

THE BAMFORD REVIEW OF MENTAL HEALTH AND LEARNING
DISABILITY (NORTHERN IRELAND)

**PROMOTING THE
SOCIAL INCLUSION OF PEOPLE
WITH A MENTAL HEALTH PROBLEM
OR A LEARNING DISABILITY**

August 2007

FOREWORD

This further report from the Bamford Review covers the important area of promoting the social inclusion of people with a mental health problem or a learning disability. It complements, in particular, the Review's Human Rights and Equality of Opportunity report, which was published in October 2006. Together they set out the ethical values for the entire Review and its central vision of valuing people with a mental health problem or a learning disability and enabling them to enjoy their rights to full citizenship.

The report also fulfils the dual purpose of providing the Department of Health, Social Services and Public Safety's latest contribution to the Office of the First Minister and Deputy First Minister on the Promoting Social Inclusion initiative, which is part of the New Targeting Social Need strategy.

Preparation of the report has involved discussions with and contributions from several other Northern Ireland Departments, users of services, their carers and families. It makes a number of practical recommendations on how people with a mental health problem or a learning disability can lead more inclusive and meaningful lives.

We commend the report to you.

Roy J. McClelland (Professor)
Chairman,
Bamford Review

Leslie Frew
Director,
Mental Health and
Disability Services,
DHSSPS

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1. INTRODUCTION

Purpose

- 1.1 The purpose of this report is to identify the reasons why people with mental health problems or a learning disability are often excluded from the kind of everyday life that others take for granted and to make recommendations that will improve their inclusion in society.

Background

- 1.2 This review forms part of Northern Ireland's Promoting Social Inclusion policy, which encourages Government Departments to form inter-departmental groups to tackle key areas of social exclusion. As the Department of Health, Social Services and Public Safety (DHSSPS) had commissioned an independent Review of Mental Health and Learning Disability policy and legislation, it was agreed that this Review was the most appropriate vehicle to consider the social inclusion of people with a learning disability or mental health problems.
- 1.3 Promoting Social Inclusion involves the statutory, private and voluntary sectors. In particular, the contribution of the voluntary sector in terms the promotion of social inclusion of people with mental health needs and learning disability has been welcomed in terms of stigma, housing, employment and health.

Promoting Social Inclusion (PSI) Policy

- 1.4 The Northern Ireland Executive agreed that Promoting Social Inclusion involves Departments working together and with social partners:
- To identify and tackle factors which can contribute to social exclusion.
 - To undertake positive initiatives to improve and enhance the life and circumstances of the most deprived and marginalised people in our community.

The Bamford Review of Mental Health and Learning Disability

- 1.5 The DHSSPS commissioned a Review of Mental Health and Learning Disability policy and legislation in October 2002. The main reasons for commencing the Review were:
- The focus of existing legislation was on treatment and care in hospitals rather than in the community.
 - Increased expectations for amended legislation following reviews of mental health legislation in neighbouring jurisdictions.
 - The requirement to ensure that legislation is updated to reflect human rights, equality and European legislation.
 - Major changes in the modern methods of providing treatment and care.
- 1.6 A Steering Committee, initially chaired by the late Professor David Bamford, was established

to oversee the Review. The Committee has representation from a wide range of professional interests, the voluntary sector, individuals, carers and includes members from neighbouring jurisdictions.

1.7. The vision of the Review is:

- Valuing those with learning disability and mental health problems, their rights to full citizenship, equality of opportunity and self-determination.
- Addressing the challenges facing people with mental health problems or a learning disability.
- A process of review, reform, renewal and modernisation of services that will make a real and meaningful difference to the lives of people with mental health problems or a learning disability and to their carers and families.

1.8. The key values of the Review are:

- Respect for people as individuals – through openness and honesty in the provision of information, respect and courtesy in individual interactions with individuals, partnership and empowerment in service planning and delivery – with Government, providers and the wider society each accepting their respective responsibilities.
- Demonstrating justice and fairness – resources for services should be allocated and managed according to criteria which are transparent, and which demonstrate equity.

1.9. The principles of the Review are:

- Partnership with users and carers in the development, evaluation and monitoring of services.
- Partnership with users in the individual assessment process, and in the development of their programme of treatment and care and support.
- Delivery of high quality, effective treatment, care and support.
- Equity of access and provision of services, including the needs of people from minority cultures, people with disabilities, people subject to the criminal justice system.
- Provision of services that are readily accessible.
- Delivery of continuity of care and support for as long as is needed.
- Provision of a comprehensive and co-ordinated range of services and accommodation based on individual needs.
- Taking account of the needs and views of carers, where appropriate, in relation to assessment, treatment, care and support.
- Provision of comprehensive and equitable advocacy support, where required or requested.
- Promotion of independence, self-esteem, social interaction and social inclusion through choice of services and opportunities for employment and social activities.
- Promotion of safety for individuals, carers, providers and members of the public.
- Provision to staff of the necessary education, training and support.
- Services subject to quality control, informed by the evidence.

- 1.10. During the PSI review it was noted that there is a lack of local research in Northern Ireland in promoting social inclusion for people with mental health problems or a learning disability.

2. VISION, PRINCIPLES, POLICIES AND LEGISLATION

- 2.1. The Promoting Social Inclusion Group (see Annex 1) decided that it was important to set a vision and principles for social inclusion that were easy for everyone to understand. The vision and principles would operate within the wider national and international legal and policy context.

Vision – ‘Just Like You’

- 2.2. People with a learning disability or mental health problems can often be denied access to services that everyone takes for granted. The ‘Just Like You’ vision is that people with a learning disability or mental health problems are the same as you, with the same needs for everyday life including education, employment, housing, health, transport and a social life.

Principles – ‘Just Like You’

- 2.3. The ‘Just Like You’ principles identify the key areas of life that people with a learning disability or mental health problems require the same access and opportunities as everyone else.

Employment

- 2.4. We need employment to meet our potential and provide economic opportunities in life – ‘Just Like You’.

Education

- 2.5. We need education to motivate us to achieve our potential, build our confidence, enrich our lives, and provide the foundation for an inclusive society – ‘Just Like You’.

Housing

- 2.6. We need the opportunity to access decent, affordable housing in safe and sustainable communities that contribute to our improved health and social well-being – ‘Just Like You’.

Health

- 2.7. We need to be provided with opportunities to promote our health and mental well-being and have easy access to quality health and social services, when required – ‘Just Like You’.

Transport

- 2.8. We need to have adequate transport to access employment, education, health and provide opportunities to meet families and friends – ‘Just Like You’.

Social Life

- 2.9. We need to be able to fully participate in social activities with friends, family and the local community – ‘Just Like You’.

Mental Health Declaration for Europe

- 2.10. The Ministers of Health of Member States in the European Region of the World Health Organisation agreed a Mental Health Declaration for Europe in January 2005. The statement acknowledged that mental health and mental well-being are fundamental to the quality of life and productivity of individuals, families, communities and nations.
- 2.11. A key priority in the Mental Health Declaration is to 'collectively tackle stigma, discrimination and inequality, and empower and support people with mental health problems and their families to be actively engaged in this process'.

The Madrid Declaration

- 2.12. In March 2002, a European Congress of People with Disabilities was held in Madrid under the Spanish Presidency. An outcome of the Congress was the so-called 'Madrid Declaration'.
- 2.13. The vision of the Madrid Declaration: "Our vision can best be described as a contrast between this new vision and the old vision it seeks to replace:
 - (a) Away from disabled people as objects of charity...and towards people with disabilities as right holders.
 - (b) Away from people with disabilities as patients... and towards people with disabilities as independent citizens.
 - (c) Away from professionals taking decisions on behalf of people with disabilities... and towards independent decision making and taking responsibilities by people with disabilities on issues which concern them.
 - (d) Away from a focus on individual impairments... and towards removing barriers, revising social norms, policies and promoting a supportive and accessible environment.
 - (e) Away from labelling people as dependents or unemployable... and towards an emphasis on ability and the provision of active support measures.
 - (f) Away from designing economic and social processes for the few... and towards designing a flexible world for the many.
 - (g) Away from unnecessary segregation in education, employment and other spheres of life... and towards integration of people with disabilities into the mainstream.
 - (h) Away from disability policy as an issue that affects specialised ministries...and towards inclusion of disability policy as an overall Government responsibility".

