lines when visiting the Court.

☐ Half of the garden area could be used to create more car spaces.

No wheelchair access at Kiln's Court

☐ The site presents difficulties that cannot be overcome.

☐ Certain houses can only be let to non-wheelchair users.

☐ Future properties will have a proportion that are fully accessible.

Resolving conflicts/disagreements among the tenants

☐ These should be discussed at tenant meetings and plans made for resolving these.

☐ People sharing houses may need particular help in overcoming their disagreements.

☐ Training might be offered to tenants on how to resolve disagreements through negotiation and to repair 'fall-outs' with other people.

Tenant's Development

Some tenants having more control of their money

☐ All tenants have daily access to their money but some are strongly guided on their budgeting. However if they demonstrate that they can be trusted to spend their money wisely, they can be given more control.

☐ Some tenants might be able to use bank cards to withdraw their money rather than going through staff. This would help them feel more in control of their money.

More planned training programmes in independent living

☐ Tenants could take part in Health and Safety Training, either alongside staff or through adapted courses.

☐ Tenants can be assessed on what they can and cannot do. Training goals can be agreed with them and step-by-step teaching programmes devised to help them gain the skills.

More opportunities for some tenants to become more independent.

☐ This may be limited for certain tenants because of Guardianship Orders.

☐ Risk assessments should be undertaken by staff in order to guide their decision-making.

☐ As tenants demonstrate their competence and that they can be trusted, they can be given more independence.

More opportunities to move on from the Court's to more independent living.

☐ This has happened in the past and some tenants are due to move from Kiln's Court to new accommodation in Ballymoney which will give them more independence.

☐ Tenants should be encouraged to visit different properties so as they can gain more information about the options available to them.

☐ Tenants should put their names down on waiting lists for other forms of accommodation that they may require in the future.

Staffing Issues

Employment of more staff

- ☐ A third member of staff has now been appointed at Tower Court. The possibility of doing this at Kiln's Court will be explored. However the money available to employ staff is cash-limited.

Staff having more time to spend with tenants

- ☐ More staff should help here (see above)
- ☐ A review of staffing times in the Courts will be undertaken to identify if more time can be freed up to allow staff to have more time with clients.

Better communication between staff and other professionals etc.

- ☐ A book is available for staff to record all messages.
- ☐ Particular attention should be paid to links with day centres. Court staff might visit when 'nothing is wrong' to build up relationships.
- ☐ A district gathering could be organised to let staff in different services meet each other and to put names to faces.

Better continuity of staffing/dedicated staff for the Courts

- ☐ Staff rotate between the house and Courts as a way of sharing the workload and equalising the jobs in the two places. It also means staff get to know all the people with learning disabilities on site. There are no immediate plans to change these arrangements.
- ☐ Tenants need to know that their key-worker remains the same and accessible to them when they move back to the House. Staff may also need time to visit their tenants in the Courts.
- ☐ The staff who 'back-up' the key-workers need to be clearly identified for tenants.

Address the training needs of staff

- ☐ Some staff felt that there was a full programme of training at present although counselling courses and information on benefits were mentioned as two topics for further training. However new staff need to be given opportunities to attend training courses.
- ☐ The future training needs of staff should be identified at appraisals and through supervision.

Contacts with the wider community

Although most staff felt that there was good community contacts, this was not the view of the tenants. Only two of the 25 tenants mentioned having friends in the wider community. This surprised managers as a number of the tenants are involved with befriending schemes and are being supported in employment with local businesses. One Trust staff did note though: *"few (tenants) have developed relationships with the community as the townspeople tend to keep themselves to themselves".*

Review existing connections through befriending and employment

☐ Tenants may not discriminate between paid staff and befrienders and co-workers. Their ideas of friends and what they want from friendships might be usefully explored with them.

☐ Are tenant expectations too high? In modern society there is less socialising. We need to discover their expectations and ideas.

Enabling tenants to build their own network of friends.

☐ Tenant reviews and care plans should examine their social integration and networks. Plans can then be made to link tenants into befriending and employment schemes as well as availing of opportunities in the local community.

☐ Prepare a directory of local community facilities and social clubs for staff and tenants to use in planning their social activities.

☐ Avoid doing activities in large groups.

☐ Should future schemes be more centrally placed so that tenants can more easily go to social events?

☐ Could more tenants learn to travel independently?

☐ Could more contacts be encouraged with their extended families and family friends?

Recommendations for Next Steps

Following meetings with managers and the second stake-holders meeting it was agreed that the following steps would be taken to follow-up the evaluation of the Courts.

1. The suggestions made in connection with the issues raised during the evaluation should be further discussed at the next tenants' meetings and at the next staff meetings in the two Courts. The management team should also discuss them further at their meetings.

2. An agreed action plan should be drawn for each of the Courts with dates given as to when the step will be started. This should be shared with all tenants and staff working in the Courts.

3. In 12/18 months time, a similar evaluation could be undertaken to identify any changes in tenant and staff perceptions. This would ascertain if the

actions taken had proved successful and if they had not, the reasons for this. This form of evaluation would be in keeping with the best value agenda.

4. Future evaluations might also embrace the contribution of other agencies to the lives of the tenants. This would help to strengthen partnership working as well as identifying areas that no one agency can tackle on its own.

Conclusions

Tenants are broadly happy living in the Courts; most feel safe living there; they are given choices in their lives and they have changed for the better since moving there. They appreciate the help of staff and the sleep-over arrangements provide extra security of them. Contact with relatives is good but there appears to less contact with the wider community than the tenants would like.

The main issues that needed addressing in addition to community linkages were improvements to the houses and the location; greater opportunities for tenants to become more self-reliant and increasing staffing levels along with having dedicated staff who supported the tenants.

Part 6: Comparisons of the Supported Living Schemes

Overview

This section contrasts the three supported living schemes in terms of the characteristics of their tenants and the outcomes for them in terms of choice, perceived risks and life experiences. Comparisons are made with data reported by Emerson et al (1999) for supported housing schemes in Great Britain. In addition data for tenants at Gray's Park Court is compared for the two years 1999 and 2000 in order to monitor any changes that may have occurred. Finally information is given on costs and sources of funding.

Measuring client need and service outcomes

The costs of services are often related to the needs of the clients they serve, particularly in terms of the severity of their disability but also in terms of challenging behaviours they pose and additional physical or mental health needs. However the 'best value' agenda requires attention to be paid to outcomes that services attain for their clients. This is has received less attention in the past and debate is ongoing as to the indicators that should be used to appropriately assess the outcomes of housing and support services.

For the purposes of this evaluation the following measures were chosen. These were largely based on the work of Emerson and colleagues in their major study of various forms of residential accommodation.

Client measures

The following measures were used to describe the characteristics of the tenants:

- *Part 1 of the Adaptive Behaviour Scale – Residential and Community 2nd Edition. (Nihara et al, 1993)* Key-workers rated the tenants' competence on a range of skills needed for independent living, such as personal self-care, physical development, communication and socialisation.
- *Aberrant Behaviour Checklist* (Aman et al, 1994) Again key-workers rated each tenant on a range of behaviours which are then grouped into four dimensions, namely irritability, lethargy, stereotypical behaviours, hyperactivity and inappropriate speech.
- *The PAS-ADD Checklist* (Moss et al, 1998) is a screening tool that can be used by key-workers to screen for potential mental health problems.

Service outcomes

Four measures were used to assess the 'outcomes' for tenants in the different schemes plus information was gathered on preventative health measures..

- *Choices Scale* (Emerson et al 1999). This scale identifies the extent to which tenants exercise choice and control over key aspects of their life.
- *Risk Scale* (Emerson et al, 1999). This was used to measure the perceived level of risk as seen by key-workers of the each tenant's exposure to accidents, injuries, abuse and exploitation.
- *Life Experiences Checklist* (Ager, 1998) This measure gives an indication of the 'normal life' experiences which tenants had available to them. These are arranged in five dimensions: home. Leisure, relationships, freedom and opportunities.
- *Health Screening* Data was gathered on the preventative measures taken to ensure the tenant's health and well-being.

All the above measures were completed by the tenant's key-worker or in a few instances by the member of staff who knew them best if the key-worker was not available.

Comparisons

Three comparisons are made when presenting the results.

1. Gray's Park Court tenants (N=6) are compared on two occasions over a 12 month period. These differences could be tested statistically although the small number of tenants made it unlikely that significant differences would be found.
2. Gray's Park Court tenants (N=7) are compared with the tenants of the two other supported living schemes managed by Triangle Housing Association. These differences were also tested for statistical significance.
3. The tenants in all three schemes are compared with the results reported by Emerson et al (1999) in their study of 63 tenants randomly selected from all the tenants in six supported living schemes in Great Britain which were rated by independent agencies and informants as being examples of 'good practice'. They included independent providers and NHS trusts and all had been operational for at least five years. Of the 63 tenants; 32 were living alone; 18 with one other person who had learning disabilities and 13 were living with two people who had learning disabilities.

No statistical comparisons could be undertaken with the N. Irish data but apparent differences are highlighted.

Tenants

Table 1 summarises the ages and sex of the tenants in the three N. Irish schemes and those of the tenants in Emerson's study.

Table 1: The number, age and gender of tenants in the comparison groups

	Gray's Park 1999	*Gray's Park 2000*	*Kiln's Court*	*Tower Court*	*Emerson's data*
Number of tenants	6	7	10	15	63
Mean Age	40 years	41 years	46.7years	54.1 years	44.2 years
Range	31-46 yrs	32-47 yrs	27-65 yrs	32-68 yrs	21-85yrs
S.D.	7.4	7.3	13.2	11.7	14.6
% men	33.4	42.8	70.0	26.6	71%
% women	66.6	57.2	30.0	73.3	29%

Although there are more women than men in two of the Irish schemes this was not the case for the British data. (Men tend to outnumber women in learning disability populations in the order of 60:40. The census of residential accommodation in NHSSB[4] found that 54% of the residents were male).

The British sample encompassed a wider age range than those of tenants in the N. Irish schemes with Gray's Park Court tending to have more people under 50.

Adaptive Behaviour

Table 2 gives the mean standardised scores overall for the Adaptive Behaviour Scale as well as the scores on the ten subscales that measure discrete aspects of functioning. A higher score is indicative of a more able person and likewise comparisons can be made across the subscales to identify aspects of competences which are particular strengths and weaknesses of the tenants.

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[4] *McConkey, R. & Barr, O. (2000) Future Housing and Support Needs of People with Learning Disabilities and their Families: A report to the Northern Health and Social Services Board and the Northern Ireland Housing Executive.*

able 2: The group Means (and SDs) on standardised scores on the Adaptive Behaviour Scale

& (SD) ores	Gray's Park 1999	Gray's Park 2000	Kiln's Court	Tower Court	Emerson's data
BS Score	171.7(71.5)	160.9 (35.9)	224.4 (52.9)	246.5 (28.7)	174.8 (79.2)
scales					
dependent Functioning	63 (25.1)	63.4 (21.8)	93.(18.5)	99.3 (12.6)	70.6 (31.1)
Physical velopment *	17.0 (6.5)	15.9 (6.4)	21.0 (2.8)	21.8 (4.5)	18.6 (4.8)
Economic Activity *	7.0 (5.6)	2.9 (1.9)	12.7 (4.8)	12.9 (4.4)	7.5 (7.5)
Language evelopment	27.0 (11.9)	21.0 (7.8)	31.9 (7.3)	29.4 (6.5)	22.6 (12.3)
umbers and time *	7.0 (4.2)	4.7 (2.1)	11.1 (11.8)	9.9 (2.7)	5.7 (5.2)
Domestic Activity *	8.5 (6.2)	7.7 (6.9)	14.5 (6.2)	18.8 (3.5)	11.1 (7.5)
re/vocational activity	4.2 (1.7)	5.0 (1.2)	6.3 (4.3)	6.7 (2.6)	5.4 (3.2)
Self-direction	10.0 (4.9)	12.0 (4.2)	17.3 (3.9)	17.1 (3.8)	12.3 (7.3)
esponsibility*	6.5 (4.2)	6.3 (2.1)	8.0 (1.5)	8.7 (0.9)	5.6 (3.5)
Socialisation	15.7(7.2)	21.7 (5.5)	22.9 (3.4)	23.3 (4.9)	15.5 (6.5)

** differences significant between Gray's Park and the other two courts. (p<0.05 level)*

terms of overall scores, the tenants in Gray's Park Court are closer to ose in the British study with those in Tower and Kiln's Court being more le. However these differences were not statistically significant because of e large standard deviations in the scores. This indicates a wide spread of ores among the tenants in the grouping. This is particularly so in merson's sample and for Gray's Park Court in 1999. This suggests that upported living arrangements can cope with a wide spread of ability among e tenants. Tower Court tenants were the most homogeneous in terms of verall adaptive functioning.

he subscales scores also confirm similarities between tenants in Gray's ark and the British tenants. Indeed for a number of subscales the tenants Tower and Kiln's Court are significantly more competent; notably in hysical development, economic activity; numbers and time; domestic ctivity and taking responsibility.

Although the tenants in Gray's Park also did not show a significant improvement overall from 1999 to 2000, the reduction in stereotypical behaviours was significant (p<0.05) and that for lethargy almost so (p<0.07). Even so their scores tended to be higher than for the tenants in Tower and Kiln's Court on irritability, lethargy and hyperactivity.

If people have different forms of aberrant behaviour as is often the case among small groupings of people, then summary scores of this sort are not likely to show significant overall improvements unless nearly all the tenants show improvements in their particular behaviour. In that sense this data is encouraging in highlighting improvements for at least a number of tenant's in Gray's Park Court over the year.

Mental Health Problems

A higher score on the mini Pas-ADD scale is indicative of possible mental health problems. A separate measure is also taken of life events in the previous 12 months that might cause extra stress to the individual. As Table 4 shows, the mean scores for the three N. Irish Courts were similar although the scores of Gray's Park tenants in 1999 were the most similar to the British tenants. Again the higher standard deviations is indicative of people having significant mental health problems; notably in Gray's Park Court in 1999 and in the British sample. However the apparent improvement in tenants at Gray's Park from 1999 to 2000 was not statistically significant although the figures suggest that some tenants did make an improvement given the lower standard deviation.

Table 4: The group means and SD's on scores from the mini PAS-ADD

Mean & (SD) scores	*Gray's Park 1999*	*Gray's Park 2000*	*Kiln's Court*	*Tower Court*	*Emerson's data*
Total score	3.7 (4.3)	1.1 (1.6)	1.6 (2.2)	2.0 (3.3)	3.1 (4.1)
Life events*	6.0 (9.9)	3.7 (4.3)	0.6 (1.3)	1.1 (1.2)	Not given

However the life events scores tended to be significantly higher for Gray's Park Court tenants in 2000 compared to the other two Courts (p <0.06) and in turn their scores were significantly higher in 1999 compared to 2000 (p<0.04). This may indicate that life for the tenants in Gray's Park Court was starting to become more settled but had not reached the same degree of stability as the tenants in the other Courts.

Epilepsy

Information was also gathered about the tenants who had epilepsy and the results are summarised in Table 5. Significantly more of the tenants had epilepsy at Gray's Park Court than in the other two N. Irish schemes.

Table 5: Number (and Percentage) of tenants with epilepsy

% users reported to have	*Gray's Park 1999*	*Gray's Park 2000*	*Kiln's Court*	*Tower Court*	*Emerson's data*
No medication and no seizures	3: (50%)	4: (57.1%)	9 (90%)	13: (86%)	32: (59%)
Seizures controlled by medication	0	0	1(10%)	1: (7%)	7: (11%)
Seizures less than monthly	3: (50%)	3: (42.9%)	0	0	10: (16%)
One or more seizures per month	0	0	0	0	9: (14%)
Missing data	0	0	0	1: (7%)	0

However there were nine tenants in the British sample who had regular seizures compared to none of the N Irish tenants. Hence tenants with epilepsy are living in supported housing.

Conclusions

The tenants in the Tower Court and Kiln's Court schemes tend to be more competent than those at Gray's Park Court with fewer behavioural and mental health problems and fewer have epilepsy. However the Gray's Park Court tenants more closely resemble those in supported living arrangements in Britain which suggests that supported living is a feasible option for more dependent tenants with challenging behaviours, mental health problems and epilepsy.

Over the course of one year there were few significant changes in the Gray's Park Court tenants with the exception of a reduction in stereotypical behaviours. However there were indications of improvements in their socialisation skills and decline in their number and time skills. They tended to be less lethargic and to have had fewer stressful life events.

Outcome measures

This section compares the three N. Irish schemes on a number of service 'outcome' measures.

Choice

Using a scale developed by Emerson and colleagues, the tenants were rated as to the amount of choice they experienced in their lives. A higher score is indicative of more freedom to make choices. As Table 6 shows the mean scores were broadly similar across the three N. Irish schemes and comparable with that reported for the British sample.

Table 6: The group means, range and S.D on Choice Scale

	Gray's Park 1999	*Gray's Park 2000*	*Kiln's Court*	*Tower Court*	*Emerson's data*
Mean Individual choice score	78.2	82.6	76.7	84.6	79.1
Range	48-88	76-91	36-96	39-103	41-102
Standard Deviation	15.6	6.2	21.3	14.5	16.4

Equally the range of scores was wide within each scheme which indicates that some tenants are able and/or willing to exercise more choices than others. The main change in Gray's Park Court from one year to the next was that certain tenants began to exercise more choice although the mean scores for the group as a whole only increased slightly.

On the scale used, the maximum possible score was 104 and some tenants came close to attaining this. However it is worth noting that the mean choice scores for these schemes is nearly twice as high as the mean scores reported by Emerson et al (1999) for people living in 'residential campuses' (i.e grouping of homes with 7 to 10 people in each); the mean score was 46 (range 26 to 80).

Life experiences

A specially developed checklist for use with persons who have learning disabilities was used to assess the quality and variety of the tenant's life experiences in different domains such as their home, leisure pursuits, relationships, freedom of movement and opportunities for community engagement. (N.B. Comparable data was not available for the British sample.)

Overall, the tenants scores were similar for the three schemes (see Table 7). However the subscales showed a different pattern.

Table 7: Means (and S.D's) on The Life Experience Checklist

Mean & (SD) scores	*Gray's Park 1999*	*Gray's Park 2000*	*Kiln's Court*	*Tower Court*	*General Population*
Total Score	36.2 (3.3)	36.3 (3.0)	33.9 (4.5)	34.6 (5.6)	34.8 (6.6)
Subscales					
Home*	9.7 (0.5)	9.4 (0.8)	7.5 (0.9)	7.8 (1.7)	8.0 (1.9)
Leisure	6.2(1.0)	6.3 (1.6)	4.5 (2.0)	4.9 (1.7)	4.6 (2.0)
Relationships	5.3 (1.0)	3.7 (0.8)	6.1 (1.6)	5.1 (1.6)	6.6 (2.2)
Freedom *	8.2 (1.0)	8.3 (1.0)	8.0 (0.9)	9.6 (0.9)	8.0 (1.8)
Opportunities	6.8 (1.5)	6.9 (1.1)	7.8 (1.8)	7.3 (2.3)	7.5 (1.6)

** differences significant between Gray's Park and the other two courts. (p<0.05 level)*

Tenants in Gray's Park were rated as having better housing and tended to have wider choice of leisure options although this was not statistically significant (p<0.11). However tenants at Tower scored higher on the freedom subscale.

The authors of this scale provide comparable data for samples of the general population in urban and rural settings (N=410). Tenants in the three Courts generally scored at or above the mean scores for the general population although scores for relationships tended to be lower.

Risks

A particular concern about supported living arrangements is that the tenants might be exposed to greater risks than they would if living with families or in more traditional settings.

Information was gathered about past accidents and incidents from key-workers along with their assessment of the perceived risks. Table 8 summarises these results.

Emerson reports that one quarter of tenants had had an accident or injury in the past five years but this has not happened with tenants at Tower and Kiln's Court. At Gray's Park Court some tenants had had an accident but this may have occurred before they came to live there. (Emerson's figures are nearly three times higher than the percentage of people living in residential campuses and group homes who had accidents.)

The other incidents are broadly similar across the three Courts although tenants at Kiln's Court appear to have experienced more verbal abuse and teasing than elsewhere (P<0.06).

Table 8: The percentage of tenants in each Court at risk

% of individuals who have	*Gray's Park 1999*	*Gray's Park 2000*	*Kiln's Court*	*Tower Court*	*Emerson data*
Suffered accidents or injuries requiring hospital treatment in past 5 years	33.3%	28.6%	0%	13.3%	25%
Suffered accidents or injuries requiring medical attention					
- in the home in the past year	16.7%	14.3%	10%	0%	20%
- out of home in the past year	0%	0%	0%	20%	22%
Been the victim of physical or sexual abuse in the past 5 years	0%	0%	0%	20%	7%
Been the victim of crime	0%	0%	0%	13.3%	25%
Had their current home vandalised	0%	0%	10%	6.7%	17%
Been verbally abused by members of the public	16.7%	14.3%	60%	20%	27%
Perceived to be at some risk					
- of accidents in the home	16.7%	29.0%	30%	13.0%	16%
- of traffic accidents	50%	43.0%	20%	20.0%	13%
- from dangers outside the home	16.7%	14.0%	30%	0%	10%
Perceived to be at risk of physical or sexual abuse by					
- other service users	16.7%	14.3%	0%	0%	11%
- people living in the community	0%	0%	10%	0%	14%
-staff working in services	0%	0%	0%	0%	6%
- any other persons	0%	0%	0%	0%	8%
Perceived to be at risk of exploitation by					
- other service users	0%	0%	30%	7.0%	9%
- people living in the community	50%	42.9%	30%	13.3%	25%
- staff working in services	0%	0%	0%	0%	13%
- any other persons	0%	0%	0%	0%	10%

Staffs' perceptions of risks are also broadly similar across the three Courts although key-workers at Kiln's Court tended to rate more of their tenants at risk from the dangers outside the home and from a risk of exploitation from other service-users.

Traffic accidents are also seen as a risk for Gray's Park Court tenants despite being located in a quiet cul-de-sac but with a major road at the back of the properties. These are higher than the ratings for British tenants although their competence levels were similar. However N. Irish staff perceived little risk to tenants from staff or other persons.

Health Screening

Table 9 summarises the percentage of tenants who had various health checks in the previous two years.

Table 9: The percentage of tenants who had a Health Screen

% in the last year have had	*Gray's Park 1999*	*Gray's Park 2000*	*Kiln's Court*	*Tower Court*	*Emerson's data*
A routine health check	100%	71.4%	40%	46.7%	69%
Blood pressure measured	66.7%	28.6%	60%	53.3%	72%
A cervical smear (women) *	25%	0%	66.7%	27.3%	44%
A mammogram (woman)	0%	0%	10%	36.3%	8%
A testicular check (man)	0%	0%	0%	0%	24%
Sight tested	33.3%	85.7%	80%	80%	71%
Hearing tested	0%	14.3%	20%	26.7%	73%

** differences significant between Gray's Park and the other two courts. (0.05 level)*

Among the three N. Irish schemes the only significant difference was that more women at Kiln's Court had had a cervical smear compared to those at Gray's Park Court.

It appears that a higher proportion of the British tenants had had hearing tests done; blood pressure checked and testicular checks done than the N. Irish samples.

Conclusions

The tenants in supported living appear to have more choices open to them and to enjoy better quality of life experiences. Sizeable proportions will have had health checks carried out although not to the same extent as reported in Britain. There were concerns about the risks that tenants might experience and in some instances these appear to be higher than those reported in Britain.

Costs of Supported Living

Information about the costs of supporting tenants in three schemes was obtained from Triangle Housing Association (see Table 10). Comparisons could be made with similar data provided by Emerson for six schemes in Britain.

7. Conclusions and Recommendations

Overview

In this part, the main conclusions to emerge from this study of supported living in N. Ireland are summarised. Recommendations are made on a number of issues that the schemes are having to contend with and which have implications for how future schemes may be structured.

Tenants

Supported living is a feasible option for people with learning disabilities and more complex needs. Gray's Park Court has demonstrated this and the English experience also shows that people with challenging behaviours, mental health problems and recurring epilepsy can be accommodated in supported living schemes. In addition two of the tenants in the north Antrim schemes are on Guardianship Orders.

This of course is only possible if appropriate staffing procedures are in place. All three N. Irish schemes have 24 hour staff cover with staff sleeping-in. Equally back-up cover is readily available from adjacent residences and on-call staff. The issue is the extent to which revenue income is available to provide for this intensity of staffing; especially in dispersed housing schemes. However in future this may have to be tempered against an individual's right to housing.

Supported living provides a better quality of life

Emerson's study in Britain confirmed that supported living offered better outcomes for their tenants than residential campuses (i.e. people living in housing clusters with 7 to 10 persons in each.) Equally the benefits of small group living arrangements over larger residential facilities have been extensively documented in the literature.

Although no direct comparisons were made for N. Irish services, the supported living schemes do appear to offer advantages that compare well with the British sample. Moreover the qualitative data collected from tenants and relatives confirm their preference for this model of housing with no-one wishing to return to the residential homes, hostel, hospital or family care from whence they had come.

The issue then becomes one of best-value; namely is it worth paying more to achieve better outcomes?

Supported living reduces costs to Health and Social Services

The capital costs of all the schemes were met by the Department of the Environment through grants to the Housing Association. Two of the schemes in N. Ireland are run at no cost to Health and Social Service Trusts while at Gray's Park, the Trust contributes around £180 per tenant per week (exclusive of day service costs). This contrasts with upwards of £750 per week that Trusts pay towards to placements in specialist residential homes[5].

The bulk of the costs in supported living arrangements are presently met from housing support and disability benefits, including the Independent living fund. The impact of proposed changes to the payment of these monies is not yet known but given that the aim of government policy is to 'cap payments' it is likely to result in less money being available to fund new placements.

Staffing

Insufficient staff and staff turn-over were the two main issues identified in the evaluation of the N. Irish schemes. The latter was particularly felt in the Belfast scheme and indeed the Trust has experienced difficulties in filling vacancies in their other residential projects. This echoes experiences in the United States (Larson and Lakin, 1999).

Among the reasons for staff turn-over that were given by the various parties consulted are:

- The low levels of pay (£5.27 an hour at best) for the responsibilities involved in the job.
- The wider availability of jobs in the area
- Younger staff going on to promoted posts in related services as there are limited career opportunities within supported housing.
- The stresses and routines inherent in the job of caring for people with complex needs.
- The lack of team-work or staff 'pulling together' that has been apparent in the past 12 months.
- The failure of 'top' managers to listen to staff and appreciate their work although the support from front-line managers was favourably noted.

This illustrates the complexity of factors associated with staff turn-over that money alone will not solve. However the success of supported living schemes is dependent on a reliable, stable and well-trained staff team. Thus greater attention will need to be paid to achieving this as our society moves towards full employment with greater competition to attract part-time women workers. Among the strategies used by other agencies are:

- Increased hourly payments
- Loyalty bonuses
- Provision of accredited training opportunities
- Creating a career structure within the service

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[5] McConkey, R., McConachie, J., Mezza, F. and Wilson, J. (2000) *Moving on from Muckamore Abbey Hospital.* Belfast: EHSSB.

- Offering recognition 'awards' to staff.

Supported Living or Clustered Living

The three N. Irish schemes are distinctive from other supported living arrangements in that the tenants live in clustered accommodation. Moreover in the two longer-established schemes, these clusters were in the grounds of a registered residential home and staff worked in both settings. By contrast, the British schemes were largely in dispersed housing with staff deployed across the tenants as needed. However the outcomes for the tenants appeared to be broadly similar.

The clustered arrangements in N. Ireland were justified primarily in financial terms; namely offering 24 hour staff cover, especially sleep-in staffing. However by having the houses adjacent although segregated from other housing, other benefits were.

- It provided some element of protection while allowing tenants to easily meet one another without having to be dependent on public transport or availability of drivers.
- Staff can easily move from one house to another; thereby cutting out travel time between visits.
- It is easier to provide adequate cover when staff are ill or on holiday.
- Staff feel less isolated.

However these arrangements make it difficult to avoid some features that are typical of residential homes.

- Although the scheme is financed through individual funding packages; the staff costs in particular are apportioned over all tenants. However some tenants require more support and supervision than do others.
- The staff team are rota'd for shifts rather than for individuals; although within a shift, time may be allocated to individual tenants.
- All staff on shift have to provide personal support to tenants; it cannot be done by the same personal care assistants.
- In Tower Court and Kiln's Court, staff move between the Courts and the residential homes on site; although they do spend three months at a time allocated to one or the other.
- Tenants who share may have to continue living with people whom they do not want to live. Concerns have been expressed about this for two tenants at Gray's Park Court.

Hence these clustered living arrangements have inherent tensions that require careful management if the aspirations of supported living are to be attained; particularly in separating out housing and support arrangements. This means that:

- the ‘rules’ and procedures will have to be adapted as experience unfolds; especially for those tenants with more complex needs. This has been so in the past and will probably continue to be the case but management needs to provide clear rationales for their decisions to staff, relatives and tenants.
- Dogmatic stances about what is or is not good ‘supported living’ arrangements should be avoided in favour of realistic compromises with the ultimate test being the preferences and well-being of the individual tenants. Person-centred reviews; circles of friends, independent advocacy alongside the increased confidence and communication of tenants will make these tests easier to apply in the future.

It might be argued that the use of Direct payments, whereby tenants employ their own personal care assistants could offer a way forward and reinforce the separation of housing and support that is seen as central to the concept of supported living (Kinsella, 1993). However there is very little precedent in N. Ireland for this and little experience of making it work. Moreover it is difficult to foresee how some of the present tenants could assume responsibility for recruiting staff; arranging their salary payments and finding cover when staff are ill, on holiday and so on. Nonetheless this option is worthy of further exploration.

Finally, careful thought needs to be given to the mix of tenants within clustered living schemes; both in terms of their compatibility with one another socially as well as in terms of care needs. Although this may help balance the tensions for staff, the danger is that individuals requiring a tenancy may be denied a place because they do ‘fit in’; the same issue that besets small group homes.

In sum, clustered living may be pragmatic response to enabling people with learning disabilities to experience a form of supported living but it is neither the best way of doing this or the only way of doing this. It is an alternative that has been found to work with some degree of success.

Moving on from supported living

A significant minority of tenants in the three schemes expressed a wish to live elsewhere. For some it was to be with their family; others wanted to move to another scheme and a few to have their own place in the community. Hence it has to be acknowledged that some people may not be well placed in supported living settings. Their needs and aspirations could be better met in other forms of living arrangements.
This means that:

- Moving from the Courts must not be seen as a failure; otherwise undue pressure may be placed on tenants and staff to maintain an unsuitable placement.
- Still other forms of support may need to be developed by Trusts and Housing Associations; for example, adult placements (where a person lives with another family) or shared housing (living with chosen friend or friends). For certain people there may be a continuing role for residential and nursing home provision; as some staff commented: *"they miss the buzz of community living"*. Equally some people will never be happy wherever they live and it then becomes a case of choosing the least unsuitable option.
- If possible, tenants should have the opportunity of experiencing other forms of accommodation and support options before committing themselves to a move. However it seems clear that most of the tenants in the Courts do not want to go back to the settings from whence they came; that is family home or hostels.