Improving the Life Chances of Disabled People

- 2.14. The Department of Work and Pensions Strategy Unit's report, 'Improving the Life Chances of Disabled People', was published in January 2005 as agreed Government policy. The report set out an ambitious vision for improving the life chances of disabled people over the next twenty years.
- 2.15. The report focuses on four key aspects of disabled people's life chances: independent living; early years and family support; transition to adulthood; and employment. The practical measures are designed to:
- Increase disabled people's ability to live independently - to enjoy increased choice and control over how their needs are met through individualised budgets - and to have the opportunity of a full home, work and community life.
 - Enable young disabled children and their families to enjoy 'ordinary' lives, through access to childcare, early education and early family support, to enable them to care for their child effectively and remain socially and economically included.
 - Support disabled young people and their families through the transition to adulthood. Transition will be better planned around the needs of the individuals and service delivery will be smoother across the transition.
 - Increase the number of disabled people in employment while providing support and security for those unable to work. Employers will be able to access the right advice and information.

The UN Convention on the Rights of Persons with Disabilities

- 2.16. The UN adopted a new draft treaty in August 2006 giving greater rights to disabled people around the world. The United Nations Convention on the Rights of Persons with Disabilities requires:
- Participating countries to change laws and ban discriminatory customs and practices.
 - Disabled people to have an equal right to life.
 - Equal rights for disabled women and girls.
 - Protection for children with disabilities.
 - A right to own and inherit property, to control financial affairs and have equal access to financial services.
 - Disabled people not to be deprived of their liberty 'unlawfully or arbitrarily'.
 - Medical or scientific experiments without consent to be banned.
 - An end to enforced institutionalisation.
 - Freedom from exploitation, violence and abuse.
 - A right to privacy and access to medical records.
 - Countries to remove barriers to accessing the environment, transport, public facilities and communication.
 - A right to independent living.
 - Essential equipment to be made affordable.
 - A right to an adequate standard of living and social protection.

- An end to discrimination relating to marriage, family and personal relationships.
- Equal access to education.
- An end to discrimination in the job market.
- A right to equal participation in public life.
- A right to participate in cultural life.
- Developing countries to be assisted to put the convention into practice.

UN Convention on the Rights of the Child

- 2.17. The human rights of children and the standards, to which all governments must aspire in realizing these rights for all children, are detailed in one international human rights treaty: the UN Convention on the Rights of the Child.
- 2.18. The Convention has been ratified by almost every country in the world and by ratifying the Convention governments have committed themselves to protecting and ensuring children's rights.
- 2.19. The Convention on the Rights of the Child is a universally agreed set of non-negotiable standards and obligations. It spells out the basic human rights that children everywhere – without discrimination – have: the right to survival; to develop to the fullest; to protection from harmful influences, abuse and exploitation; and to participate fully in family, cultural and social life. Every right spelled out in the Convention is inherent to the human dignity and harmonious development of every child. The Convention protects children's rights by setting standards in health care, education and legal, civil and social services. These standards are benchmarks against which progress can be assessed. States that are party to the Convention are obliged to develop and undertake all actions and policies in the light of the best interests of the child.
- 2.20. The Convention on the Rights of the Child is the first legally binding international instrument to incorporate the full range of human rights – civil and political rights as well as economic, social and cultural rights. On 20 November 1989, the governments represented at the General Assembly agreed to adopt the Convention into international law.

The Disability Discrimination (Northern Ireland) Order 2006

- 2.21. The Disability Discrimination (NI) Order 2006 strengthens and extends the coverage of the Disability Discrimination Act 1995, increasing the scope of legislation to include more people with disabilities. For example, people with mental health problems will no longer have to prove their condition is “clinically well-recognised”. The new laws will also provide extra protection for disabled people in other areas such as private clubs and in discriminatory job advertisements. Under the new laws disabled people living in rented premises will now find it easier to have their homes adapted to meet their needs. Transport will become more accessible to disabled people as the legislation will require all trains to be fully accessible by 2020. The legislation also introduces an important provision that will enable lifting of the transport exemption from Part III of the Disability Discrimination Act 1995 for land-based public transport, vehicle hire, breakdown services and leisure and tourism transport vehicles.

The Order also extends current legislation to bring the functions of public authorities within the scope of disability legislation for the first time and imposes a new duty on them to promote positive attitudes towards disabled people and encourage their participation in public life. The extension of the Act in this way will impose further duties on the public sector not to discriminate against disabled people across the whole range of its public activities.

Northern Ireland Act 1998 – Section 75

- 2.22. The Northern Ireland Act 1998 places on public bodies a duty to promote equality of opportunity and this includes people with mental health problems and learning disabilities. The relevant text is:

“75. - (1) A public authority shall in carrying out its functions relating to Northern Ireland have due regard to the need to promote equality of opportunity-

- (a) Between persons of different religious belief, political opinion, racial group, age, marital status or sexual orientation,
- (b) Between men and women generally,
- (c) Between persons with a disability and persons without,
- (d) Between persons with dependants and persons without.

(2) Without prejudice to its obligations under subsection (1), a public authority shall in carrying out its functions relating to Northern Ireland have regard to the desirability of promoting good relations between persons of different religious belief, political opinion or racial group.”

3. STIGMA

Background

- 3.1. Mental health problems affect people of all ages, in all kinds of jobs and at all educational levels. Often, the only way to know whether someone has mental health problems is if they tell you. The majority of people are unaware of how many people with mental health problems they know and encounter every day (it is estimated in Great Britain that 1 in 6 people have a mental health problem at any one time).
- 3.2. Stigma is a reality for people with a mental illness or a learning disability and it is reported that how others judge them is one of their greatest barriers to a complete and satisfying life. Society feels uncomfortable about mental health problems and it is not seen like other health problems such as heart disease and cancer. Due to inaccuracies and misunderstandings, sometimes people have been led to believe that an individual with a mental illness has a weak character or is inevitably dangerous.
- 3.3. We all have an idea of what someone with a mental health problem or a learning disability is like, but society and the media have distorted most of our views and interpretations. Newspapers often portray people with mental health problems as “psychos”, “nutters” or loony and news coverage focuses on the violence and mental illness. This type of language distorts people’s views and reinforces stigma.
- 3.4. A Survey of the Stigma, Taboos and Discrimination Experienced by People with Mental Health Problems, ‘Not Just Sticks & Stones’(Jim Read and Sue Baker November 1996) found that:
 - A large majority (69%) of people had been put off applying for jobs for fear of unfair treatment.
 - Half (50%) of people felt unfairly treated by general health care services.
 - Almost half (47%) of the people had been abused or harassed in public, and some (14%) had been physically attacked.
 - Almost half (45%) of people thought that discrimination had increased in the last 5 years compared with 18% who thought it had decreased.
 - A third of people (34%) said they had been dismissed or forced to resign from jobs.
 - A third (33%) complained that their GP had treated them unfairly.
 - A quarter (25%) of people felt at risk of attack inside their own homes and a quarter (26%) of people were forced to move home because of harassment.
 - A quarter (25%) of people had been turned down by insurance or finance companies.
 - Almost a quarter (24%) of parents said their children had been teased or bullied, or that they were afraid it would happen.
- 3.5. The Mental Health Foundation’s survey of people’s experiences of stigma and discrimination as a result of mental distress, ‘Pull Yourself Together!’ (2000) found that:
 - 70% had experienced discrimination in response to their own mental distress or in response to that of a relative or friend.

- The fear of stigma and discrimination had prevented individuals from telling others about their own mental distress - 66% said that they could not tell some people.
 - The main sources of discrimination in response to people's own mental distress were from within the family (56%), and from friends (52%). Many people referred to name calling, labelling and unhelpful instructions such as 'Pull Yourself Together'.
 - Some people reported that they had not told their family (42%) or friends (42%) about their experience of mental distress. People were afraid that family members would not understand or would be judgmental towards them.
 - The workplace appeared to be the second most likely place to receive discrimination (30%). A lack of understanding was most frequently cited as a reason for this. Some respondents gave very serious examples of discrimination, including a number of people who said that they had been dismissed or forced into redundancy, due to their experience of mental distress. Fear of discrimination also prevented people from disclosing details of their mental health history on application forms (e.g. for employment and insurance).
 - A significant number of respondents reported discrimination from their GPs (44%) and other healthcare professionals (32%) in response to their own mental distress.
 - A number of people (19%) reported that they were unable to talk to their GP about their own mental distress.
- 3.6. Repeated surveys of learning disability in Ireland and Britain have highlighted how little contact neighbours have with community residences or day centres (McConkey, 1986). People with learning disability are still perceived as belonging to the learning disability services and not as belonging to the community. Many community facilities for people with learning disability are separate from the community in which they are sited.
- 3.7. The 'ordinary life' philosophy for people with a learning disability means people living in ordinary houses, with support from paid staff, joining in neighbourhood leisure pursuits and finding employment in local businesses (Sutcliffe, 1990). Antagonistic reactions from an poorly informed public threaten the successful social inclusion of people with a learning disability in the community. An informed community is an important outcome in its own right, but more significantly it is a step towards an involved community.

Qualitative Survey of Users and Carers

- 3.8. In a Qualitative Survey of users and carers in Northern Ireland it was discovered that it was routine to not disclose mental health problems, for example for jobs applications and driver licences etc.

Where are we now?

- 3.9. The Scottish Executive's National Programme for Improving Mental Health and Well-Being has been working nationally and locally, since its launch in October 2001, to raise the profile of, and to support further action in, mental health improvement (promotion and prevention), to address the stigma of mental ill-health and to prevent suicide in Scotland. A National Advisory Group, chaired by the Minister for Health and Community Care, was established in January 2002 to advise and steer the work of the Programme.

- 3.10. In England, the National Institute for Mental Health in England (NIMHE) published a review in May 2004, of what works to address stigma and discrimination on mental health grounds. The key principles in tackling stigma were:
- Involving people with first-hand experience of discrimination and carers throughout.
 - National programmes that support local activity.
 - Targeting specific audiences.
 - Long-term planning and funding.
 - Monitoring and evaluation.
- 3.11. In June 2004, NIMHE launched 'From Here to Equality', a five-year plan to tackle stigma and discrimination. It is based on international evidence of what works and brings together agencies from the voluntary sector and Government. This programme will be nationally co-ordinated, but will be implemented at regional and local level. Initial target audiences will be young people, the media, health and social care, public sector organisations, and private and voluntary sector organisations (see www.nimhe.org.uk).

Recommendations

1. There is an ongoing need to monitor negative stereotypes within the community and to change the attitudes that reinforce these negative stereotypes. Communities need to be educated to ensure the successful social inclusion of people with a mental health problem or a learning disability in their community
2. There is a fundamental need for a campaign to challenge the images that communicate negative stereotypes. The campaign needs to directly involve people with first-hand experience of discrimination, target specific audiences and monitor and evaluate its effectiveness.
3. All service providers must be encouraged to provide information in a form that is understood by people with mental health problems or a learning disability.
4. There is a need to establish a group to address the stigma associated with mental health problems and learning disabilities.

4. EMPLOYMENT

Background

- 4.1. Long-term unemployment is both a key characteristic and a primary economic cause of social exclusion and, in consequence policies to reduce work exclusion are crucial to creating a more inclusive society.
- 4.2. Only 36% of disabled people are in employment within Northern Ireland compared to 77% of non-disabled (Northern Ireland Labour Force Survey: Autumn (Sep-Nov) 2004).
- 4.3. People with a learning disability or mental health problems are more likely to be unemployed than other people. The Northern Ireland Health and Social Well-being Survey 2001 indicates that the unemployed were almost twice as likely to show signs of a possible mental health problem (30%) as those in employment (16%).
- 4.4. Data about disabled people from the Labour Force Survey show that 628,000 adults of working age in Great Britain regard mental disorder as their main disability. Only 21 per cent of these adults are in employment – the lowest rate for any group with disabilities (Office for National Statistics, Labour Force Survey, 2002).
- 4.5. Mental and Behavioural Disorders are the largest diagnosis group (36.5%) for claimants to incapacity benefits in Northern Ireland (Northern Ireland Summary of Social Security Statistics 2004). Statistics are collected for both mental health and learning disability combined and it is not possible to breakdown these figures.
- 4.6. The Report-Safety First: National Confidential Inquiry into Suicide and Homicide by People with Mental Illness (2001) stated that in relation to suicide of people with mental illness in Northern Ireland 60% were either unemployed or long term sick.
- 4.7. In England and Wales, the Social Exclusion Unit's report 'Mental Health and Social Exclusion', June 2004, highlighted particular issues concerning employment:
 - Due to stigma and discrimination fewer than four in ten employers would consider employing someone with a history of mental health problems, compared to more than six in ten for candidates with physical disability.
 - Three-quarters of employers would not consider employing someone with schizophrenia, even though schizophrenia can be controlled with medication and would not require physical adaptations to the work environment.
 - One-third of people with mental health problems report having been dismissed or forced to resign from their job, because of their previous psychiatric history and more than two-thirds had been put off applying for jobs for fear of unfair treatment.
 - There is anecdotal evidence of some employment contracts including, within their definition of gross misconduct, clauses such as "if you become of unsound mind or a patient under the Mental Health Act 1983" which would trigger instant dismissal.

- 4.8. People with long-term mental health problems have the lowest employment rate of any of the main groups of disabled people – according to the Labour Force Survey definition only 24 % are currently in work in England. By comparison, research from the US found that with effective rehabilitation support, up to 58 % of adults with severe and enduring mental health problems are able to work using the Individual Placement and Support approach.
- 4.9. Many people with a learning disability aspire to having a job and increasing numbers of parents share this aspiration for their teenage sons and daughters. Traditionally, the majority of school leavers from Severe Learning Disability schools have been placed in day centres commissioned by health and social services agencies.

Good Practice Examples

Southwest London and St. George's Mental Health NHS Trust: *In this service Occupational Therapists act as clinical vocational leads, working with specialist services to increase access to employment and education for clients. There is a vocational support worker on each team. Prior to intervention > 60% clients Seriously Mentally Ill group were not engaging in any work, education or structured activity. This reduced to 20% after 1 year's experience on the programme. 888 people have specific vocational input in the period from Nov. 01 – Nov. 02. After 1 year 469 were involved in open employment.*

Action Mental Health's New Horizons and Accept: *These services provide vocational training, personal development and employment programmes to people with mental ill health. AMH's clients have a wide choice of programmes aimed at helping them lead inclusive lives in their communities and wherever possible to find jobs. The training they receive is accredited and enables them to acquire vocational skills as well as regaining self-confidence and self-esteem. Employment preparation programmes include advice on job search, completion of employment application forms, interview skills and work experience placements. More than 1000 people are assisted each year.*

Action Mental Health's Careers programme: *The programme is funded by Peace 2 monies, provides help for people with a history of mental illness who are in low paid jobs. It is essentially a career advancement programme aimed originally at the Greater Belfast area and more recently in North Antrim. The programme enables participants to acquire new skills and compete successfully for better paid jobs. More than 40 people are assisted each year.*

The programme operates in partnership with employers who have given their full support. Employers are given advice on how to make adjustments for people with mental ill health and how their potential might be developed. Employers are also advised on how to raise awareness of mental health issues amongst their workforce. In this way mindsets are changed and the stigma attached to mental illness is reduced.

User perspective

Catherine works part-time for Dunnes Stores in Newry. She has worked for Dunnes since 1998.

As a member of Mencap's Northern Ireland Board Committee, Catherine guides and supports the work of Mencap in Northern Ireland - a voluntary organisation that provides a range of services, supports a membership network of over 60 local groups and campaigns for equal chances for people with a learning disability. Catherine is Vice Chairperson of the Committee and of Mencap in Northern Ireland. Catherine also chaired the 2005 Mencap in Northern Ireland conference, which was attended by over 130 people.

Catherine is Chairperson of Mencap's Southern District Committee. The District Committee brings together everyone with an interest in learning disability to find out about local needs and to campaign on issues in the area.

Catherine plays an active role in the current Review of Mental Health and Learning Disability - as a member of the Learning Disability Working Committee and as a member of Equal Lives, a group of people with a learning disability, established to advise and inform the Review.

Talking about the Review of Mental Health and Learning Disability, Catherine has said "It is important for me to speak up and be a voice for all people with a learning disability. I hope that, together, we can change other people's ideas on what people with a learning disability can do".