Community engagement

A core concept of supported living is to network people into their local communities. Although commendable efforts have been made to do this in the three schemes, the perceptions of most tenants and some relatives is that they have few friends and they would like to be more involved in community activities. That said, it would appear that the tenants were experiencing a reasonable quality of life as measured by the Life Experiences Checklist and data from Britain (Emerson, 2,000) and the United States (Howe et al, 1998) suggest that supported living arrangements do result in more social integration and use of leisure and recreational facilities than other residential options.

Perhaps the tenants' aspirations are unrealistic; perhaps clustered living does isolate people while offering better protection or perhaps yet more effort needs to be expended on this issue. Certainly Lowe and de Paiva (1991) highlighted the lack of friendships among residents in small group homes despite increased community contacts over a five-year period.

Simons and Watson (1999) emphasise the need to integrate supported living with supported training, employment, befriending and advocacy schemes. Triangle Housing and S&E Belfast Trust are actively pursuing these options by setting up projects or working in partnership with others to provide them. They have recognised the truth of which others have written, namely that supported living is not just another residential option but rather a radical different approach to service delivery for this client group.

The fact that these initiatives have not produced the expected outcomes may reflect the difficulties in overturning years of exclusion for this client group as well as managing the conflicting pressures on staff to protect 'their clients' while taking the risks inherent in stepping outside specialist services. There is much still to be learnt how best to support people for social inclusion.

Registration and Inspection

None of the supported living schemes in N. Ireland are registered and inspected by the Health and Social Boards. This is also the case in Great Britain. This issue was not mentioned by any of the stake-holders consulted in the evaluation. Arguably this may leave the tenants more vulnerable although it is questionable as to whether or not existing inspectorial procedures are adequate for this task.

However both Triangle Housing Association and S&E Belfast HSS Trust were well aware of this issue and have instituted advocacy schemes for the tenants. These coupled with Tenant Forums and the proactive encouragement of befriending schemes will provide a voice for many tenants. Particular efforts must be made to extend these initiatives to tenants who have more complex needs, especially if their verbal communication is limited or they have challenging behaviours.

Policy directives

The recently completed reviews of learning disability services in Scotland (2000) and in England and Wales (2001) have strongly recommended an expansion of supported living options. To date, a strong policy lead has not been forthcoming from the Department of Health, Social Services and Public Safety in N. Ireland.

However the Northern Irish review of services (DHSS, 1995) arguably anticipated the outcomes of the reviews in the other countries when it stated:

> *The aim of Government policy for people with a learning disability should be inclusion ... which stresses citizenship, inclusion in society, inclusion in decision-making, participation so far as is practicable in mainstream education, employment and leisure, integration in living accommodation and the use of services and facilities, not least in the field of health and personal social services.*

Supported living is one of the few means empirically shown to achieve these ambitions.

Finally the new equality and rights legislation may also have far-reaching implications for services although it is too soon to identify these with any certainty.

Conclusions

Supported living is no longer a novel concept. It is well established in North America and is increasing used in Britain. There is strong empirical evidence that it delivers better outcomes for tenants than other forms of residential options.

Experience in N. Ireland confirms this. Supported living here has been done at remarkably low cost to Health and Social Services bodies. This has resulted from partnerships with Housing Associations and the use of social security payments; housing benefits and the Independent Living Fund.

Although supported living may not suit everyone, it does meet with the approval of tenants and relatives who have experienced it. It also seems to be the preferred option when people with learning disabilities and their families were consulted on future living options[6].

Hence HSS Trusts and Boards in N. Ireland should urgently develop plans to extend the number of supported living placements they can offer to people being resettled from Muckamore Abbey Hospital; people living with family carers who are no longer able or available to care for them; and people in existing residential homes and hostels who want to move on.

The roles and conditions of staff in supported living services need to be reviewed and payments made commensurate with the demands placed on them.

Clustered living arrangements may be a pragmatic response to supporting more dependent people but it does bring inherent tensions. It is neither the best or only option but rather one of several possibilities.

Supported living per se does not result in greater social inclusion. Rather these schemes need to integrate with a range of initiatives in employment, advocacy and befriending.

In Scotland, England and Wales, there are now policy directives placed on housing bodies, health and social services to extend supported living options. This has not happened in N. Ireland.

In the future, new equality and rights legislation may make supported living an essential means of providing housing and support to a client group who are not ill, who do not require nursing care and who are not elderly.

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[6] *McConkey, R. and Barr, O. (2000) Future housing and support needs of people with learning disabilities and their families.* Ballymena: NHSSB & NI Housing Executive.

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Developing Better Services

Modernising Hospitals and Reforming Structures

Department of Health, Social Services and Public Safety
An Roinn Sláinte, Seirbhísí Sóisialta agus Sábháilteachta Poiblí

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June 2002

DEVELOPING BETTER SERVICES

MINISTER'S FOREWORD

I commissioned a review of acute hospital services in August 2000, and asked the review group to make recommendations on the future profile of hospital services, taking account of issues of accessibility, safety, clinical standards and quality of services.

The review was set up against a background of many years of under-funding of health services, which has undermined and weakened their capacity to deliver the quality of service demanded of a modern hospital system. My objective was to develop an agenda for a major, and long overdue, modernisation of the acute hospital system.

The Executive has recognised the need to boost health and social care expenditure and has invested an additional £523 million in healthcare since the establishment of the Assembly. Of this, 80% has been required merely to maintain existing services.

While this additional and much needed expenditure is welcome, extra spending alone is not the answer. To provide a modern hospital system that will meet the needs of all our people, well into the future, will require a fundamental change in the way services are delivered and administered. Otherwise we will see services continue to decline and fall behind standards elsewhere.

In this paper I am setting out how I consider our hospital services need to be modernised and the decisions required to take these changes forward. My proposals are not about reducing acute services. Rather they aim to build upon the firm foundations of current services, to ensure that everyone will have prompt access to high quality acute care, delivered close to their homes wherever possible.

I would expect my proposals to bring about a new, modern and more effective hospital service, a service that is set up and resourced to meet the needs of the expected numbers of patients that it serves; deliver a world-class service with much improved outcomes, in areas such as cancer and heart disease; eliminate the problem of people waiting for admission and delayed discharges; meet peak demands without postponing normal activity; and substantially reduce waiting times, bringing them down to a maximum of three months for non-urgent cases, with priority cases treated much sooner.

Delivering quality care also demands organisational structures that are fit for purpose and equal to the challenges facing a modern health service. The need for organisational reform has been evident for some time, but the issues are complex. Before coming to decisions, I would like to consult as widely as possible on the options set out in this paper for structural change. I also want to take account of the emerging principles/criteria from the Executive's recently announced Review of Public Administration.

The acute hospitals review, now in its final stages, should not be seen in isolation. It is directly linked to work that I have commissioned covering: *Investing in Health,* which is the Executive's strategy for improving the health and well-being of the population; *Building the Way Forward in Primary Care*, a new approach to primary care; *Best Practice, Best Care*, which sets out proposals for improving the quality of services; and *Review of Community Care – First Report*, which is the first stage of a review of community care.

Taken together, these initiatives form the main components of a unified and coherent approach to improving health and social services. I intend to bring them together in a new Regional Strategy, which will be published next year.

The Executive's 2002-2005 Programme for Government commits it to developing proposals for a modern acute hospital service, with the declared expectation of taking decisions on the way forward in the course of 2002.

This is a challenging agenda for change, which will not be delivered overnight. However, we now have a robust strategy that will deliver a modern, caring, quality hospital and health care system. A system capable of delivering high-quality care and treatment today, and well into the 21st century.

Bairbre de Brún

Bairbre de Brún
Minister for Health, Social Services and Public Safety

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EXECUTIVE SUMMARY

Introduction

1. The ability of acute hospitals here to deliver safe, effective and timely acute services has come under increasing strain. Pressures for change are coming from many and varied directions - new patterns of illness and disease, new medicines and treatments, new technologies, new skills and changes in how doctors, nurses and other health professionals train and work. These changes, combined with years of under-investment, are placing sustained pressures on hospitals and their staff.

Why Change is Needed

2. Our pattern of hospitals is based on an outmoded approach to acute care. As medical practice has developed, the trend has been for health professionals to specialise and become expert in particular aspects of treatment and care. This has resulted in great advances in treatments and improved outcomes for patients.

3. There is also a great deal of evidence to suggest that outcomes are better where treatments and care are delivered by specialist, multi-disciplinary, teams. But such teams must be large enough to work effectively. The teams need to care for sufficient numbers of patients to make best use of their skills, and to maintain those skills throughout a lifetime of practice. This is particularly important, as all health care practitioners will, in the future, be required to demonstrate their continued professional competence on a regular basis.

4. Smaller hospitals are now finding it increasingly difficult to deliver services to modern standards. They are beginning to lose recognition as training hospitals, as they do not provide sufficient opportunity for health professionals to develop the skills and experience necessary, and some are now finding it difficult to attract and retain staff.

What Kind of Change

5. If our hospitals are to provide patients with the full benefits of modern medicine, they must change to make best use of new technologies and to support new working practices. The further concentration of acute services for patients with more complex conditions will greatly improve the quality of care and the outcomes of treatment.

6. However, concentration must be balanced against the accessibility of services for patients and their families. Developments in medicine and medical technology are also opening up the way for smaller hospitals to provide high quality diagnostic

services and a wider range of operations and medical procedures, often on an outpatient or day-case basis.

7. The effective delivery of services through managed clinical networks will, by supporting services across a number of sites, underpin a more convenient and accessible service for patients, without compromising standards of care or treatment.

Model for Future Hospital Services

8. Under the new model, none of the current hospitals delivering acute services will close - rather they will be adapted to support the new pattern of provision. The vast majority of people will be within 45 minutes, and everyone will normally be within one hour of emergency care and consultant-led maternity services. In the future, acute services will be more strongly patient-focused and organised around population groupings rather than facilities.

9. A number of new Local Hospitals will be established to deliver a wide range of services on a local basis. They will network with acute hospitals and local primary and community care to provide services that do not need to be delivered in a large acute hospital. The Local Hospitals will be the Mid-Ulster, South Tyrone, Whiteabbey, Downe, Lagan Valley, Mater and Tyrone County hospitals.

10. In view of the long journey times for some people, the Downe Hospital will be an Enhanced Local Hospital[1], and the provision of Enhanced Local Hospital services at Tyrone County Hospital is also proposed. As well as acting as a Local Hospital, Lagan Valley Hospital will become a specialist centre for planned (elective) surgery. Work will be undertaken to develop a second, protected elective centre in a Local Hospital west of the Bann.

11. There will be 9 acute hospitals at the Royal Group, Altnagelvin, Antrim, Belfast City, Causeway, Craigavon , Daisy Hill, the Ulster, and a new hospital in or to the north of Enniskillen. All of the 9 acute hospitals will support a broad range of acute services, each having their own characteristics and individual service profiles.

12. Consultant maternity in-patient services will be provided on 9 sites[2]. The development of midwife-led maternity units will be encouraged alongside consultant-led units, and 2 stand-alone midwife led units will also be piloted.

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[1] *See paragraph 4.22*
[2] *See paragraph 4.63*

13. Opportunities for co-operation between the North and South on a range of healthcare issues will be developed to their full potential.

Changes in Administrative Structures

14. It is essential that the organisational structures support a partnership approach between all parts of the Health and Personal Social Services (HPSS) and reinforce the effective and efficient delivery of services. A number of options for reforming the HPSS structures have been identified. These include:

- replacing the 4 HSS Boards;
- creating a single Regional Authority with responsibility for strategic planning, workforce planning and commissioning of regional services;
- bringing together Local Health and Social Care Groups as commissioning bodies for local health and social services;
- combining HSS Trusts or replacing them altogether; and
- replacing the 4 HSS Councils with a single, statutory health and social care consumer body.

15. Following consideration of responses to the proposals for structural change set out in this paper, further consultation will take place before decisions are taken on final configurations.

Equality Implications

16. A preliminary assessment has been carried out as to whether the proposals would have an adverse or negative impact on people in the Section 75 equality groups. This involved examining travel times under the current pattern of 15[3] acute hospitals and comparing these to travel times under the proposed 9 site model for acute services. Overall, the 9 site model for acute services would not appear to have a significant differential impact on any of the equality groups.

Resources

17. Substantial investment is essential to implement the proposals. Around £1.2bn of capital at today's prices will be required over a 9-year development period. The capital funding gap between the capital expected to be available over the period and what is required is estimated as £842m at today's prices.

[3] *South Tyrone hospital has temporarily losts its acute services pending the outcome of the Acute Hospitals Review*

18. A significant increase in staffing will be needed to deliver these proposals: a 30% rise in the numbers of consultant medical staff; a 20% rise in qualified nurses; a 25% rise in other health professionals; and a 25% rise in doctors undergoing GP training. By 2010, the additional recurring funding required to support the increased workforce would be around £165m per annum at today's prices.

19. The new pattern of hospital services will lead to greatly improved performance, including reduced waiting times and the elimination of the problem of people waiting for admission and delayed discharges. While the Executive is committed to providing extra resources for hospital services, the extent and speed of that investment will be determined by the Executive, taking full account of available resources and relative priorities across all of its responsibilities.

CHAPTER 1: INTRODUCTION

1.1 The ability of acute hospitals here to deliver safe, effective and timely acute services has come under increasing strain in recent years. This reflects significant growth in the demands made on these services against a history of under-funding that has impeded service development over the past decade. At the same time, advances in medicine, medical technology, professional practice and standards of treatment have changed the nature of the services delivered by these hospitals.

1.2. It was against this background that the Minister for Health, Social Services and Public Safety commissioned an independent review of the current provision of acute hospital services.

1.3. The Acute Hospitals Review Group's (AHRG) report, published in June 2001, was subsequently issued for consultation. The report and the comments received covering its approach and conclusions have contributed to the proposals set out in this paper. The paper is structured as follows:

Chapter 2	Explains why change is needed.
Chapter 3	Explains what kind of change is required.
Chapter 4	Sets out a model for future hospital services.
Chapter 5	Sets out options for the changes in the administrative structures of the Health and Personal Social Services.
Chapter 6	Makes an initial assessment of the equality implications of the changes.
Chapter 7	Sets out the required resources and timing.

1.4. The proposals outlined in this paper have been discussed and agreed by the Executive for consultation. They will significantly affect the ways in which our hospital services are delivered, the ways in which staff do their work, the pattern of our hospitals, the range of services that they provide, and their accessibility.

Have your Say

1.5. The paper is being sent for comment to a wide range of organisations and individuals. It is also available direct to the public on request, and through libraries, health and social services premises and the Internet. The document is available in large type, braille, audio-cassette, Irish and Cantonese. Requests will be considered for translations into other minority languages.

1.6. If you want to express a view on the proposals set out in this paper, or on any of the issues it covers, you should write to, fax or e-mail the contact point below before 30 September 2002. In keeping with the Department's policy on openness, responses may be made available to the public. If you do not wish your response to be used in this way, or if you would prefer it to be used anonymously, please indicate this when responding.

1.7. Your views will help the Minister and Executive to reach final decisions on the future shape of hospital services and administrative structures. All the responses to the consultation along with any new information which might emerge out of, or during, the consultation, will be taken into consideration before final decisions are made on hospital services, around the end of November 2002, and before moving ahead with structural reform of the HPSS.

1.8. A telephone helpline for enquiries on how to obtain copies of the paper has been set up – the telephone number is (028) 9052 0210

1.9. Consultation meetings are being arranged at which people will have an opportunity to discuss the paper with representatives of the Department.