Qualitative Survey of Users and Carers

- 4.10. A Qualitative Survey of users and carers in a number of voluntary organisations in Northern Ireland (Annex 2) identified a number of employment issues for mental health users.
- 4.11. The Survey identified that there is little support for employees with mental health problems and that employers are not equipped to identify or deal with people with mental health problems.
- 4.12. There are few employers that have policies on promoting good mental health in workplace.
- 4.13. There is a fear of discrimination by employers, which leads to people not informing their employers of mental health problems.
- 4.14. The survey identified that the benefits system is a major risk in moving to employment. It is difficult to get benefits in the first place. If a person in receipt of benefits gains employment and gives up their benefits, but then becomes unwell again, their benefits may not be renewed or they may receive a lower level of benefit than before. These risks can inhibit people from seeking employment. There have been recent improvements in social security rules, but the rules remain complex and a barrier to people moving from incapacity benefit into work.
- 4.15. Employment opportunities are normally limited to low skill work. While people from all walks in life, representing the full spectrum of abilities and skills, can suffer from mental health problems, it can be extremely difficult to return to their previous jobs.

Where are we now?

4.16. One of 4 key strategic areas for the Department for Employment and Learning (DEL) is 'Helping People into Work'. DEL has a particular focus on assisting people with disabilities to prepare for work, to obtain and retain employment. DEL has a dedicated Disablement Advisory Service (DAS) to provide an employment service specifically for people with disabilities. The service is provided through Jobs and Benefits Offices and JobCentres, and is supported by an Occupational Psychology Service. The service is pan-disability, and includes a good deal of activity as support for clients with a learning disability and mental health problems. It is the role of DAS to:

- Provide an employment service for adults with disabilities who need special help.
- Help disabled people find and retain employment and to support them with a range of programmes, tailored to meet their needs.
- Help employers retain disabled people in work and develop employment policies in line with the Employment Right of the Disability Discrimination Act 1995 (DDA).

4.17. The main activities include:

Working with Employers

- Visiting employers to promote the abilities of disabled people and to secure employment opportunities.
- Promoting the range of DAS help available, including New Deal for Disabled People (NDDP), Access to Work (NI) and the Job Introduction Scheme.
- Advising on the retention of disabled employees in the workplace.

Working with Disabled Adults

- Maintaining an active caseload of jobseekers and, through an action planning process, providing help to enable the client find suitable employment or training placements.
- Establishing rapport with disabled jobseekers in order to help them reach their full potential in the workplace.
- Acting as New Deal Personal Adviser to disabled clients in the 18-24 year old, 25+ and 50+ programmes.
- Working as New Deal Personal Adviser for severely disabled clients, who are part of the NDDP target group and give them benefits information using the Integrated Benefit Information System (IBIS).
- Providing appropriate help under the Access to Work (NI) scheme.
- Providing support under the full range of DAS programmes i.e. Employment Support, Job Introduction Scheme, NDDP, Access to Work (NI) specialist training, employment assessment.

Working with Voluntary sector/Disability Sector/Health Professionals etc.

- DAS works very closely with this network, through a programme of visits,

presentations etc Disablement Employment Advisors (DEAs) establish contact with the above sectors in their local areas to encourage referral of people with disabilities who want and need the help of DAS to find, keep or prepare for work.

Job Clinics

- Job Clinics are a partnership between DAS, Action Mental Health and Occupational Therapists (OT) in various HSS Trusts. They exist to help people with mental health disability progress through training and where appropriate into employment. JobClinics aim to pool the expertise in the three partners involved to best meet the needs of the client. Professional medical advice and employment assessment are accessed quickly through this system. The main referral agent is the OT although any of the partners can raise referrals. The partners have agreed defined roles within JobClinics and work through a Steering Group made up of key representatives from each of the member organisations.

Vocational Training

- DAS provides funding for a range of vocational training which is delivered by a number of disability organisations. DEL also offers the Jobskills programme which, through Jobskills Access, has particular support for young people facing particular difficulties, including disability.

Strategic Dialogue with Disability Sector

- DEL has initiated a strategic dialogue with the disability sector about the programmes and services offered by DAS. The Dialogue is being led by a Steering Group, which includes organisations representing people with learning disability and mental health problems, providing excellent opportunities for relevant organisations to help to shape provision.

4.18. The development of vocational training and the introduction of Supported Employment to Northern Ireland have opened up new possibilities for improving the employment prospects of people with a mental health problem or a learning disability:

- The Department for Employment and Learning's DAS provides assistance to people with a disability to access employment. Programmes on offer include Access to Work, Employment Support, Job Introduction Scheme and NDDP. Mainstream programmes like Jobskills and Worktrack are also available. Significant numbers of young people with a learning disability enter the Jobskills Programme.
- Access to these programmes can be limited by factors such as admission criteria, outcomes required, duration of the programme and the pattern of provision.
- There has been considerable growth in Supported Employment in Northern Ireland over the last decade. The Northern Ireland Union of Supported Employment has over 15 non-statutory agencies in its membership and many other day centres are involved in this work. A number of other approaches to securing paid work have also

developed including vocational training and social enterprises. Evaluations of such schemes have evidenced the benefits to individual participants, although few of the trainees had made the transition to paid work. European monies from either the Building Sustainable Prosperity or Peace Programmes have funded most of this provision. Urgent consideration needs to be given to mainstreaming the funding and the learning.

- 4.19. A range of external factors impinge on the potential for men and women with a learning disability gaining employment including; inflexible rules in relation to benefits, absence of clear intra-agency partnership and low expectations.
- 4.20. Department of Employment and Learning and the Social Security Agency are currently piloting 'Pathways to Work'. This work aims to encourage and support those people with long term ill-health back to work. Major reform to Incapacity Benefit is due to come on stream during 2008. The recent Department of Work and Pensions green paper 'A new deal for welfare: empowering people to work' recognised the particular difficulties faced by people with mental health problems or a learning disability. There is, however, little detail as to how the new arrangements will specifically work for people with mental health problems or learning disabilities.

Recommendations

5. The Labour Force Survey (2002) indicated that only 21% of people with a mental health problem or a learning disability are in employment yet research from the US found that with effective rehabilitation support, up to 58 % of adults with severe and enduring mental health problems are able to work using the Individual Placement and Support approach. Therefore the Northern Ireland target should be at least 50% of people with mental health problems or a learning disability should be in full time employment.
6. Employment Advisors should work with community mental health teams and community learning disability teams to provide pathways to employment.
7. European monies have funded a number of supported employment positions and Departments should mainstream this funding, where it has been shown to achieve positive outcomes.
8. Permitted work rules for Incapacity Benefit and Severe Disablement Allowance should be further improved, simplified and promoted effectively to reduce the barrier from moving from benefit to work. Returning to work should be on a voluntary basis and people should not be disadvantaged if their condition changes and prevents them from continued working.

5. HOUSING

Background

- 5.1. The Office for National Statistics report, "Better or worse: a longitudinal study of the mental health of adults living in private households in Great Britain", 2003, has provided estimates for the prevalence of mental disorders among people aged 16 to 74 years living in private households. The survey included evidence of neurotic disorders, psychotic disorders, alcohol problems and drug dependence. In this study, the proportion of adults found to have at least one neurotic disorder was 17% and the figure for assessed psychotic disorder was 0.4%. People who were of lower socio-economic status were less likely to recover from common mental disorder, as were the long term sick and disabled and the unemployed. The study found an annual incidence of suicidal thoughts of four per cent overall (three per cent among men and five percent among women). Incidence was highest among 16-24 year olds, 10 per cent of them reported onset of suicidal thoughts compared with 4-6 per cent of those in other age groups.
- 5.2. The ONS Survey collected data on the housing and household characteristics of people with mental health problems. The findings give an overall picture of housing status and reveal some key differences between people with mental disorders or substance dependency and those recorded as having no such disorder or dependency. The findings are contained in a separate report, 'The Social and Economic Circumstances of Adults with Mental Disorders' (Meltzer, H. 2002), the main findings being:
- People with a mental disorder or dependency were much more likely to be living in rented accommodation (38% compared to 24% in the no disorder group). Among those with a psychotic disorder, almost two-thirds (62%) were in rented accommodation and just under half (49%) were living in accommodation rented from a housing association or local authority.
 - People with a mental disorder or dependency were more likely to be single, divorced or separated and less likely to be married. The group with a probable psychotic disorder had the highest percentages of divorced and separated people: 26% and 7% respectively, compared with the sample average of 8% and 3%.
 - Lone parents made up 9% of the group with a neurotic disorder, compared to 4% of the no disorder group. Among those with a psychotic disorder, 43% were living in a one-person family unit (which includes certain types of shared household), almost three times the rate for those with no disorder (15%). While 38% of people with a psychotic disorder actually lived alone, the figure for the sample as a whole was only 12%.
 - People with a disorder were more negative than the no disorder group about the standard of their accommodation: 11% and 5% respectively said they were very dissatisfied. Those with a disorder were also more likely to describe the state of repair of their home as poor: 9% compared with 4%. The most frequent complaint about housing was lack of space; this was reported by 20% of all respondents and about 30% of those with a neurotic disorder.
 - 8% of people assessed as having a mental disorder felt that their health was made

- worse by their accommodation, compared with 2% of the no disorder group. This figure increased to 14% for those with a probable psychotic disorder.
 - Around 12% of people with a mental disorder had doubts about the security of their accommodation (i.e. whether they could stay there indefinitely), compared to 6% of the overall sample. The main reasons given for feeling insecure were: financial problems (20%); lease running out (18%); illness (14%); domestic problems (8%); and problems with the landlord or agent (7%).
- 5.3. Poor housing, housing insecurity and homelessness have also been shown to have a profound impact on mental illness and mental health service use. Research evidence suggests that poorly housed and homeless people have more serious mental health problems and require more intensive service support, including more frequent hospital admissions.
- 5.4. Having a home is a basic human need. The Audit Commission (1994) found that:
 - Poor housing is particularly common among people with mental health problems.
 - Mental illness is a frequent cause of tenancy problems and tenancy breakdowns.
 - Poor housing and inappropriate accommodation can lead to the development or exacerbation of mental health problems.
- 5.5. Suitable accommodation is a fundamental element of effective services to support people with mental health problems or learning disability. A number of principles need to be considered in order to ensure an appropriate range of accommodation and support:
 - People with mental health problems or a learning disability should have a choice of the type of accommodation they wish to live in. This has to be balanced in relation to the degree of risk posed to themselves or others.
 - Assessment of accommodation needs should be a component of an overall assessment.
 - Support for people receiving mental health services should be available to people with mental health problems or a learning disability regardless of where they are accommodated.
 - Providers of accommodation should receive training and should be supported regardless of whether the accommodation is statutory, voluntary or private.
- 5.6. People with mental health problems or a learning disability generally want the same kinds of housing that everyone wants and not housing that is identified as mental health or learning disability housing, however, the evidence indicates that this is not happening.
- 5.7. The provision of group housing for people with mental health problems or a learning disability needs to be re-considered because of the danger of becoming institutionalised, like the long-stay hospitals of previous generations. Specialised housing can stigmatise people with a learning disability or mental health problems preventing successful integration into the community.
- 5.8. Supporting individuals in suitable housing in ordinary settings will help them gain access to a wide range of mainstream services and resources.

- 5.9. People who require support to stay in their own or rented accommodation may require essential support at a practical level to ensure the maintenance of the tenancy, e.g. home help, mental health support workers, learning disability support workers. Those who need respite on a short-stay basis to prevent acute admission may require emergency or non-emergency respite. Non-emergency respite may be required to accommodate people whose mental health is deteriorating and who require input from experienced staff over a period.
- 5.10. Crisis diversion/non-hospital accommodation may be provided as part of Crisis Response to prevent inappropriate admission to hospital.
- 5.11. People with challenging behaviour require specialist facilities with high staffing levels. It is important that the layout of the accommodation provides adequate personal space and there is access to daytime occupations and intensive staff support. Staff require specialist training in relation to dealing with challenging behaviour and potential violence.
- 5.12. Homeless people and rough sleepers present particular challenges. A recent study in Belfast identified some kind of mental health problems among 86% of single homeless people. (McGilloway S, Donnelly M (1996). 'Don't Look Away'. Homelessness and Mental Health in Belfast. The Health and Health Care Research Unit, Queen's University, Belfast).
- 5.13. Homelessness may have been caused or exacerbated by their mental health problems. Some may have been rejected from accommodation as a result of their mental illness or degree of challenge posed to staff. Some may have become displaced because of their mental health problems. Many have dual diagnosis. It is essential that homeless mentally ill people have access to mainstream services at primary and secondary care level. Accident and Emergency Services provide an important access point to care for homeless mentally ill people. Good communication between generic and mental health services is essential if effective interventions are to be made.
- 5.14. Discharge protocols in mental health services in Northern Ireland require further refinement to ensure that people leaving mental health facilities have appropriate accommodation on discharge. Close co-operation is required between Housing and Mental Health Services.

Learning Disability

- 5.15. Nearly all children with a learning disability (up to 19 years of age) live in family homes either with natural, adoptive or foster parents (McConkey, Spollen and Jamison, 2003).
- 5.16. Adults with a learning disability in Northern Ireland live in the family/own home (79%), residential home (17%) or hospital (4%).
- 5.17. The bulk of people live with family carers (66%), although a small proportion have their own accommodation (10%) or live with a spouse/partner (3%). Around 450 are resident in hospitals (mostly learning disability hospitals) and on average will have lived there for 20 years.

- 5.18. Nearly 1900 people are in some form of residential provision and have lived there for around 8 years on average. Comparable figures across these 3 forms of provision for the Republic of Ireland (Health Research Board, 2003) are: hospitals (4%); residential services (5 day and 7 day) (39%); community (57%).
- 5.19. In Great Britain, an estimated 63% of adults live in private households and 37% in some form of residential accommodation. The numbers living in long-stay hospitals are now less than 1% (Kavanagh and O'pitt, 1999). This data suggests that over twice as many adult people are in residential provision in Great Britain and in the Republic of Ireland than in Northern Ireland.

Qualitative Survey of Users and Carers

- 5.20. The Qualitative Survey of users and carers in a number of voluntary organisations in Northern Ireland identified a lack of knowledge about housing services for people with a learning disability or mental health problems.
- 5.21. It also identified a lack of local choice in the type of supported housing available and the absence of a seamless service between Housing and Social Services.

Good Practice Example

Following a successful pilot scheme, the Multidisciplinary Homeless Support Team (MDHST) was set up in Belfast (2005) and managed by Extern, a voluntary organisation. It is funded by the Northern Ireland Housing Executive, Health and Social Services Trusts, the Eastern Health and Social Services Board and the Probation Board for Northern Ireland. This team covers multiple disciplines including learning disability, addiction, family and childcare, young people, older people and has incorporated a floating support element, to sustain those who secured tenancies.

The focus of much of the work is with people with mental health problems. The 2005/06 statistics highlight this, with 330 of the total 1070 referrals having mental health problems as a primary issue and an additional 375 having mental health problems as a secondary issue. The MDHST has also received 33 referrals for clients with a learning disability as a primary issue. In many cases, the issues are very complex and the clients have been excluded from traditional service provision, advocacy and negotiation along with a commitment to support the client continues to be a major part of the Team's success.

Having a closer relationship with the Housing Executive has made a significant impact for the service users with assessment, planning and support being co-ordinated earlier and more effectively, resulting in more suitable and sustainable accommodation being located. The team is more than a housing assessment team; the focus is on the individual client need.

Where are we now?

- 5.22. The Department for Social Development (DSD) is committed to providing more information in a form that is understood by the recipient.

- To foster better communication between all those involved in providing services.
 - To attempt to get supported housing provided as an integral part of general housing provision.
- 5.23. To continue to involve the complex needs tenants in all areas of the service, the Northern Ireland Housing Executive (NIHE) is responsible for establishing the needs of tenants, including maintaining a waiting list for complex needs tenants, having assessed those requirements. Supported Housing schemes for people with an array of special needs, but including those with mental health or learning disabilities, form an integral part of the Social Housing Development Programme (SHDP). Certain Housing Associations actively try to develop schemes which mix general needs (e.g., families) with dwellings for people with special needs, e.g., mental health or a learning disability.
- 5.24. To continue to break down barriers in the community, in terms of housing, forms part of the consultation process carried out by Housing Associations in helping the community to understand the need for schemes for people with mental illness or a learning disability (and indeed other special needs).
- 5.25. To foster better communication between all those involved in providing services, regular meetings take place between all parties involved in the delivery of the SHDP (NIHE, DSD, Housing Associations and DHSSPS) in order to secure funding for Supporting People, which is key in the provision of support for people with these special needs.
- 5.26. The Department for Social Development has been leading on a cross-departmental cross-sectoral working group, set up to consider homelessness in the context of Promoting Social Inclusion. This report details a number of recommendations which address the needs of people who are homeless, including those with mental health problems and learning disabilities.