Contact Point

1.10. The central point of contact for all responses and copies of the paper is:
Department of Health, Social Services and Public Safety,
Modernisation Unit, Room C4.22, Castle Buildings,
Stormont, Belfast, BT4 3SG.
Tel: (028) 9052 2349
Fax: (028) 9052 0535
E-mail: modernisationunit@dhsspsni.gov.uk

Closing date for receiving comments

1.11. All comments should be submitted no later than 30 September 2002

CHAPTER 2: THE NEED FOR CHANGE

Background

2.1 Hospital services are facing critical and mounting problems. Too many people wait long periods for hospital treatment, and patients requiring emergency admission too often have to wait for a bed because hospitals are working to full capacity. With pressures on beds growing annually, peak pressures, previously associated with winter, are becoming a year-round problem.

2.2. It is also becoming increasingly difficult to keep services going in some hospitals, where the existence of small clinical teams means that services can be particularly vulnerable. Some services have failed in recent years; others are fragile and cannot be sustained much longer in their current form.

2.3. Hospital services have changed considerably in the past fifty years. However, the funding to match these changes has not kept pace and the necessary investment in these services has not been made. Too often, acute services are located in worn-out buildings, with staff doing their best to deliver 21st century treatments using outdated equipment and facilities.

2.4. This has led to the quality of some services falling. Hospital services must change radically if they are to achieve modern standards and to deliver the high quality care that people need. The following paragraphs outline the main pressures for change, the opportunities that are being created by new ways of working, and the drive to improve standards.

Pressures Facing Acute Services

2.5. Many of the pressures facing hospitals are inescapable and will, inevitably, affect the way future services are provided. Some fundamentally affect their ability to deliver safe and effective care.

Changing service needs

2.6. People are living longer. With advancing age, people are more likely to suffer from chronic diseases such as diabetes, heart disease or arthritic problems and may have two or more chronic health problems. They require continuing health care, co-ordinated and delivered by a wide range of health care staff in different places and at different times.

2.7. The expected growth in the number of elderly people here will give rise to substantial and increasing pressures on acute hospital services. Much more can be done for older people, who can now benefit from advances in medicine and surgery, including procedures such as renal dialysis, hip replacement or open heart surgery – treatments that would not have been available to them until relatively recently.

2.8. In addition to the increase in healthcare needs as a result of an ageing population, there are also more children and young people suffering from chronic diseases such as asthma and diabetes. Children today can also survive to adulthood with diseases such as cystic fibrosis. However, they may require regular and complex hospital-based treatments throughout their lives.

Developments in Health Care

2.9. New medicines to treat both chronic and acute illnesses are now available: chemotherapy for the treatment of malignant disease; advanced therapies, such as 'clot-busting' drugs, for the treatment of heart disease; and new medicines to relieve the symptoms of multiple sclerosis and rheumatoid arthritis. These treatments often replace older, less effective treatments, but usually at a higher price.

2.10. Many new treatments can now reduce short-term discomfort for patients or significantly improve their quality of life in the longer term. This is demonstrated by the significant increases in the number of hip replacements, cataract operations, coronary artery bypass operations, and organ transplants undertaken in recent years.

2.11. There have been many advances in surgical techniques. 'Key-hole' surgery has reduced post-operative pain and complications and accelerated recovery. Improvements in surgical techniques and anaesthesia have meant that more surgical procedures can be carried out on an outpatient or day-case basis, enabling patients to avoid long stays in hospital.

Developments in Medical Technology

2.12. Advances in medical engineering technology have also produced significant successes. For example machines (lithotripters) can generate shockwaves to smash stones in the kidney or urinary tract, and lasers can be used to destroy tumours and to eliminate clots in arteries. Medical imaging advances, such as CT and MRI scanners, and more recently PET scanners, will revolutionise diagnosis.

New ways of working

Specialisation

2.13. As medical practice has developed and widened it has become increasingly difficult, if not impossible, for doctors, nurses and other health workers to acquire knowledge and relevant skills in sufficient depth across the full range of health care services. As a consequence, they now train to develop narrower, more focused, interests in 'sub-specialties', in which they become expert.

2.14. Increased expertise has resulted in great advances in treatments and, most importantly, improved results for patients. For example, the advent of consultants specialising in spinal surgery, joint replacement or specialist hand surgery has directly improved outcomes for patients. However, it also means that the era of medical 'generalists', trained to span a wide range of specialties, is approaching its end. Such doctors have often provided the core of acute services in smaller hospitals here. As these doctors retire or move on, it is becoming impossible to replace them.

Information and Communications Technology

2.15. The information and communications technology revolution has the potential radically to improve medical diagnosis. It opens the way for much better use of information, through a greater integration of systems. This will mean that information held in different locations can be combined to gain a fuller understanding of the progression of illnesses and the effectiveness of treatments, thus supporting the development of new and more effective practice.

2.16. The developing ability to shrink distances through advanced communication systems will also transform how hospitals work. Telemedicine, for example, allows a GP to transmit a photograph of a patient's skin condition to, and receive advice from, a dermatologist who may be located hundred of miles away. Similarly, if a patient has severe chest pain, the technology to transmit a patient's heart tracing (ECG) to a cardiologist by cellular telephone for expert advice is already in use.

A Team Approach

2.17. People often seek help with healthcare problems that do not fit within a single specialist area. Patients with chronic diseases, affecting many body systems, are becoming more common. Health care practitioners of all types need to work in teams, pooling their knowledge and skills to provide the best available care for such patients.

2.18. There is a great deal of evidence to suggest that outcomes are better if treatments and care are delivered by specialist multi-disciplinary teams. This is particularly so in the delivery of cancer services, but has also been shown to be the case for many chronic diseases. It is now accepted that services are better if they can be organised in a way that allows multi-disciplinary teams to develop.

2.19. Such teams must be large enough to work effectively and to provide reasonable working conditions for all the staff involved. They also need to care for sufficient number of patients to make best use of their skills and to maintain those skills throughout a lifetime of practice. This is particularly important, as all health care practitioners will be required to demonstrate their continued professional competence on a regular basis.

Training

2.20. The healthcare workforce is highly skilled, with one in five a graduate in their professional discipline. However, graduation is only the first rung on the ladder to specialist practice. Training takes place largely within the health service over several years. Traditionally this has mainly involved learning on the job. There have been significant changes to this approach throughout the past decade, which have recognised that it is not the most efficient way of equipping staff for specialist practice.

2.21. Increasingly, the jobs available to junior doctors, and other professional staff, do not provide the opportunity to develop the skills and experience necessary for modern practice. More stringent requirements covering the degree of supervision, the specific nature of the work undertaken by trainees and facilities for study available, are being applied by professional standard-setting bodies when considering, or reviewing, the suitability of a post for training.

2.22. The acute sector has been heavily reliant on staff in training to supplement the provision of patient care. This can no longer continue. At present, in hospitals which cannot meet training needs, the loss of training recognition has the potential to critically undermine service provision.

Supporting Hospital Staff

2.23. The hospital service depends on the commitment and motivation of its staff to deliver the quality of care achieved. Staff often work long hours, frequently beyond their contractual commitments, in the interest of their patients. They may work in a less than ideal environment, and find themselves dealing with situations that can be harrowing and disturbing. They do so with professionalism and dedication.

2.24. It is important that the commitment and motivation of staff is built upon rather than undermined. If the current organisation of acute services does not provide staff with adequate support in an acceptable physical environment, there is a significant risk that:

- local recruitment of doctors, nurses and other health professionals will become increasingly difficult;
- staff will leave to find jobs elsewhere; and
- international recruitment will become progressively less fruitful.

Improving Standards

2.25. Improving the quality of hospital care, and the environment in which this care is delivered, is a major priority. The responsibility for quality has been addressed at both an individual and a corporate level. Individual doctors, nurses and other health professionals must now ensure that their professional development keeps their knowledge and skills up to date. At a corporate level the duty on Trusts to provide quality care will soon become a statutory responsibility. Accountability for the delivery of the services will be strengthened through the introduction of robust clinical and social care governance arrangements.

2.26. These requirements, along with new arrangements for the production and dissemination of standards, will ensure that individual members of staff will be kept fully up to date with guidance on new technologies and standards for treatment to be applied. All of this will be underpinned by a transparent and open system of independent monitoring of the quality of services within the HPSS. The principal vehicle for this will be the planned Health and Social Services Regulation and Improvement Authority, which will be established subject to the will of the Assembly, with legislation being brought forward this autumn.

Conclusion

2.27 There have been major changes in the needs of the population, and in medical knowledge, medical technology and the way doctors, nurses and other health professionals train and work to deliver acute healthcare. The public rightly expects the highest standards of services, and these need to continue to improve. All of these factors, taken together, will have a profound effect on the way hospital services can be provided in the future.

2.28. The hospital service is constantly changing. Thanks to its highly skilled and committed workforce, hospitals continue to deliver good quality services, despite the growing pressures, and will continue to strive to do even better. However, it is increasingly difficult to deliver safe, modern and effective services in ageing hospitals, with outdated equipment and staffing complements that cannot support best clinical practice.

Pressures for Change

- Ageing population requiring increased treatment and care
- New medicines and new treatments
- Developments in medical technology
- New ways of working
- More stringent training requirements
- Improving standards

CHAPTER 3: WHAT KIND OF CHANGE

3.1 At present, there are 15 hospitals providing acute services here (see map at Appendix 1) and one further hospital that has temporarily lost its acute services, serving a population of around 1.7 million people. They range in size from large acute hospitals, such as the Royal Group and the Belfast City Hospitals, each serving the Belfast area and the whole population in some regional specialties, to the Downe hospital, serving a local population of around 55,000 people.

3.2. In order to meet the pressures for change outlined in the previous chapter, there needs to be a radical re-shaping of acute hospital services, with a greater differentiation between the roles of the current range of hospitals, concentrating specialised services where necessary, and decentralising other services where possible.

3.3. The trend internationally has been towards a greater concentration of hospital services on fewer sites. A number of professional medical bodies, including the Royal College of Surgeons, consider that an acute hospital, providing a full range of facilities and acute specialties, should be sufficiently large to serve a population of around 450,000-500,000 people. This would equate to three acute hospitals here. In practice, they recognise that most acute hospitals will continue to serve populations of around 200,000-300,000 for the foreseeable future.

3.4. It is their view that the specialist teams and technology necessary to treat acutely ill patients, and those with complex conditions, can only be maintained in large hospitals serving substantial numbers of patients. Such hospitals can be staffed to deliver complex modern treatments, ensure proper under-graduate and post-graduate professional training and raise clinical standards. Patients benefit by being treated by professional teams that treat enough patients to develop and maintain expert skills across a wide range of subspecialties.

3.5. Larger facilities are considered better able to use sophisticated diagnostic and other support services efficiently and economically, and support the number of clinicians necessary to provide 24 hour medical cover.

3.6. The Acute Hospitals Review Group and earlier reviews of acute services, conducted by the Health and Social Services Boards, have separately concluded that, to improve services for patients, a further concentration of acute services is necessary here.

Providing Local Services where Possible

3.7. Such reviews have also acknowledged that the improved quality of care and treatment arising from concentrating acute services must be balanced against the accessibility of these services to patients and their families. People want the best services available but prefer to have these in their own local area unless there is a good reason to travel further. They also want prompt and ready access to life-saving treatment in the event of an emergency.

3.8. Local hospitals foster the development of relationships with community and primary care services. Moreover, with developments in new technology such as telemedicine and teleradiology, local hospitals can now more easily link to specialist advice and support in larger acute hospitals. These developments in technology open the way for these hospitals to draw on medical and other expertise at a distance, and to provide patients with better diagnoses, of a potentially higher quality and with a minimum of delay.

3.9. The advances in medical treatment also mean that many more, formerly specialised, operations and medical procedures are becoming 'routine'. These can be more readily de-centralised and can often be treated on a day procedure basis.

Managed Clinical Networks – A New Way of Working.

3.10. In looking at how acute hospitals may change, it is important to take account of the advent of Managed Clinical Networks. Although still in its infancy, this approach to collaborative working opens the prospect of re-focusing services on populations rather than facilities.

3.11. The Acute Hospitals Review Group report noted the potential benefits of managed clinical networks and, in particular, *"their ability to facilitate the concentration of specialist skills and complex diagnostic equipment, when appropriate, without necessarily having to close down local services which are so highly valued by local communities"*.

3.12. Managed Clinical Networks have the potential to provide services to patients in a different way. They will support doctors, nurses and other health professionals, working together across different facilities and geographical/organisational boundaries to provide the right care for patients delivered from the most suitable location.

3.13. An effective clinical network for hospital based cancer services is already operational here. Staff at Cancer Units in Antrim, Craigavon, Altnagelvin and the Ulster hospitals work with the Belfast Cancer Centre to ensure that all patients receive high quality care. Regular multi-disciplinary meetings at the Cancer Centre and the Cancer Units provide the opportunity for health professionals to discuss an individual patient's diagnosis, and to agree the best medical or surgical care for that patient.

3.14. By providing services across a number of sites a more convenient and accessible service is provided for patients, without compromising standards of care or treatment. For example, a surgeon may provide outpatient clinics in a local hospital, carry out day-case surgery in a designated elective facility and perform major inpatient surgery at a large acute hospital.

3.15. Networks depend not just on individuals working across sites but on all the health professionals and their organisations working together to share good practice, communicate with one another, and provide a seamless service to patients. They offer the possibility of organising services differently, with the prime focus on the needs of the patient.

Conclusion

3.16. To support the development of modern hospital services, acute services here must change. Our pattern of hospitals is based on an outmoded approach to acute care. This does not facilitate the development of robust modern services that are sustainable and able to provide patients with both the full benefits and the level of quality of outcome which modern medicine can provide.

3.17. There is a limit to how much re-adjustment can be made to the current pattern of acute hospital services, and smaller hospitals are now finding it increasingly difficult to deliver services to modern standards. Consequently, they are beginning to lose training recognition and some are now finding it difficult to recruit and retain staff.

3.18. Action is needed now to identify where and in what ways services need to be concentrated to achieve higher quality; and where they can be decentralised, to make them even more accessible. A new pattern of services, supported by innovative managed clinical networks, will make an important contribution to transforming the quality and responsiveness of hospital services.

Re-shaping Acute Services

- Concentrating services can bring considerable benefits
- Benefits of concentration must be balanced against accessibility
- De-centralisation of more hospital services now possible
- Managed Clinical Networks can support more convenient and accessible services

CHAPTER 4: A MODEL FOR FUTURE HOSPITAL SERVICES

Current Arrangements

4.1. At present, the acute hospitals here all deliver a wide range of acute inpatient, day-patient and outpatient acute medical and surgical services. All but one of the hospitals have an A&E department and thirteen of them provide in-patient maternity services, with the number of deliveries ranging from around 450 to 5000 each year.

4.2. Serving a population of around 1.7 million people, these hospitals each year treat around 380,000 in-patients, 150,000 of whom are emergency admissions, and 120,000 day-patients. They also manage 1,200,000 outpatient and 670,000 A&E attendances.

4.3. The factors outlined in previous Chapters underline the need for significant change in the way hospital services are delivered in the future. The challenge is to build on the strengths of the current service, and to develop a modern and effective hospital service that meets the needs of patients, and delivers the full benefits that modern medicine can offer.

4.4. To meet these requirements will require a shift away from stand-alone hospital facilities towards an integrated service that delivers a comprehensive range of treatment and care from a variety of hospital and primary care settings, all operating collaboratively as an inter-dependent care network.

Principles

4.5. In seeking to achieve the right relationship between quality, safety, accessibility, sustainability, equity, and affordability, the proposals in this Chapter are guided by the following principles:

- none of the current hospitals offering acute services should be closed – rather, they must be adapted to play their part in a new configuration of service provision;

- services should be decentralised wherever the opportunities created by service and technological developments make this possible and sustainable;

- the range and quality of hospital services should aim to match the best standards achieved in other parts of Europe;

- access times to emergency care and consultant-led maternity services, in an appropriate facility, should be the minimum achievable, with the vast majority of people within 45 minutes, and everyone normally within one hour, of these services; and

- acute services must be re-focused, to achieve the concentration of expertise and experience required to deliver the highest possible levels of clinical care.

A systematic Approach to Hospital care

4.6. In developing these proposals, account has been taken of the AHRG report and the outcome of the public consultation on its findings. They follow a similar approach to the AHRG recommendations, in that they are built around a network of acute hospitals and Local Hospitals. However, the proposals go further than the AHRG recommendations in that they do not categorise acute hospitals into different levels and open the way for:

- the provision of a second Enhanced Local Hospital, in the West;
- the provision of a second protected elective centre, west of the Bann; and
- the piloting of two mid-wife led stand-alone maternity units, one in the East and the other in the West.

4.7. The hospital service has to be developed as an integral part of the total health system. Hospitals need to work as a dynamic element of that system, if they are to function effectively. The hospital service ultimately relies on primary and community care services, working effectively to channel the right patients to it and to re-integrate them back into the community at the end of their acute treatments.

4.8. The approach set out in this Chapter is based on the expectation that acute services will be patient –focused and organised around population groupings rather than facilities. This will require a much greater movement of staff within the system to support local activity and to ensure the proper decentralisation of services.

The Approach

- Closer integration of primary, community and secondary care
- Patient-focused acute services, organised around populations
- Greater movement of staff within system
- Local Hospitals a vital bridge in the new integrated health system

Links to Primary and Community Care

4.9. The boundaries between primary and hospital care are becoming increasingly blurred. Primary Care Teams, which bring together GPs and community health and social care professionals, including pharmacists and general dental practitioners, are most often the first point of contact that people have with the Health and Social Services. They play an increasingly important role in sustaining vulnerable and chronically ill people in the community, and managing their access to appropriate levels of acute care.

4.10. This role is set to expand, with the development of Local Health and Social Care Groups providing a better focus for modernising primary and community care.

4.11. The further enhancement of primary care will directly support the localisation of services, with an increased emphasis on providing them as close as possible to the people relying on them. In addition to established relationships with existing community hospitals, such as Ards and Bangor hospitals, primary care teams will have the opportunity to work closely with Local Hospitals, which will form a bridge between acute and primary care.

4.12. Given proper investment, it is envisaged that primary care, secondary (hospital) care and community care professionals will work together, in modern facilities, to provide the vast majority of hospital and community services required by the local communities that they serve.

A New Model for Hospitals

- Strikes the right balance, proposing a network of acute hospitals and Local Hospitals, including:
    - ➤ 9 acute Hospitals
    - ➤ 2 Enhanced Local Hospitals
    - ➤ 2 protected elective facilities
    - ➤ 9 consultant-led maternity units
    - ➤ 2 pilot stand-alone midwife-led maternity units
- Links to primary and community care

New Local Hospitals

4.13. In providing an effective health care system, local access to services is important. **Local Hospitals** will work directly in partnership with acute hospitals, forming a crucial bridge between hospital and primary and community care and helping to achieve cohesion between the different care sectors.

4.14. Local Hospitals are an important new concept, building on recent service developments here and elsewhere. They will be developed to provide the vast majority of services that people get in hospital settings (some 70%), and that do not need to be delivered in a large acute hospital.

4.15. Developments in clinical practice and technology are making more local treatment and care increasingly possible. Many investigations, treatments and procedures, previously requiring hospital admission, can now be carried out effectively and safely outside a major acute hospital.

4.16. Local Hospitals will provide increasingly sophisticated methods of investigation, diagnosis and day procedures that go considerably beyond what is currently available from Community Hospitals. They will provide a local base for expert clinicians, specialist nurses and other health professionals, who will relate to local populations rather than to individual facilities and provide a wide range of services, including:

- Extended-hours access to a minor injuries unit,
- an increased range of day case surgery,
- a wider variety of high quality diagnostic services,
- a wider range of outpatient clinics,
- pre and post natal maternity services,
- intermediate care, and
- rehabilitation and step-down beds, supporting people who require less intensively supported care as they complete their recovery from in-patient treatment.

4.17. The accessibility of Local Hospitals, their size and their local character, will ensure that they make a distinctive contribution to the overall provision of modern, high quality hospital services.

4.18. Developing Local Hospitals in this way will require considerable and continuing investment in modern equipment and in the training of staff. However, the proper development of Local Hospitals will greatly benefit the people who make use of their services.

4.19. The Mid-Ulster, South Tyrone , Whiteabbey, Downe, Lagan Valley, Mater, and Tyrone County hospitals will be developed as Local Hospitals. To take account of local circumstances, a number of these will have some additional services, as set out in the following paragraphs.

Downe Hospital

4.20. The AHRG report proposed that the Downe should provide, among other things, a 24 hour A&E service and emergency medical service, including coronary care. It should also provide planned (elective) day procedures but not emergency surgery.

4.21. This model raises a number of issues relating to the nature, extent and sustainability of the proposed services at the Downe. To address these, further clarification was sought regarding the detail of the model and the journey times in the Down area.

4.22. Journey times from some districts served by the Downe to the nearest acute hospital can be as much as 55 to 60 minutes. It is therefore proposed that the Downe should provide some additional services, as an **Enhanced Local Hospital**. The hospital will be linked to the acute hospital network and supported to maintain a 24 hour A&E unit, capable of providing resuscitation and emergency coronary care, and a consultant-led in-patient medical service, in addition to out-patient, diagnostic and day procedures.

4.23. In proposing this Enhanced status for the Downe as a Local Hospital, account has been taken of the particular problems of delivering emergency services to the dispersed rural population relying on this hospital. This approach builds on a model for the hospital previously developed by the Eastern Health and Social Services Board in collaboration with the Down Lisburn Trust, and the hospital consultants who provide current services at the hospital and in Belfast.

4.24. This hospital will have to work as part of a clinical network if it is to sustain these additional services. This will be challenging for staff at the Downe hospital and the acute hospitals working in partnership with it. The approach will be evaluated on a regular basis to confirm its continuing viability.

4.25. The consultant-led inpatient maternity services provided by the Downe will be transferred, in line with proposals on Maternity services later at paragraph 4.61.

Tyrone County Hospital

4.26. A new Local Hospital is proposed for Omagh. Analysis of the journey times to an acute hospital in or to the north of Enniskillen shows that some people served by the Tyrone County Hospital would have journey times approaching 60 minutes.

4.27. Recognising that traffic volumes and other factors may also push journey times over the hour at certain times of the day, it is proposed to site an Enhanced Local Hospital in Omagh. The Western Health and Social Services Board will be asked to lead a process involving local Trusts, clinicians, other hospital staff, and other interested parties, including service users, to develop a model for such an enhanced service.

4.28. The model will need to demonstrate that any proposals are viable, sustainable and will not undermine the new acute hospital in the area.

Lagan Valley Hospital

4.29. Recognising the current capacity problems in Belfast, Lagan Valley Hospital will have to continue to provide a wide range of acute services for much of the period leading to the establishment of a new pattern of hospital services, pending its transformation to a modern Local Hospital.

4.30. As a Local Hospital, Lagan Valley Hospital will have a minor injuries unit linked to one of the Belfast A&E centres, and a rehabilitation role, particularly for local older people. It will also provide state of the art outpatient and diagnostic services for the major specialties.

4.31. Given its location and facilities, it is proposed that the Lagan Valley Hospital becomes a specialist centre for planned (elective) surgery for Greater Belfast , protected from short-term emergency pressures and developed so as to maximise its elective capacity. This would facilitate the development of elective beds, allowing the hospital to make a significant contribution to decreasing waiting times for surgery in the East.

Other Protected Planned Admissions Provision

4.32. A single protected centre of this type, located adjacent to the Greater Belfast area, is unlikely to be sufficient to meet needs, reduce waiting lists, and ensure equality of access.

4.33. There exists a particular sense of inequity west of the Bann. Public concerns that services have been run down, withdrawn and made less accessible have generated understandable fears of being left without services.

4.34. Noting that accessibility is an important consideration, further work will be undertaken by the Department to identify a second major protected elective centre in a Local Hospital west of the Bann. In conjunction with other proposals in this paper, this centre will provide an important contribution to decreasing waiting lists in the West.

Mater Infirmorum Hospital

4.35. Recognising the current capacity problems in Belfast, the importance of making full use of the modern facilities of the Mater hospital is accepted. The Mater must therefore continue to provide a range of acute services for much of the period leading to the establishment of a new pattern of hospital services, pending its transformation to a modern Local Hospital. The Mater has a long and distinguished history as a teaching hospital. As a new Local Hospital, with good clinical links to the Royal Group of Hospitals and the Belfast City Hospital, and in close proximity to them, the Mater will be ideally placed to play an even more significant role in contributing to training of doctors, nurses and other health professionals of the future.

4.36. To enable the hospital to make this vital contribution, the Mater Hospital will be further supported in developing and expanding its role as a key institution in the fields of medical and nurse training. In particular the Department will formalise its role as a teaching hospital by putting its links with Queen's University on a statutory basis in the same way as the two main teaching hospitals. As a result the University would be given representation on the Trust board. These arrangements will be reviewed as necessary in the light of the decisions taken on HPSS structures.

4.37. The Mater has been experiencing increasing difficulties in maintaining the existing maternity services. The Mater's close proximity to the new centralised maternity hospital[4] may, however, open up opportunities for sustaining the service on a close partnership basis.

4.38. The AHRG concluded that: *'inpatient and other maternity services should only be maintained at the Mater on the basis of the continuation and development of existing links with the Royal Jubilee unit, including close networking and adherence to joint clinical protocols. This would involve rotation of the consultants, midwifes and junior medical staff in the two maternity units who would effectively act as a single clinical team.'*

4.39. It is proposed, on the basis of the approach suggested by the Acute Hospitals Review Group, that maternity services at the hospital will be maintained. This will be conditional upon the Mater Trust working with the new centralised Belfast maternity service, to show that robust networking arrangements can be put in place and sustained.

Modern Acute Hospitals

4.40. It is proposed to create a stable pattern of modern acute hospitals, comprising nine acute hospital sites. This approach will ensure that, regardless of where they live, most people will have access to acute services, effective emergency care and consultant-led maternity services within 45 minutes, and all the population will normally be within one hour of these services.

4.41. A core element of this approach is the establishment of a more integrated and mutually supportive network of acute and local hospitals. This will provide an inter-locking and seamless high quality care hospital network that links directly to primary and community care arrangements.

4.42. Some 'regional' services, such as chemotherapy, have already been decentralised from the Belfast hospitals. Future moves, such as the development of consultant-led fracture clinics in all acute hospitals, and full in-patient fracture services at Antrim and Craigavon, will also be brought forward.

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[4] *A new Centralised Maternity Service will be sited on either the Royal Group or the Belfast City Hospital site. Maternity services at the Mater Hospital should link directly to this Service.*

4.43. In addition Musgrave Park Hospital will continue in its role as a regional orthopaedic centre providing protected elective orthopaedic procedures. Steps will be taken to enhance services at the hospital, to facilitate a reduction in current long waiting times for operations.

4.44. Commissioners and providers of services will be expected to continue to pursue decentralisation opportunities as and when medical and technological advances permit.

4.45. Future acute services will be provided from nine hospitals: Royal Group, Altnagelvin, Antrim, Belfast City, Causeway, Craigavon , Daisy Hill, Ulster, and a new hospital in or to the north of Enniskillen, to serve the Fermanagh/Tyrone area. The rationale for the location of the new hospital for the Fermanagh/Tyrone area is addressed in paragraphs 4.51-4.60 below.

4.46. These acute hospitals will each have their own characteristics and individual service profiles. They should be seen as part of a mutually supportive network of complementary services. All of the nine acute hospitals will support a broad range of acute services. Each will have 24 hour A&E services, and a wide range of in-patient, outpatient and day procedures. Eight of the nine will have consultant led in-patient maternity services[5]. These services will meet most of the acute service needs of the population.

4.47. Additional specialist services, for the minority of patients with severe or complex conditions that require very specialist care, will be provided from some of the acute hospitals with larger patient volumes, for example inpatient fracture surgery. Where a patient requires services that are not provided in the acute hospital closest to their home, they will be admitted directly to, or transferred to, the nearest facility providing such services.

4.48. To provide patients with modern and effective treatments to the highest standards, specialist services need to be resourced accordingly. To deliver them, acute hospitals require the facilities, equipment and specialist medical, nursing, health professional and other support staff necessary to provide a multi-disciplinary approach to the management of complex clinical treatments.

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[5] *A new Centralised Maternity Service will be sited either on the Royal Group or the Belfast City Hospital site.*

4.49. There are a small number of services, such as neurosurgery or renal transplantation, which are distinguished by their highly specialised nature or by the relatively low number of patients, often with rare or complex conditions, that they treat. These will only be provided, on a region-wide basis, from one or two of the acute hospitals.

4.50. In addition, a number of Belfast hospital based specialties will be re-located, in line with the recommendations of the Eastern Health and Social Services Board's report: *Taking forward the Pattern of Acute Hospital Services in the Eastern Board Area, (December 2000).* These cover the future siting of specialties covering Plastics, Dermatology and Rheumatology. In the case of paediatric and adult ENT services, appropriate account will be taken of subsequent work by the Board with Trusts and clinicians on the separate siting of these services.

A New Fermanagh/Tyrone Acute Hospital

4.51. A new acute hospital in the Fermanagh/Tyrone area is necessary to provide accessible, high quality services to people in that area.

4.52. An acute hospital must have a workload sufficient to ensure its long-term viability. The Department's assessment is that a new acute hospital, at any of the locations considered, is sustainable, provided it is part of a larger managed clinical network. Potential partnership arrangements with acute hospitals in the South would further support the sustainability of an acute hospital in Fermanagh/Tyrone area.

4.53. The choice of locating the hospital in or to the north of Enniskillen, in Omagh, or in a location elsewhere, was finely balanced, and further analytical work was undertaken to guide this decision.

4.54. The over-riding concern was to ensure that the new facility meets the acute service needs of the population. The consultation on the AHRG report generated a number of detailed proposals as to the location of the new hospital and information was provided in support of each location.

4.55. To further inform the decision-making process, some additional analysis was undertaken in assessing journey times within Fermanagh/Tyrone and between the counties and adjacent hospitals in the South (See Appendix 5). An independent review and analysis of the reports supporting a number of locations/sites was commissioned; and activity and staffing data, covering Sligo, Cavan, Monaghan and Letterkenny hospitals, were analysed to help to establish the current potential of these hospitals to contribute to the provision of acute services here. Deprivation indices were also reviewed.

4.56. The results of these analyses can be summarised as follows:

(i) If the use of hospitals in the South is not taken into account and a new Fermanagh/Tyrone hospital is situated in or to the north of Enniskillen, around 8,744 people in the Fermanagh/Tyrone area would have travel times of over 45 minutes, of whom 2,131 would be between 50 and 55 minutes travelling time from the hospital. None would be more than 55 minutes away from the hospital. This compares with an Omagh location where 24,250 people in the Fermanagh/Tyrone area would be more than 45 minutes away, of whom 21,234 would be more than 50 minutes away, with 9,749 more than 60 minutes travelling time from the hospital. A location at Ederney, a location half way between the two towns, would place 17,802 people in the Fermanagh/Tyrone area more than 45 minutes away from the hospital, of whom 7,260 would be between 55 and 60 minutes travelling time away from it, and none would be more than 60 minutes away.