Recommendations

9. DSD and housing providers should develop a housing strategy to ensure people with mental health problems and learning disabilities can, where possible, live in the accommodation of their choice, subject to normal financial constraints.
10. People with mental health problems or learning disabilities should have the choice to live independently but the use of specialised group housing has a role to play, for example as step-down accommodation after leaving hospital.
11. DSD should ensure participation of people with mental health problems or a learning disability in the planning of housing services

6. PERSONAL FINANCE

Background

- 6.1. People with mental health problems consistently identify personal finances as a major source of difficulty and distress (Davis: 1996; Dick: 1994; Dunn: 1999; Matthew Trust: 1997; Morgan et al: 2001; Rose: 1996; Sayce: 2000). Key factors contributing to this situation are:
 - The impact of poverty and social exclusion on mental health and well-being.
 - The high levels of benefit claiming amongst mental health individuals.
 - The stigma of mental illness with institutions concerned with personal finances.
 - The ways in which the stigma, discrimination and the impairments experienced by people with mental health problems impact on access to and management of personal finances.
- 6.2. The association between mental ill-health, poverty and deprivation is well established. People living on incomes below the average wage are twice as likely to develop mental illness as people on average and higher incomes. High socio-economic status has been found to decrease the likelihood of experiencing serious depressive episodes. Adults in the lowest social class are four times as likely to experience this form of mental distress compared with adults in the highest social class (Howarth et al: 1999; Gordon et al: 2000; ONS: 2000; Palmer et al: 2002; Payne: 2000). Surveys of people with mental health problems have confirmed that the majority of individuals live on low incomes and consider that their mental health problem has contributed to their income level (Dunn: 1999; Hogman & Chapman: 1998; MIND: 1998; Morgan et al: 2001).
- 6.3. People living in economic hardship on a long term basis are more likely to be suffering from clinical depression than those living in more comfortable economic circumstances (Lynch et al: 1997). Amongst adults of working age, research has found that mothers living in poverty are particularly vulnerable to mental ill health, the vulnerability of this group of women increases when material deprivation is combined with low social and personal support (Baker & Taylor: 1997; Hobcraft & Kiernan: 1999; Maughan and Lindelow, 1997).
- 6.4. Social security benefits are the major form of financial support for over 75% of UK adults of working age who find themselves faced with mental health problems for short, long or recurring periods of their lives. (Labour Force Survey: 2002).
- 6.5. A range of benefits relating to income, mobility, care and housing may be relevant to individuals with mental health problems. The current system is not flexible enough to meet the income needs of people whose mental health condition varies over time. Citizen Advice in Britain raised a number of concerns about the inadequacies of the medical assessment system in research published in 2005. The assessment of incapacity and disability in the benefit system poses particular problems for people with mental health problems (Davis & Betteridge: 1997; Hirst & Sainsbury: 1996; Sainsbury: 1995). The interaction between income related and non-income related benefits is also an issue that is not fully recognised by Government policy in this area.

- 6.6. Evidence suggests that while people with mental health problems who claim benefits face many of the same difficulties as other claimants, they are disproportionately affected by the complexities of the benefits system. (Bird et al: 2001). Each benefit claim made requires the completion of lengthy forms at regular intervals, to establish eligibility, the production of evidence to support each claim and the submission of additional information about changes in circumstances. The focus, investment of time and energy required by these procedures is considerable.
- 6.7. People with mental health problems when asked to describe some of the common physical and behavioural effects of having a diagnosed mental illness mention - lack of motivation and interest; fear of making contact with people and leaving home; paranoia, feelings of hopelessness and despondency; problems of concentration, confusion, permanent feelings of anxiety and worry (Ritchie et al: 1988). People with mental health problems with these common behaviours find it difficult to meet the ongoing claiming requirements of the benefits system.
- 6.8. The evidence of the under-claiming of benefits by adults with mental health problems from UK studies and initiatives demonstrates one of the negative outcomes of the lack of accessible information, advice and support (Keenan: 1995; Matthew Trust: 1997; Pacitti & Dimmick: 1996). The factors which contribute to this situation include the low priority given to this area of work by mental health and benefit agencies (Bird et al: 1998; Sharpe & Bostock: 2002) and staff in mainstream advice and benefit agencies experiencing difficulties in understanding and communicating with people with mental health problems (Bird et al: 1998; Regnier: 1996). 'Advice in Mind' produced by Citizen Advice Northern Ireland in 2005 illustrated the need for and importance of people with mental health problems getting access to good quality advice.
- 6.9. User based evidence from national and local survey work testifies to the discrimination, trauma and exclusion experienced by users in contact with such agencies (Beresford et al: 2000; Davis & Betteridge: 1990; Dunn: 1999).
- 6.10. The fluctuating nature of mental health conditions, the changing use of hospital and community based services and life changes can destabilise the security of the weekly benefit income paid to people with mental health problems.
- 6.11. Evidence of the financial exclusion of people with mental health problems can be found in the reports and campaigns of advice, legal and national mental health charities as well as surveys of user experiences. For example, a 1996 survey of mental health individuals found that 25% of users had had the experience of being turned down by a finance or insurance company. Evidence submitted to the 1999 MIND Inquiry into social exclusion and mental health problems led the inquiry panel to state that lack of access to banking services is a common problem for mental health individuals, and a key determinant in social exclusion.
- 6.12. People with mental health diagnoses report problems in obtaining insurance cover for a range of items including motor, life, travel, payment protection and health insurance (MIND: 2000). It appears to be common practice in the insurance industry to either refuse cover where the

consumer is known to have a mental health problem or to ask people with mental health problems to pay increased premiums (ABI: 2001; Marks: 2003; MIND: 2000).

- 6.13. In addition, some people with mental health problems who do have insurance report difficulties in getting insurance companies to make payments in situations where mental ill health is seen to be a factor. Evidence from advice agencies and mental health organisations suggest that this response can affect a range of life areas e.g., being unable to claim payment protection designed to help consumers meet their credit and loans commitments when they experience an unexpected reduction in or loss of income due to ill health or redundancy, or being unable to draw on insurance to cover mortgage payments when income is lost.
- 6.14. The current strategy for social security is 'work for those who can, security for those who cannot'. As a result, a considerable effort has been put into encouraging the long-term sick and disabled back into work, but the current strategy contains an element of compulsion. People on Incapacity Benefit who fail to attend interviews can be penalised by loss of benefit or incapacity status. This fails to acknowledge the pressure having to attend such interviews can cause for someone with a severe mental illness.
- 6.15. Medical assessment is a regular feature of establishing and retaining entitlement to key disability benefits (notably Incapacity Benefit and Disability Living Allowance) and the quality of such assessments has been subject to significant scrutiny. Rushed assessments, lack of knowledge of mental health problems, disbelief of claimants, a disregard of specialist evidence and cultural insensitivity are not uncommon experiences. A report on the Social Security Agency's Medical Referee Service by the Advice Services Alliance in 2002 was also critical of the quality of assessment and sensitivity of some doctors. The Social Security Agency (Northern Ireland) has recently announced a review of the Medical Referee Service. This could usefully lead to greater use of occupational nurses and mental health specialists (medical and non-medical). This review was suspended and never completed.

Easing the Transition to Work

- 6.16. People with mental health problems who have been on benefit for long periods often need intensive support to get back to work. The current social security system does not allow for a continuum that would enable a person to move gradually through voluntary work to part-time work and full-time work or to stay at one level for a prolonged period if appropriate. The Government has improved flexibility within the Social Security system to encourage a return to work, but the current arrangements are complex, fragmented and not easily understood by claimants. An understanding of the arrangements requires extensive knowledge of social security and concerns have been raised that a move into training or work triggers a review on the assumption that a person's condition has improved. This is a disincentive to rehabilitation through work or training.
- 6.17. Improvements have been made to claim forms in recent years, but there is a considerable way to go. The claim form for disability living allowance remains complex and significantly oriented towards physical impairments. The claim form for Incapacity Benefit has an open question about mental health with no guidance as to the information required.

- 6.18. The Social Security Agency is moving towards providing greater support to assist with claims for disability benefits. It has also worked with the voluntary sector to look at ways of enhancing its customer service to particular groups (for example, physically disabled people and ethnic minorities). A similar exercise working with voluntary sector and other interested parties to examine customer service issues for people with mental health problems would be a welcome development.
- 6.19. There is a need to ensure that all those involved in frontline benefit administration and decision-making receive mental health awareness training that incorporates interaction with people with mental health problems. This also applies to the Medical Referee Service personnel, as well as chairpersons and members of The Appeals Service (NI). People with mental health problems should have access to an independent dedicated advice and advocacy service to deal with social security problems.

Qualitative Survey of Users and Carers

- 6.20. The Qualitative Survey of users and carers in a number of voluntary organisations in Northern Ireland identified a lack of competence of some Social Security staff in recognising customers with mental health problems.
- 6.21. There was no specific training for staff dealing with people with mental health problems or a learning disability.
- 6.22. Users identified difficulties with complex benefit forms and of understanding the complex legislation of benefit entitlement.

Where are we now?

- 6.23. The Social Security Agency provides a number of benefits including Disability Living Allowance, Attendance Allowance, Incapacity Benefit, Carers Allowance, Income Support, Pension Credit and Social Fund payments.
- 6.24. The Social Security Agency provides a Disability and Carers Service, which provides improvements to make services more accessible including provision of Disability Benefit Advisers. This pilot is ongoing, providing outreach service and taking an holistic approach to providing information and advice on benefits.
- 6.25. The Social Security Agency's Incapacity Benefits Branch has a Customer Care Team, which can deal with the needs of different customers. The Agency also provides awareness sessions in special schools and presentations to healthcare professionals.
- 6.26. The Social Security Agency has created a Direct Payment information booklet, produced in partnership with Mencap.
- 6.27. Jobs and Benefits Offices have Disablement Employment Advisers and Social Security Offices have Customer Enquiry Teams.

Recommendations

12. Independent advice and advocacy services should be embedded in mental health and learning disability services to help support and enable people with mental health problems or a learning disability to live independently with dignity and a good quality of life, both in and out of work.
13. There should be partnership schemes between Government, commercial companies, housing associations and credit unions to extend insurance cover and other financial products and services to financially excluded people with mental health problems or a learning disability.
14. The Social Security Agency should work with the voluntary sector and other relevant organisations to examine customer service issues for people with mental health problems and/or learning disability.
15. Social Security Agency decision-makers, Medical Referee staff, front line benefit staff and the Appeals Service (NI) chairpersons and tribunal members should receive more in-depth mental health and learning disability awareness training.
16. Financial institutions should review their policies to ensure that they treat people with mental health problems or learning disabilities no less favourably than they treat others in order to comply with the Disability Discrimination Act 1995.

7. EDUCATION

Background

- 7.1. Education and Library Boards (ELBs) and Boards of Governors of schools have a statutory responsibility to make special educational provision for pupils/children who have Special Educational Needs (SEN). A child has Special Educational Needs as defined in the Education (Northern Ireland) Order 1996 if he/she has a learning difficulty which calls for special educational provision to be made. The Order goes on to define 'learning difficulty' as meaning a child who:
- a). Has a significantly greater difficulty in learning than the majority of children of his/her age.
 - b). Has a disability which either prevents or hinders him/her from making use of educational facilities of a kind generally provided for children of his/her age in ordinary schools.
 - c). Has not attained the lower limit of compulsory school age and is, or would be if special educational provision were not made for him/her, likely to fall within a) or b) above when he/she is of compulsory school age.
- 7.2. Actual provision will depend upon the individual needs of the pupil/child and can be made in a variety of settings ranging from mainstream schools, special units attached to mainstream schools or special schools and in some cases in the home. Again the 1996 Order defines the term 'special educational provision' as:
- a). In relation to a child who has attained the age of two years, educational provision which is additional to, or otherwise different from, the educational provision made generally for children of his/her age in ordinary schools
 - b). In relation to a child under that age, educational provision of any kind. The ELBs have a statutory power to make special educational provision for children with Statements of Special Educational Needs, in order to meet the individual needs of the child. ELBs are responsible for the decisions about making, maintaining and ceasing to maintain Statements. There is a statutory right of appeal to the Special Educational Needs and Disability Tribunal about ELB statementing decisions.
- 7.3. According to the 2004 Annual Census of Schools, there are some 25,646 pupils with learning difficulties on SEN Registers. In terms of inclusion, and looking at the full range of pupils with SEN, there are 63% of pupils with Statements in mainstream classes or units. This figure has increased from 39% in 2000.
- 7.4. In order to effectively meet the SENs of pupils with a learning disability or mental health problems, strong partnerships between the health and education sectors are required. Those pupils with a learning disability require both tailored educational input and input from a range of Allied Health Professionals (AHP). There are existing pressures on the provision of AHP services to meet the needs of pupils in special schools or unit settings. It could be

anticipated that pressures might increase in future years, as both the number and percentage of SEN pupils educated in mainstream settings increases in light of the greater emphasis on the right to mainstream education as a result of the Special Educational Needs and Disability Order 2005 (SENDO).

- 7.5. For pupils with mental health problems, support from mental health professionals is vital in order to sustain school placements, in whatever sector and to provide support for teachers as well as pupils.
- 7.6. Education and training relates to activities compatible with both vocational outcomes and personal development.
- 7.7. Effective links to voluntary work and organisations such as Further Education Colleges, Educational Guidance Service for Adults and the various job brokers and training organisations will expand the opportunities for people with severe mental health problems.
- 7.8. Some individuals will require considerable support in order to access mainstream services. Supported education initiatives for employment or leisure services have been shown to be effective in relation to health gains for people with more enduring mental health problems. The key worker should maintain overall responsibility for the client with the health services taking the lead in providing and promoting employment opportunities. Studies have emphasised that the positive effects of participating in college activity i.e., having structure to day, gaining strengths and skills, developing self identity and social inclusion need to be balanced with possible negative effects. Sensitive, needs-led, flexible support must be maintained to reduce anxiety and alleviate barriers to engagement.
- 7.9. Assessment of an individual's occupational performance, exploration of vocational goals and networking with local service providers is currently being performed by many Community Mental Health Teams (CMHT) within Northern Ireland. However, many teams do not have access to OT expertise or when present in teams they are engaged in generic work due to high caseload numbers amongst multi-disciplinary team members.
- 7.10. There is scope for development of opportunities for men and women with a learning disability within Further Education (FE) in Northern Ireland.
 - Significant variation exists across colleges in the number of students with a learning disability enrolled as a proportion of the student body ranging from 1% - 13% in 2002. (Department for Employment and Learning 2002, FSER Snapshots)
 - Average level of enrolments appears to be lower in Northern Ireland, 4.1% in 1999, as compared with 5.7% in England.
 - The number of students enrolled on full-time courses is also lower, 32% in 2002 in Northern Ireland (ranging from 10% to 67% across the Colleges) as compared with 45% in England in 1999. (Department for Employment and Learning)
 - Concerns exist about the lack of progression from FE provision; students not able to gain accredited awards from their study; the lack of links with job training and work experience; students repeating the same course content in subsequent years.

- It is encouraging that studies in Northern Ireland have highlighted a range of initiatives that are affording positive opportunities for young people with a learning disability to be involved in activities within the FE sector. This provision points the way towards the positive outcomes that might be achieved if such opportunities were more widespread and consistently available.

Qualitative Survey of Users and Carers

7.11. The Qualitative Survey of users and carers in a number of voluntary organisations in Northern Ireland identified the following issues:

- Teachers not well equipped to deal with emotional and mental well-being issues.
- Lack of awareness by children (e.g. bullying by children of other children with a relative who has mental health problems).
- Falling behind in education because of mental health problems.
- For pupils, physical education is compulsory, but not education in emotional and mental well-being.
- No systems or procedures in place for dealing with people with a mental health problems.
- Difficulty in obtaining and waiting time for assessments (although with statutory assessments, ELBs have a period of 26 weeks, subject to certain exclusions, to produce a final Statement, non-statutory assessments are subject to resources being available).
- Private psychological assessments not allowed. (While private assessments are allowed, they are not allowed to access provision earlier than would have ordinarily been the case.)
- Availability of concessions regarding transfer test.
- Additional stress caused by the transfer test.
- Lack of counsellors.
- Extremely difficult to access mainstream education for children with learning disabilities (e.g. the Independent Panel for Special Educational Advice, a voluntary organisation exists with the sole purpose of assisting parents' access mainstream education).
- Teacher resistance of children with mental health problems or learning disabilities, believed to be because of resources and performance tables, although DE does not actually publish performance tables.
- Mainstream access to education does not always allow access to schools' summer schemes.
- Need to fight for access to nursery, primary and secondary school.