Site	**Total no in Fermanagh/ Tyrone with journey time over 45 mins**#	**Of those with journey time over 45 mins**		
		Journey time Over 50 min	**Journey time Over 55 min**	**Journey time Over 60 min**
Enniskillen*	8,744	2,131	0	0
Omagh	24,250	21,234	9,749	9,749
Ederney	17,802	7,260	7,260	0

** Times are calculated on the current hospital. If the new hospital was to the north of the town, journey times would be reduced.*

 # Calculations assume that people will travel to their nearest hospital in the North for treatment. While this may be the case for Accident and Emergency attendances, patients will travel to other hospitals for elective treatment, particularly for certain specialities

(ii) If hospitals in the South were able to provide A&E and a full range of acute services to the population, and if this were factored into travelling times, no-one in Fermanagh or Tyrone would have to travel more than 55 minutes to an acute hospital, regardless of the location chosen. In this scenario, the differences between access times are much closer. If the hospital is located in or to the north of Enniskillen, around 6,525 people in the Fermanagh/Tyrone area would have travel times of over 45 minutes, none of whom would be more than 50 minutes away from the hospital. This compares with an Omagh location where 4,626 people would be more than 45 minutes away, of whom 2,365 would be between 50 and 55 minutes away from the hospital. A location at Ederney, which is half way between the two towns, would place 4,072 people more than 45 minutes away, none of whom would be more than 50 minutes travelling time away from the hospital.

Site	Total no in Fermanagh/ Tyrone with journey time over 45 mins#	Of those with journey time over 45 mins		
		Journey time Over 50 min	Journey time Over 55 min	Journey time Over 60 min
Enniskillen*	6,525	0	0	0
Omagh	4,626	2,365	0	0
Ederney	4,072	0	0	0

** Times are calculated on the current hospital, if the new hospital was to the north of the town, journey times would be reduced.*

 # Calculations assume that people will travel to their nearest hospital in the North or South for treatment. While this may be the case for Accident and Emergency attendances, patients will travel to other hospitals for elective treatment, particularly for certain specialities.

4.57. There has been communication at a senior level between the Department of Health, Social Services and Public Safety and the Department of Health and Children concerning the potential of hospitals in the South to provide services to patients from the North. From this, it is apparent from the current stage of planning for hospital services that there is uncertainty as to whether the relevant hospitals in the South will deliver, over the longer term, the capacity and services equivalent to those provided by the nine acute hospitals in the North. This degree of uncertainty has to be taken into account in deciding the best location of the new hospital with a potential life-span of 60 or more years.

4.58. The revenue and capital costs of the new hospital would be largely the same whether it is located at Enniskillen, Omagh or a location somewhere between the two towns. However, some additional infrastructure costs, for example for services and road improvements, may be required if the hospital is located well outside the two main towns.

4.59. Given the difficulties that the Erne and Tyrone County hospitals are currently experiencing in maintaining acute services, it is essential that a decision on the location for the new hospital is reached as quickly as possible. In these circumstances and on the information available, the balance of advantage lies in locating the new hospital in or to the north of Enniskillen.

4.60. This proposal is firmly based on the available information, and any new information that emerges during the course of the consultation will be taken into consideration before reaching a final decision.

Maternity Services

4.61. Women want maternity services that are safe, provide high quality care, and offer real choice in the range of care available. They are particularly concerned about having to travel long distances during pregnancy or labour.

4.62. It is the intention that maternity services should be provided as close to people's homes as possible. Consequently, Local Hospitals, as well as the acute hospitals, will provide ante-natal care, ultrasound screening, assessment of complications and post-natal care for mother and baby.

4.63. Moreover, all mothers-to-be should normally be within one hour of the nearest consultant-led maternity unit. The safety of mother and baby is paramount, and women need to have confidence that safe and satisfactory arrangements are in place for their care and support in all maternity units. All of the 9[6] consultant-led maternity units will therefore provide cover, on a 24 hour basis, supported by teams of consultant obstetricians, consultant anaesthetists and consultant paediatricians.

4.64. It is clear that, in the future, the number of expectant mothers who will deliver their babies in the smaller maternity units will not be sufficient to enable staff in these units to maintain their expert skills. In such units, the small numbers of deliveries make it impossible to sustain the full team necessary to deliver a consultant-led maternity service.

4.65. Alongside the concentration of consultant-led maternity services, delivered on fewer sites, the development of midwife-led units, within or adjacent to a consultant-led maternity unit, will be taken forward. Such units can allow mothers with a low risk of having a complicated labour, to have a more natural birth in a safe but homely environment. The further development of these units will be actively promoted.

Midwife-led Stand Alone Units

4.66. The opportunities to move beyond this approach towards stand-alone midwife-led units are already being demonstrated in pilot schemes, in England, Wales and the South. Preliminary evaluations indicate that such units are capable of providing a safe, alternative option of care during delivery for mothers-to-be who are assessed as 'low risk', by putting in place appropriate and effective transfer arrangements to cover unexpected emergencies.

4.67. The opportunities for such developments here should be fully explored. It is proposed that the Department, in consultation with HSS Boards and Trusts, will arrange for local pilot projects to be established. Two initial pilot schemes are envisaged, one in the East and one west of the Bann. The proposed pilots will establish clear protocols to ensure that, where risks are identified at any stage, mothers-to-be are referred to a consultant-led maternity unit, which will be supported by the establishment of an effective region-wide neonatal transport service. The training and skills of midwives in the Stand Alone Units will also be enhanced.

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[6] *A new centralised maternity service will be sited on either the Royal Group or Belfast City Hospital site. Maternity services at the Mater should link directly to this.*

Supporting Rural Communities

4.68. The development of Local Hospitals, working with appropriately sited acute hospitals, will ensure that rural communities are not disadvantaged when it comes to accessing hospital services.

4.69. Recognising that, no matter how hospital services are arranged, dispersed rural communities will be some distance from them, early additional steps will be taken to put in place supporting measures. These will add to and complement the provision of hospital services and ensure that the needs of rural people are adequately addressed. These include:

- **Rapid Responder Schemes**– providing 24 hour cover within defined geographical areas. These are ambulance service paramedical staff, with pre-hospital trauma and life-support skills. Using rapid response vehicles, they will respond to emergency calls, assess the situation, and either deal with the incident themselves or provide support and care until an ambulance arrives;

- **First Responder Schemes** – these schemes provide a network of local people with the skills to respond to life-threatening emergencies;

- **Improved Ambulance Services** – the Department's plans will improve ambulance response times for many rural areas, and ambulance crews will be trained to provide thrombolysis (clot-busting drugs) for appropriate patients before they arrive in hospital;

- **Transport services** - a more flexible interpretation of 'clinical need' will be applied when considering eligibility for transport to and from hospital provided by the HPSS for people in rural areas; and

- **Innovative planning** –Boards and Trusts will set up task groups to develop imaginative ways of addressing the problems that people in rural areas face, especially those areas with long and difficult journeys. Examples include making greater use of vehicles other than ambulances for patients who do not require skilled ambulance aid, and enhancing services provided by primary care teams, drawing on the expertise of other emergency services.

4.70. The aim is not to substitute local services for hospital-based care but to develop a range of pre-hospital support services, to ensure that the overall service available to rural communities is as good as that available to people living in communities closer to hospitals. The service for each area will be tailored to meet particular local circumstances.

Working in Partnership with the South

4.71. The AHRG recommended that collaborative working with health services in the South should be encouraged. This is fully in keeping with work already agreed and in progress.

4.72. For example, in 2000 the North South Ministerial Council (NSMC), established the North South Regional Hospital Services Group (NSRHSG) to consider the opportunities for developing partnerships covering the wider regional and supra-regional services. It has been tasked with identifying service areas/specialities where cross border or all-island co-operation can be of mutual benefit.

4.73. Cooperation and Working Together (CAWT) is an organisation formed in 1992 to promote cooperation in improving the health and social well-being of the populations of the North Eastern and North Western Health Boards in the South, and the Southern and Western Health and Social Services Boards in the North. A number of local cross-border initiatives are being developed by CAWT, which has been exploring opportunities for building greater collaboration between hospitals in border areas.

4.74. The Health Departments here and in the South are working collaboratively on A&E services, planning for major emergencies, co-operation on high technology equipment, cancer research and health promotion. For example, as part of work on planning for major emergencies, the NSMC has approved the joint commissioning of a feasibility study of an all-island Helicopter Emergency Medical Service and this is currently being taken forward. A joint contract is already in place for the disposal of clinical waste.

4.75. Such collaboration is in the best interests of patients North and South, and it is important that the full potential of such co-operation is realised.

Conclusion

4.76. A number of new Local Hospitals will be established to deliver a wide range of services on a local basis. This will go considerably beyond what is currently available from Community Hospitals. They will network with acute hospitals and local primary and community care and provide the backbone of the new hospital service.

4.77. There will be greater differentiation between the roles of the current range of hospitals, concentrating specialised services where necessary, and decentralising other services where possible.

4.78. The nine acute hospitals, including a new acute hospital for Fermanagh/Tyrone, located in, or to the north of Enniskillen as outlined in this paper, represent a viable, robust and sustainable approach to delivering modern and accessible acute services.

4.79. Maternity in-patient services should be provided on nine sites. Midwife-led services should be further developed and two stand-alone midwife-led units will be piloted.

4.80. Opportunities for co-operation between the North and South on a range of healthcare issues should continue and be developed to their full potential.

CHAPTER 5: THE NEED FOR CHANGE IN STRUCTURES

Introduction

5.1. The HPSS is administered by the Department, 4 HSS Boards, 19 Trusts and 5 Special Agencies. There are also 4 Health and Social services Councils. The four Boards were originally set up to deliver the full range of health and social services, under the direction of the Department. With the creation of the internal NHS market in the 1990s, Boards were given responsibility for determining the needs of their population for health and social services. They became commissioners of services, purchasing them from a range of service providers

5.2. The main providers of services were the Trusts, which inherited the responsibility for the delivery of services from the Boards. The newly established Trusts were given a high degree of management autonomy, and competed with each other for contracts covering the delivery of health and social services.

5.3. Recognising the potential for GPs to influence the delivery of hospital services, the then government also established GP Fundholding practices. These were also given commissioning powers and were funded to buy a range of hospital and other services directly from Trusts.

5.4. At present, 19 Trusts and 5 Special Agencies deliver a wide range of hospital, community health and social care services . These consist of 7 Trusts that provide acute hospital services only, 5 Trusts that provide community health and social services only, 6 fully integrated Trusts providing both hospital and community health and social services, and one regional Ambulance Trust. The Special Agencies provide a number of services, including payments to independent practitioners, regional supplies, blood transfusion services, medical physics, guardian ad litem services for children, and health promotion.

5.5. The need for structural reform has been evident since moves to abolish the internal market began. The structures set up to promote the development of an internal market do not reflect the new emphasis on partnership and co-operation. Nor do they readily support the objectives of empowering local communities, targeting social need and removing inequalities, which feature strongly in the Executive's Programme for Government.

5.6. The competitive, internal market, approach has been replaced by a more collaborative approach. GP Fundholding has been abolished, and Local Health and Social Care Groups, (LHSCGs) are in the process of being set up, with the intention of bringing a much more inclusive approach to the identification of local needs and the commissioning of services.

5.7. The current roles of the Department, the 4 HSS Boards, the 19 HSS Trusts, the 5 Special Agencies, and the 4 HSS Councils all need to be reviewed, to determine whether they are appropriate in the new environment of partnership and cooperation signalled in the Executive's Programme for Government.

Relationship with Review of Public Administration

5.8. The Executive has announced its intention to launch a comprehensive review of all aspects of public administration in Northern Ireland. The draft terms of reference which are to be finalised shortly state that the intention is to *"review the existing arrangements for accountability, development, administration and delivery of public services in Northern Ireland, and to bring forward options for reform which are consistent with the arrangements and principles of the Belfast Agreement, within an appropriate framework of political and financial accountability."*

5.9. The review is to be launched in the coming weeks. It is anticipated that there will be a major consultation exercise in the autumn of 2002, with an initial report on progress being produced in spring 2003. It is envisaged that firm conclusions are unlikely to emerge before the end of 2003.

5.10. Clearly there will need to be a two-way inter-relationship between the Review of Public Administration (RPA) and work on structural reform within the HPSS. However, there is no question of this work being unnecessarily delayed because of the RPA. The Executive has agreed that work such as reforming the HPSS should be progressed, but decisions should be taken in a co-ordinated manner, taking account of the emerging principles/criteria from the RPA in determining the final configuration of HPSS structures.

5.11. Following consideration of the responses to the proposals for structural change a further consultation will be required before final decisions can be taken on structural reform.

The Acute Hospitals Review Recommendations on Structures

5.12. The Acute Hospitals Review Group, as part of its consideration of the need for change in the organisation of hospital services, looked at the current organisation of the HPSS and made a number of suggestions for streamlining its structures.

The following paragraphs take account of these suggestions and set out for consultation a number of options for reforming HPSS structures.

5.13. The AHRG proposed that:

- the four HSS Boards should be replaced by a Regional Strategic Health and Social Services Authority outside the Department and by (possibly) three Commissioning Consortia or Partnerships, made up of local health and social care commissioning bodies,
- the 18 HSS Trusts (excluding the Ambulance Trust) should be replaced by 3 integrated Health and Social Care Systems for delivering services; and that
- the four HSS Councils should replaced by a single, statutory consumer body.

5.14. Responses to the initial consultation on the Acute Hospitals Review Group's report showed a general welcome for the proposal for a Strategic Health and Social Services Authority separate from the Department. Mixed views were expressed on the proposal to establish three Health and Social Care Systems.

5.15. Many of those who commented felt that any review should be considered as part of the Executive's proposed Review of Public Administration. However, the Assembly's Health, Social Services and Public Safety Committee felt that a review of the current structures should proceed as quickly as possible, and need not await the forthcoming Review of Public Administration (RPA).

Options for the Reform of HPSS Structures

5.16. The case for reform of HPSS structures is clear, and there is a strong public and professional expectation that Boards will be abolished and that the number of HSS organisations will be reduced significantly. In developing health and social care services for the 21st century, it is essential that the organisational structures support a partnership approach and reinforce the efficient and effective delivery of acute and other vital services. Proposals for reform are set out in the following paragraphs.

Proposals for Reform of Structures

- Creating a single Regional Authority with responsibility for strategic planning, workforce planning and commissioning of regional services
- Replacing the 4 HSS Boards
- Bringing together Local Health and Social Care Groups as commissioning bodies for local health and social services
- Combining HSS Trusts or replacing them altogether
- Replacing the 4 HSS Councils with a single statutory health and social care body

A Single Regional Authority

5.17. It is proposed to create a single Regional Authority, which would have a strong strategic planning and accountability focus. The Authority would carry out key functions such as workforce planning and the commissioning of some regional services, and would have overall responsibility for managing change.

5.18. Following the launch of *"Investing for Health"* in March 2002, the Department is also undertaking a review of the Public Health function. This will be conducted in parallel with, and will take account of, the Review of Public Administration. As many of the functions within Public Health are delivered within the HPSS, this will also have a bearing on any structural reform.

Have your say:

Your views would be welcome on whether or not there should be a single Regional Authority, on the constitution, functions and location of this body, and whether it should be part of the Department or outside it.

Commissioning bodies

5.19. With the disappearance of the four Boards, commissioning would be a major function for individual LHSCGs to handle. In order to share the burden, enhance commissioning power and ensure that there is a consistent approach to commissioning, it is proposed that this role should be exercised by groups of LHSCGs working in partnership. There are a number of ways in which this could be done. A key determinant in setting their number and constitution would be whether they would also deliver a range of community health and social care services.

5.20. Consideration of the options for bringing LHSCGs together will be shaped by the views of the public, staff and other interested parties on whether it is still seen as important to maintain an organisational separation between commissioning and delivery. It will also be influenced by views on whether fully integrated health and social care delivery bodies are the preferred model, in the light of the perceived success or otherwise of the three main types of Trust configuration in operation since the early 1990s.

5.21. Depending on the weight given to these factors, new models for commissioning bodies could include:

- LHSCGs coming together as Commissioning Consortia or Partnerships, with delegated budgets from the regional body, to commission the full range of health and social care services in the light of the assessed needs of their local communities. In this model, given the focus on commissioning, three bodies might be regarded as sufficient for this purpose.

- LHSCGs coming together as fully integrated commissioning and delivery bodies, in which case there would be no further need for Trusts, since responsibility for the delivery of services would pass to these new bodies. Given their responsibility for delivering a wide range of hospital, primary and community health and social services, there would be a case for more than three bodies.

- LHSCGs coming together as Commissioning Consortia or Partnerships, but also with responsibility for the delivery of primary community health and social services, but not acute, services. In this model, there would continue to be a reduced number of acute-only Trusts. Given the range of service delivery responsibilities which these combined LHSCGs would have, there would be a case for more than three bodies.

5.22. Under any of these models, LHSCGs could be constituted either as statutory bodies in their own right, or as operational units of the Regional body.

Options for New Structures: Commissioning[7]

- LHSCGs as commissioning bodies
- LHSCGs as commissioning and delivery bodies
- LGSCGs as commissioning and delivery bodies with the exception of acute services

Have your say:
Your views would be welcome on whether Boards should be abolished, and on the constitution, functions and number of Commissioning bodies.

Trusts

5.23. Depending on the preferred commissioning bodies option, there are a number of different possibilities for Trusts. As a minimum, there should be a significant reduction in the number of HSS Trusts. This should aid effective networking between organisations in the delivery of services, and ensure resources are focused on service users rather than administration. The options include:

- A number of fully integrated Trusts delivering the whole range of hospital, community health and social care services.
- A number of separate acute Trusts and community health and social care Trusts.
- A number of acute only Trusts, with the delivery of community health and social care services being the responsibility of commissioning bodies.
- A number of LHSCGs coming together as fully integrated commissioning and delivery organisations, as described above, which would remove the need for Trusts.

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[7] *The Regional Authority may have some regional commissioning functions*

Options for New Structures: Delivery

These include:
- Fully integrated Trusts
- Separate acute and community Trusts
- Acute only Trusts
- LHSCGs as integrated commissioning and delivery organisations with no Trusts

Have your say:
- **Your views would be welcome on the constitution, functions and number of Trusts, and on whether there should continue to be Trusts.**
- **Any other options for delivery organisations**

A Consumer Body

5.24. It is proposed to match the functions of the 4 HSS Councils with the new structural arrangements. Should there be a new single Regional Authority, we would propose to replace the 4 Councils with a single statutory health and social services consumer body. This should enable the body to reflect the new organisational arrangements in the health and social services, and strengthen the voice of the service user on cross-cutting strategic policy issues. The new body would perform an important role in monitoring the work of the Regional Authority. It would also streamline current arrangements in relation to commissioning research, opinion surveys, and publishing information.

5.25. At the same time, it would be essential to ensure that this body would be constituted to enable it to keep in touch with the views of the public on local issues. There may be a number of ways of achieving this.

5.26. The new LHSCGs have community representation, and this will help to ensure that issues of concern to local communities will be addressed. Nevertheless, should there be single Regional Authority, a strong regional consumer body, in touch with local opinion on local issues, is also required.

Have your say:

- **Your views would be welcome on whether the four HSS Councils should be replaced by a single statutory health and social services consumer body, in the event of a single regional authority.**

- **Your views would be welcome on other ways of achieving consumer representation.**

Conclusion

5.27. It is important that the new structures being proposed will support the close working of all parts of the HPSS, and facilitate the essential linkages which are needed between health and social services and education, housing and other key public services.

5.28. The views of the public, staff and other interested bodies, together with the emerging principles/criteria from the Review of Public Administration, will be pivotal in determining the final shape of these new structures.

5.29. Following consideration of the responses to the proposals for structural change, further consultation will be required before decisions can be taken on final configurations.

CHAPTER 6: EQUALITY

Equality Implications

6.1. Under the statutory Equality obligations (Section 75 of the Northern Ireland Act 1998), due regard must be given to promoting equality of opportunity for the nine statutory equality groups specified in the legislation.

6.2. A preliminary assessment has been carried out of whether the proposals have an adverse or negative impact on people in the nine groups. (A summary of the assessment is at Appendix 2.) This has involved examining travel times using the current configuration of 15 acute hospitals and comparing these to travel times under the 9 site configuration. This was calculated for three possible locations for the new hospital in the Fermanagh/Tyrone area (Enniskillen, Omagh and a green field site half-way between the two at Ederney). The different access times were calculated under three categories, to show the number of wards and the affected population where the difference in travel time either:

(i) decreased, stayed the same or increased by less than 5 minutes,

(ii) increased by between 5 and 30 minutes, or

(iii) increased by more than 30 minutes.

6.3. The composition of each category of wards was then analysed to determine if there were any differences for each equality group living in the three categories of wards.

6.4. Overall the nine site configuration would not appear to have a significant differential impact on the Section 75 equality groups, wherever the new hospital in the Fermanagh/Tyrone area is located. The measures proposed on decentralising services, and those for ameliorating the problems that people face in rural areas, will contribute to promoting equality of opportunity for people in the nine equality groups.

6.5. Everyone cannot live close to an acute hospital but, for people who are geographically isolated, steps can be taken to minimise any risk and ensure that they are not disadvantaged because of where they live.

6.6. Living in a rural area should not prevent people from receiving the high quality care that they need.

Equality

- Effect on travel times of 9 site configuration assessed
- No significant differential impact identified
- Decentralising services and measures for rural areas will promote equality of opportunity

Conclusion

6.7. The proposed 9 acute hospitals should ensure that the vast majority of the population can normally access high quality acute hospital services, including emergency care and maternity services, within 45 minutes and all of the population normally within one hour. Local Hospitals, delivering a range of outpatient, diagnostic, day procedure will network with these hospitals and with local primary and community care. There would not appear to be a significant differential impact on the Section 75 equality groups.

Have Your Say

This Chapter covers a range of important areas. We would like to hear your views on all of the issues raised.

Specific Equality Issues

Can you identify any equality impacts which might occur as a result of these proposals for any of the following groups of people?

- persons of different religious belief,
- persons of different political opinion,
- persons of different racial group,
- persons of different age,
- persons of different marital status,
- persons of different sexual orientation,
- men and women generally,
- persons with a disability and persons without,
- persons with dependants and persons without.

Are there likely to be any specific impacts in terms of tackling deprivation; for example, in relation to the New Targeting Social Need initiative?

CHAPTER 7: RESOURCES AND TIMING

7.1. Funding is critical to the achievement of the vision of modern, high quality services. Resources are limited, and any approach to the development of services must be based on sound planning and careful use of funds. These issues have been carefully considered in the development of these proposals for hospital services which are designed to be implemented over a 9-year period. Bids will have to be made for the necessary resources as part of the normal funding processes.

Capital costs

7.2. To implement the proposals, around £1.2bn of capital at today's prices will be required, over a ten-year development period. The capital funding gap between the capital expected to be available over the period and what is required is estimated as £842m, at today's prices. In seeking to identify sources for the funding required no single solution – be it borrowing, Public Private Partnerships, (PPP) or more traditional public expenditure – is likely to meet our need, and a full range of funding options will be considered.

7.3. The detailed capital assumptions underpinning the Acute Hospitals Review are attached at Appendix 3. The proposals reflect the need for a phased, comprehensive programme of modernisation for the acute sector over the period to 2010/11.

7.4. The proposals recognise that the current pattern of hospital services is not 'fit for purpose', and is ill-equipped to provide the standards of acute hospital care which people are entitled to expect.

7.5. A key ingredient in shaping a modernisation agenda is the need to address vigorously the deficiencies in the infrastructure inherited from Direct Rule. These relate to:

- The failure to maintain the basic estate and equipment inventory;
- The failure to invest in new technology; and
- The cyclical need to replace much of the core acute hospital estate, much of which is 40 years old and older.

Revenue Costs

7.6. The AHRG report indicated that the continuing funding needed to provide the numbers of staff required, will, by 2012, be approximately £165m at today's prices.

Resources, (all at today's prices)

- £1.2bn capital required over 9-year development period
- £842m estimated funding gap
- £165m revenue costs by 2012

7.7. The Department's assessment of future staffing needs mirrors the AHRG view that current services are significantly under-staffed and that this directly impedes the improvements in quality and performance that the hospital service needs to achieve. Its estimate of the projected revenue costs associated with the necessary service developments is consistent with the AHRG figure. These estimates are based on the following:

- A 30% rise in the numbers of Consultant medical staff - this would address current deficiencies and make significant progress towards a consultant provided service, with a greatly reduced dependency on doctors in training to deliver care to service users.

- A 20% rise in the number of qualified nurses - this would address severe workload pressures relating to current nurse staffing levels and enable them to cope with the greater numbers of patients that will be cared for in a modern service. It would also support the increasingly specialised nature of nursing.

- A 25% increase in the number of qualified therapeutic staff - this would provide additional staff to address a growing need for services from speech and language therapists, occupational therapists, physiotherapists etc. These services, which are currently chronically under-staffed, are particularly important in supporting the trend towards shorter stays in hospitals and more community based support.

- The numbers of doctors undergoing GP training will have to be increased, to provide a 25% increase in numbers. This would allow GPs to take on more responsibility for treatments currently provided in hospitals.

- Investment in other staff to support the increases in clinical staff identified above.

Staffing

- 30% increase in consultants
- 20% increase in nurses
- 25% increase in therapeutic staff
- 25% increase in GPs

7.8. These further increases, building on those already in the pipeline, will ensure that there are suitably qualified staff available, to bring services close to self sufficiency in trained staff by the end of the development period.

7.9. To achieve these increases, which are broadly in line with trends elsewhere, the number of people entering pre-registration training across a range of professions will have to be significantly increased.

7.10. There should be no difficulty in attracting students. There is currently a surplus of applicants for available training places. In nursing there are currently four applicants for every place.

7.11. There will be a short-term need to make up the numbers of trained staff, as there will be a time-lag before numbers completing training can be increased. Until the additional professionals are trained and available, the extra posts will be filled by a combination of initiatives. These will include:

- continuing the successful return to practice initiative within nursing and extending this to other health professionals groups;

- taking action to increase the proportion of graduates who are recruited into HPSS when they have completed training;

- developing the role of unqualified staff and enhancing the skills of this group by providing investment in training;

- continuing to draw on the world-wide market for certain professions including nursing and medicine; and

- encouraging more staff to stay on, through initiatives such as investment in professional development and flexible working practices.

7.12. Other initiatives, such as the new consultant contract and the proposals set out in *Agenda For Change*, will also assist in retaining staff within the HPSS.

7.13. A breakdown of projected costs is provided at Appendix 4. These estimates must, of necessity, be revisited in the context of the impact of other policy and service development initiatives, particularly within the community and social services. They will also be affected by service-wide developments, such as compliance with the EU Working Time Directive.

7.14. The arrangements for workforce planning are being strengthened at a regional level. This will provide a mechanism for updating and reviewing the investment required across all HPSS services on a regular basis, as the acute hospital review strategy rolls out over the next 10 years.

Performance

7.15. The hospital service has continued to review its performance, which has improved significantly in recent years. Over the past 10 years, the number of patients treated annually has increased by 38% and, over the same period, there has been a 32% reduction in the number of hospital beds.

7.16. With the changes proposed in the organisation of hospital services, and the provision of additional staff to deliver modern acute care, the performance of the acute sector is expected to further improve, even when account is taken of the predicted growth in the number of very elderly people.

7.17. Once the new pattern of hospital services is established, it should:

- **Eliminate the problem of people waiting for admission** in all hospitals – with all patients transferred to a staffed bed as quickly as possible. All emergency cases will be admitted straight to a bed and no patients will wait more than two hours for admission post-assessment.

- **Bring waiting times for outpatient appointments down** to a maximum of three months, with urgent cases prioritised and seen much more quickly.

- **Reduce waiting times** for elective procedures to a maximum of 3 months.

- **Speed the flow of patients** through the hospital service and ensure that many more will avoid hospital admission altogether.

- **Eliminate delayed discharges** from hospital, with patients moving out of acute hospitals as soon as their acute treatment is successfully concluded.

- **Meet peaks in demand** by flexing available capacity without having to cancel procedures or delay normal work.

Timing

7.18. While the Executive is committed to providing extra resources for hospital services, the extent and speed of that investment will be determined by the Executive, taking full account of available resources and relative priorities across all of its responsibilities.

Conclusion

7.19. This substantial investment is the key to necessary changes. The investment will need to be spread over the next decade to progressively up-grade and improve facilities and to support new clinical practice. This scale of investment is crucial to developing a modern and effective hospital service. It should be seen in the context of a service that has a strong history of increasing productivity and making the best use of resources in the interest of patients.

GLOSSARY OF TERMS

Access Time - estimated time taken by road to the nearest acute hospital based on average speeds on different classes of roads

Acute Services - health care and treatment provided normally in hospitals able to manage planned and emergency procedures

Acute Trusts - Health and Social Services Trusts which provide acute hospital care only

Clinical and Social Care Governance - a framework within which HPSS organisations are accountable for continuously improving the quality of their services and safeguarding standards of care and treatment

Commissioning - the process of identifying local health and social care needs, drawing up plans to meet those needs, making agreements with service providers to deliver services, and monitoring outcomes

Community Care - health or social care provided outside a hospital

Community Trusts - Trusts which provide community health and social services but not acute hospital services

Consultant-Led Maternity Unit - a maternity in which a consultant is responsible for the clinical care of patients

Consultant-Led Services - services in which a consultant holds responsibility for the clinical management of patients

Day-Case Surgery - surgery which does not require an overnight stay in hospital

Deprivation Indices - indicators used to identify people, groups and areas in greatest social need

Differential Impact - where a particular group would be affected differently by the proposals

Elective Surgery - non-emergency surgery taking place in a hospital and planned in advance

GLOSSARY OF TERMS

Enhanced Local Hospital - a Local Hospital which provides services additional to those normally available in Local Hospitals

Health and Personal Social Services (HPSS) - includes hospital services, community health services, personal social services and general medical services

Health and Social Services Boards - organisations responsible for commissioning health and social services for their resident populations. There are 4 Health and Social Services Boards

Health and Social Services Councils - organisations responsible for representing the views of health and social services users, and for providing an independent oversight of the activities of Health and Social Services Boards

Health and Social Services Trusts - organisations responsible for providing health and social services, and for exercising certain statutory functions on behalf of Health and Social Services Boards

Integrated Trusts - Trusts which provide both hospital and community health and social services

Local Health and Social Care Groups (LHSCGs) - groups of providers of local primary and community services - there will be 15 LHSCGs

Midwife-Led Maternity Unit - maternity units in which the clinical is led by a midwife

Primary Care - care provided by the primary care team, normally led by a general practitioner

Protected Elective Centre - a centre where the surgical treatment is elective only, emergency cases being cared for elsewhere

Providers - organisations which provide health and/or social services

Regional Services - specialist services which are provided from one or two hospital sites for people throughout the region

Section 75 Equality Groups - the groups of people specified in Section 75 of the Northern Ireland Act 1998, in respect of whom public authorities, in carrying out their functions, are required to have due regard to the need to promote equality of opportunity and to have regard to the desirability of promoting good relations

Special Agencies - organisations which provide a range of specialised services. There are 5 such agencies: Central Services Agency, Health Promotions Agency, Blood Transfusion Agency, Guardian Ad Litem Agency and the Regional Medical Physics Agency

Sustainability - the viability of a hospital having regard to its ability to treat sufficient numbers of patients to maintain the expert skill base of its clinical teams.

APPENDICES

APPENDIX 1	Location of existing Acute Hospitals
APPENDIX 2	Acute Hospitals Review - Preliminary Assessment of Equality Implications of proposal for 9 Acute Hospitals
APPENDIX 3	Acute Hospitals Review - Projected Capital Costs
APPENDIX 4	Acute Hospitals Review - Projected Additional Revenue, (Staff Costs)
APPENDIX 5	Calculation of Access Times

APPENDIX 1:

Location of Existing Acute Hospitals

APPENDIX 2

ACUTE HOSPITALS REVIEW - PRELIMINARY ASSESSMENT[1] OF EQUALITY IMPLICATIONS OF PROPOSAL FOR 9 ACUTE HOSPITALS

With alternative sites for a new hospital for the Fermanagh/Tyrone area in or to the north of Enniskillen, in Omagh and a green-field site at Ederney

Aim

The aim of this preliminary assessment is to provide a quantitative analysis of whether the proposal to deliver acute services from 9 acute hospital sites is likely to lead to inequalities between people in the designated equality groups. The effect on accessibility among the equality groups is compared with the position under the status quo (15 acute hospital sites). The effect of alternative locations for a new hospital for the Fermanagh/Tyrone area in or to the north of Enniskillen, in Omagh and on a green-field site at Ederney[2], has been assessed.

Methodology

Access times from the centre of each enumeration district (E.D.) to the current 15 acute hospital sites in Northern Ireland were calculated using the software called SMOSS (Simplified Modelling of Spatial Systems). The lowest access time (i.e. time to the nearest hospital) for each E.D. was chosen. These were combined to produce an access time from each electoral ward by calculating an average weighted by the population of each E.D. within the ward[3].

This process was repeated for the 9 acute hospitals site proposal. The times from each electoral ward to the current 15 acute hospital sites were then compared to the times for the 9 acute hospital sites proposed and the difference calculated. The effect on the 566 electoral wards in the North are shown in three categories:

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[1] *A fuller assessment, of which this is a summary, is available on request.*

[2] *Ederney, Co. Fermanagh, is 16 miles from both Enniskillen and Omagh.*

[3] *It should be noted that there could be discrepancies between the individual ward access times predicted by the model and what would be the real travel time. Such discrepancies could arise due to the impact of congestion, road activities and other factors, which it is not possible to take account of in the model. However, the grouping of wards will minimise such discrepancies, as slight overestimates in one ward will be offset by underestimates in another.*

(a) **Number of Wards and population affected (with % of total), where the access time decreased, stayed the same, or increased by less than 5 minutes.**

		Decrease, Same or 0-5 min Increase	
		Wards	Population
With new Fermanagh/Tyrone Hospital at:	Enniskillen	428	1,332,211 (78.7%)
	Omagh	437	1,345,671 (79.5%)
	Ederney	414	1,295,563 (76.6%)

(b) **Number of Wards and population affected (with % of total), where the access time increased by between 5 and 30 minutes.**

		5-30 min Increase	
		Wards	Population
With new Fermanagh/Tyrone Hospital at:	Enniskillen	115	299,743 (17.7%)
	Omagh	108	288,190 (17.0%)
	Ederney	141	365.519 (21.6%)

(c) Number of Wards and population affected (with % of total), where the access time increased by more than 30 minutes.

		30+ min Increase	
		Wards	**Population**
With new Fermanagh/Tyrone Hospital at:	**Enniskillen**	23	59,869 (3.5%)
	Omagh	21	57,963 (3.4%)
	Ederney	11	30,742 (1.8%)

The composition of each category of wards (a.- c. above) was then examined to determine if there were differences in the proportion of each equality group living in the wards.

Numerical data was obtained at ward level in respect of the majority of the nine equality groups (or suitable proxies for the groups). Unfortunately, no information was available on sexual orientation and only approximate higher-level data was available in respect of racial group (the Centre for Racial Equality provided some estimates of where the majority of the main racial groups were located in the North - typically at LGD level). Data on political preference was obtained at LGD level from first preference votes cast at the June 2001 Local Government elections (The Electoral Office does not have data in respect of the votes cast for individual electoral wards).

In instances where a direct count of the numbers in a specific group were not available a suitable proxy was used. For example, the aggregate of attendance allowance and incapacity benefit claimants was used as a proxy for those with a disability. However, as there may be issues surrounding take-up of social security benefits, an alternative disability proxy was created based on numbers self-reporting a limiting long-term illness at the 1991 Census of Population (this was the only available data source for a number of the equality groups).

Once the datasets were assembled at ward (or LGD level) it was then possible to map the equality group data to the increase in access times. This then allowed each equality group to be separately analysed in terms of their increase in access times. The proportions of each equality group in the different categories of wards, was then compared.

Conclusion

In general, it can be said that the 9 acute hospitals proposal would not appear to have a significant differential impact on different equality groups wherever the new hospital in the Fermanagh/Tyrone area were to be located. There are some differences between the proportions of the different religious groupings and the different political opinion groupings were it to be located in or to the north of Enniskillen, in Omagh, or in Ederney, but these differences were only apparent in the categories with large increases in access times (c. above). In the case of the rest of the equality groups, there is virtually no difference between the groups in terms of impact.

Appendix 2

Preliminary Assessment of Equality Implications: Summary

	9 Acute Hospitals Proposal with new Fermanagh/Tyrone Hospital at		
(Equality Group)	**Enniskillen**	**Omagh**	**Ederney**
Gender	N	N	N
Age	N	N	N
Marital Status	N	N	N
Disability	N	N	N
Religious Belief	P	P	P
Dependants	N	N	N
Political Opinion	P	P	P
Racial Background	N	N	N

(N) = No differential Impact; (P) = Potential Impact

ACUTE HOSPITALS REVIEW – PROJECTED CAPITAL COSTS

ESTIMATED FINANCIAL PROFILE (PROJECTS)

(based on £814.5m & £135m Backlog Maintenance)

	2002/03	2003/04	2004/05	2005/06	2006/07	2007/08	2008/09	2009/10	2010/11	Total
Projects*	21.2	52.8	87.5	122.7	137.3	150.0	102.0	89.5	51.5	814.5
Backlog Maintenance	7.0	23.0	15.0	15.0	15.0	15.0	15.0	15.0	15.0	135.0
TOTAL	28.2	75.8	102.5	137.7	152.3	165.0	117.0	104.5	66.5	949.5

ESTIMATED FINANCIAL PROFILE (EQUIPMENT)

	2002/03	2003/04	2004/05	2005/06	2006/07	2007/08	2008/09	2009/10	2010/11	Total
General eg pendants/monitors	7	15	15	15	15	15	15	15	15	127
Major eg x-ray/labs	3	23	27	6	6	6		6	6	6 89
TOTAL	10	38	42	21	21	21	21	21	21	216

*Costs include works equipment, estimated at a total of £100m

CAPITAL FUNDING GAP

	2002/03	2003/04	2004/05	2005/06	2006/07	2007/08	2008/09	2009/10	2010/11	Total
Estimated Requirement	38.2	113.8	144.5	158.7	173.3	186.0	138.0	125.5	87.5	1,165.5
Available Provision	36.0	36.0	36.0	36.0	36.0	36.0	36.0	36.0	36.0	324.0
Difference	2.2	77.8	108.5	122.7	137.3	150.0	102.0	89.5	51.5	841.5

Notes:

- The Project Costs are based on current Business Case costs where they have been produced. The costs include equipment provision, estimated at 12.5% of the total cost of each scheme.

- Where Business Cases have not been commenced the costs are based on broad assessments at January 2002 cost estimates.

- The Estimate for the new accute hospital serving Fermanagh/Tyrone does not include utility supplies and road infrastructure works which may be required to enable the new hospital to be built in of the chosen location.

- Locations which are further removed from major conurbations are likely to attract more significant cost implications.

Backlog Maintenance:

- Allowing for these schemes, there would still need to be an allowance made for approximately £15m per annum for Backlog maintenance in light of the time it will take to implement these schemes.

Development in Medical Science & Service Delivery

- The financial projections are based on the current methods of clinical service delivery. Any radical change in clinical technologies could have consequential impact on the estate required to deliver the services and the financial projections.

APPENDIX 4

ACUTE HOSPITALS REVIEW – PROJECTED ADDITIONAL REVENUE (STAFF COSTS)

Profile of Additional Staff Costs over the 10 year period 2002/2012 (in £m)

STAFF GROUP	2002/03	2003/04	2004/05	2005/06	2006/07	2007/08	2008/09	2009/10	2010/11	2011/12	Total (£m)
Consultants	2.5	2.5	2.5	2.5	2.5	2.5	2.5	2.5	2.5	2.5	22.5
Nurses	4.5	5.1	6.9	8.3	8.3	8.3	6.9	6.9	6.9	6.9	69.0
GPs	2.9	2.9	2.9	2.9	2.9	2.9	2.9	2.9	2.9	2.9	29.0
Therapists	0.8	0.8	1.6	2.4	2.4	1.6	1.6	1.6	1.6	1.6	16.0
Education	5.5	5.0	5.5	3.5	2.5	2.5	1.0	1.0	1.0	1.0	28.5
Additional Cost Per Annum	**16.2**	**16.3**	**19.4**	**19.6**	**18.6**	**17.8**	**14.9**	**14.9**	**14.9**	**14.9**	**165.0**

APPENDIX 5

CALCULATION OF ACCESS TIMES[1]

Background to the model used

Access times were calculated using a model called Simplified Modelling for Spatial Systems (SMOSS) developed by the Geography Department of Lancaster University. This model was developed to inform a rurality adjustment in the HSS Board capitation formula, and was subsequently adapted for the Northern Ireland Ambulance Service Strategic Review. It was also used to calculate scores for the Access Domain of the Noble Measures of Deprivation. Road conditions and congestion were not taken into account in the model but average speeds on different classes of road have been incorporated. When the model was developed, cross-validation with other available data provided assurance that the model does in fact reflect reality.

The Acute Hospital Review Group (AHRG) used a model developed by consultants for the then Department of the Environment (DOE). Access times produced using the SMOSS model were compared against the times from the DOE model. While access times do differ slightly, the SMOSS model calculates times at a very small geographic area level (enumeration district) and therefore enables the longest access times to be identified. The DOE model uses groups of electoral wards called 'zones' and the longest travel times are not identified as a result. For this reason, the SMOSS model is suitable for producing more detailed analysis to build on the findings produced by the AHRG work.

It should be noted that there could be differences between the individual ward access times predicted by the model and the actual travel time for a specific journey. Such differences could arise due to the impact of congestion, road activities and other factors that could not be taken into account of in the model. However, ward access times provide a reasonable estimate of the average travel time of the ward population taking into account its spatial distribution (i.e. based on average travel times of individual enumeration districts within wards).

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[1] *See Chapter 4, paragraphs 4.55 – 4.56*

Calculation of access times for a new Fermanagh/Tyrone Acute Hospital

A number of steps were taken to derive the figures that appear in the consultation paper and these are described below:

1. The access time from the centre of each enumeration district (E.D.) to the 9 acute hospital sites proposed, was generated by the model. The model was re-run to include each of the 3 suggested sites for the Fermanagh/Tyrone hospital.

2. For each of the 3 configurations of the 9 acute hospitals (based on the 3 suggested locations for the Fermanagh/Tyrone hospital), the minimum access time (i.e. time to the nearest hospital) for each E.D. in the North was selected.

   Example: Table 1 shows access times to each of the 9 hospitals where Omagh is given as the site for the new hospital in Fermanagh/Tyrone. Times are shown from 3 of the EDs in the ward Victoria Bridge, Strabane (there are a total of 9 EDs in this ward). The minimum access time to the nearest hospital for each ED is shown in the last row of the table. For all 3 EDs, the nearest hospital is Tyrone County.

Table 1. Access times from 3 EDs in Victoria Bridge

Hospital	Access times from ED 261401	Access times from ED 261402	Access times from ED 261403
Ulster	116.51	112.57	111.28
Royal	109.52	105.57	104.32
City	109.61	105.64	104.38
Coleraine	80.36	71.57	69.8
Antrim	93.31	89.48	88.22
Craigavon	84.67	80.56	79.01
Daisy Hill	108.19	104.21	102.51
Altnagelvin	48.95	40.9	38.77
Tyrone County	**31.66**	**28.43**	**27.39**
Minimum Access Time	31.66	28.43	27.39

3. These minimum access times at E.D. level are combined to produce an access time from each electoral ward to the nearest hospital, by calculating an average weighted by the population of each E.D. within the ward.

   Example: Table 2 shows the minimum time from each of the 9 EDs in Victoria Bridge to their nearest hospital where for this example Omagh is used as the the suggested location for the new hospital in the Fermanagh/Tyrone area. The populations within each ED are multiplied by the minimum access time for each ED. These 'weighted access times' are summed together for all EDs in the ward and divided by the total population in the ward. This gives a weighted average travel time from the ward of Victoria Bridge to the nearest hospital (i.e. 70117 divided by 2277 equals 30.8 minutes)

Table 2. Access times weighted by population for each ED within Victoria Bridge

ED	Minimum Access Time (minutes)	Population in each ED	Minimum Access Time X Population
261401	31.66	197	6240
261402	28.43	205	5826
261403	27.39	329	9003
261404	25.44	201	5107
261405	28.03	221	6195
261406	32.23	122	3934
261407	28.54	252	7182
261408	32.88	247	8114
261409	36.75	504	18515
Total for ward	Weighted average = 30.8	2277	70117

This weighted average access time for a ward based on the aggregation of ED access times will not be the same as the straight access time from the centre of a ward as a whole to the nearest hospital. This is because the weighted average takes account of variations in access time and population size across the ward and therefore is a more accurate access time.

4. For each of the 3 configurations, the wards with a weighted average access time of over 45 minutes within the Fermanagh/Tyrone area were selected. The population living within each of these wards were summed together to give a figure for the total number of people in the Fermanagh/Tyrone area who had access times of over 45 minutes.

   Example: Table 3 shows the wards in the Fermanagh/Tyrone area only where the access time was over 45 minutes. Therefore the total number of people living in wards where the weighted average access times are over 45 minutes is 24,250.

Table 3. Wards with weighted average access times of over 45 minutes in the Fermanagh/Tyrone area (where the new Fermanagh/Tyrone hospital is in Omagh)

Ward	Local Government District	Population in ward	Average travel time
Derrylin	Fermanagh	2,664	76.1
Belcoo & Garrison	Fermanagh	2,532	67.4
Florence Court & Kinawley	Fermanagh	2,292	62.9
Newtownbutler	Fermanagh	2,261	61.2
Derrygonnelly	Fermanagh	2,365	54.9
Rosslea	Fermanagh	2,335	54.8
Donagh	Fermanagh	2,197	53.9
Belleek & Boa	Fermanagh	2,327	52.6
Boho, Cleenish & Letterbreen	Fermanagh	2,262	52.5
Lisnaskea	Fermanagh	3,016 Total = 24,250*	47.1

* The figures do not add to the total due to rounding.

5. The subset of the population whose travel times were over 50, 55 and 60 minutes were subsequently calculated. In our example (Table 3), 9 wards had an access time of over 50 minutes (21,234 people), 4 wards had an access time of over 55 minutes and 60 minutes (9,749 people). In this case, no wards had access times of between 55 and 60 minutes.

6. In order to assess the input of Southern Hospitals in the analysis, steps 1 – 5 were repeated with the addition of access times generated by the model from each E.D. to relevant hospitals in the South (i.e. Sligo, Cavan and Letterkenny). The final results are shown in Table 4 below.

Table 4. Wards with weighted average access times of over 45 minutes in the Fermanagh/Tyrone area (where the new Fermanagh/Tyrone hospital is in Omagh and hospitals in the South are included)

Ward	Local Government District	Population in ward	Average travel time
Derrygonnelly	Fermanagh	2,364	54.4
Boho, Cleenish & Letterbreen	Fermanagh	2,262 Total = 4,626	49.9

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