Where are we now?

7.12. There has been a presumption to mainstream education for children with special educational needs for many years within the existing special education framework. This is subject to certain qualifications which relate to parents' wishes, the efficient education of other children, the efficient use of resources and the meeting of the SENs. The Education (NI) Order 1996

strengthened this presumption, and the more recent Special Educational Needs and Disability (ND) Order 2005 (SENDO) legislation provides further rights for children with special educational needs or disabilities.

- 7.13. The Department of Education and the Education and Training Inspectorate have undertaken a review of the role of the special school of the future. The report includes commentary on how special schools can help support teachers and pupils in mainstream schools, via outreach services. The Department of Education's policy on inclusion is that a continuum of SEN provision will be mainstreamed across the school sector. There are no plans to close special schools, but it is anticipated that the number of SEN pupils in mainstream schools will continue to grow following the implementation of the SENDO.
- 7.14. The SENDO became effective on 1st September 2005. It strengthens the existing presumption to inclusion. Some of the key features of the legislation include:
- Strengthening of the right to a mainstream school place for children with a statement, unless it is against the wishes of the parents or is incompatible with the efficient education of others.
 - Education and Library Boards will provide an Information and Advice Service on SEN matters to parents of children with SEN in the area. This includes the establishment of a new, accessible website which provides a broad range of information on SEN.
 - Education and Library Boards provide a new Dispute Avoidance and Resolution Service (DARS) to attempt to resolve disputes between parents and schools and parents and Boards.
 - Responsible Bodies of schools and relevant Nursery providers are able to request a statutory assessment or re-assessment of the SEN of one of their pupils.
 - Parents have increased rights of appeal to the Special Educational Needs and Disability Tribunal when the Education and Library Board makes an assessment of SEN. Education and Library Boards must maintain statements until the outcome of an appeal is known.
 - All schools will be prohibited from discriminating against children who have disabilities in their admissions arrangements, in the education and associated services provided by the school and in relation to expulsions and suspensions from the school.
 - Education and Library Boards are subject to more clearly defined timeframes for the drafting of Statements.
 - All schools will be prohibited from discriminating against children who have disabilities in their admissions arrangements, in the education and associated services provided by the school and in relation to expulsions and suspensions from the school.
 - Schools have to take reasonable steps to ensure pupils who have a disability are not placed at substantial disadvantage, in comparison to pupils who do not have a disability, in relation to the education and associated services provided to them.
 - Education and Library Boards have to produce an 'accessibility strategy' to increase accessibility to the curriculum and school premises.
 - Education and Library Boards have to improve the delivery of information, which is provided in writing for pupils who do not have a disability, to pupils who have a

- disability, in ways that are determined after taking account of the effects of the disabilities and any preferences expressed by the pupil or their parents.
 - Schools have to produce and keep under review disability accessibility plans and will have to publish information about their plans in their annual Board of Governors report.
 - Education and Library Boards have a duty not to discriminate against a person or prospective pupil with a disability in carrying out their functions under various Orders relating to education.
 - The Special Educational Needs Tribunal (SENT) has been restructured to become the Special Educational Needs and Disability Tribunal (SENDIST) and now hears claims against disability discrimination by schools and ELBs, as well as appeals against the special educational provision made by ELBS.
- 7.15 The Department of Education (DE) has reviewed to its Code of Practice on the Identification and Assessment of Special Educational Needs as a result of the new provisions of SENDO. After consultation, a new statutory Supplement to the Code was completed and became effective on 1st September 2005. This Supplement provides user-friendly guidance on the new SENDO provisions and offers additional guidance to schools and ELBs on inclusion in general.
- 7.16 DE is currently working on a new Parents' Guide to enable parents and carers of children with SEN to gain a better understanding of the new legal framework and where to access help and support.
- 7.17 In addition the Equality Commission for Northern Ireland, on behalf of DE, has developed a new Disability Discrimination Code of Practice for Schools. This gives clear guidance on the new disability duties introduced by the SENDO and examples of how schools and Boards can make reasonable adjustments in school settings for children with disabilities.
- 7.18 DE has recently produced (January 2006) a Report of the Transitions Inter Departmental Group, which includes an Action Plan to address shortcomings in the transition process for young people with Statements of SEN. The ELBS have the statutory lead role in the transitions planning process for statemented children. The Action Plan clearly sets out actions already taken by the three Departments concerned – The Department of Education, the Department of Health, Social Services and Public Safety and the Department for Employment and Learning (DEL). The actions already taken include a restructuring of the Careers Service by DEL to better support the transitions process, additional funding from DE to ELBs for dedicated Education Transitions Coordinators, across NI, to support the young person and the parent at this stage and to enable improvements to work experience opportunities and life skills training for young people, while still at school.
- 7.19 The Children and Young People's Funding Package provided £0.9m recurrent funding for additional places, for young people with statements of Special Education Need, on transition from school settings into the community. DHSSPS has agreed with representatives from the 4 Health and Social Services Boards that 150 purposeful places will be created in the community with voluntary organisations.

- 7.20 In addition the Children and Young People's Funding Package has provide an additional £0.1m for young people with statements of special educational need to improve their life chances through enhanced life skills packages before leaving school. This is on top of a further £0.1m mainstream funding for the same purpose.

Recommendations

17. Education and Library Boards should continue to develop their policies and services to provide support to children with mental health problems or a learning disability to enable them to receive the most appropriate education.
18. Education and Health and Social Services bodies should continue to collaborate to ensure that all the needs of children with a mental health problem or a learning disability are met.
19. Schools should be pro-active in identifying pupils with possible learning disabilities or mental health problems and in getting professional help. Where that help needs to be provided by Health and Social Services, a timely response should be provided.
20. Schools and Health and Social Care providers should make arrangements to ensure that, as far as possible, a child's education is not allowed to suffer during an episode of mental health problems including people with a learning disability.
21. The principle of equal access to the full life of the school should be pursued by statutory and voluntary organisations.

8 HEALTH AND SOCIAL CARE

Background

- 8.1. There is a range of specialist health and social services designed to meet the particular needs of people with mental health problems or a learning disability both in the community and in specialist hospital units. The Mental Health Programme of Care in Northern Ireland represents about 8% of Health and Social Care spend (2003/2004) and the Learning Disability programme about 8%.
- 8.2. Other reports from the Bamford Review of Mental Health and Learning Disability (NI) have examined these specialist services in detail and making recommendations for improvements. The key challenge for mental health and learning disability services is reform and modernisation, in particular developing community mental health and learning disability provision to prevent inappropriate admissions and re-admissions to hospital, and focusing hospital services on short-term assessment and acute treatment only.
- 8.3. However, there is evidence that people with a mental health problem or a learning disability do not have the same access to general health services as other members of the public.
- 8.4. The same issue arises elsewhere. The Disability Rights Commission published (September 2006) a report of its investigation into health inequalities experienced by people with mental health problems or a learning disability in England and Wales. The report highlights the scale of inequalities, which is described as “overwhelming” and calls for action on a range of fronts. Many of the findings could apply equally in Northern Ireland.
- 8.5. People with mental health problems are at increased risk of having physical health problems. Many deaths of people with more complex and enduring mental disorder are potentially preventable by better medical treatment and attention to lifestyle, including diet and smoking. Assessment of the needs of those with mental health problems should cover physical health needs. One approach to identifying and targeting appropriate information and services to people with more severe and enduring mental health needs is the establishment of case registers at primary care level (Barr and Cotterill 1999). Primary and secondary care services, in conjunction with the service user, should jointly identify which service will take responsibility for monitoring physical health.
- 8.6. General Practitioners should consider the health promotion of people with severe mental health problems within their practice and regularly monitor their physical health. The NICE Guidelines for Schizophrenia recommend paying particular attention to endocrine disorders such as diabetes and hyperprolactanaemia, cardiovascular risk factors, side-effects of medication and lifestyle factors such as smoking (NICE 2002).
- 8.7. The prevalence of smoking is far greater among those with mental health problems than in the general population and smokers with mental health problems tend to smoke more heavily than others. Mental health professionals tend not to raise the issue of smoking with people they come in contact with. These professionals however are well placed to offer advice and

support on smoking cessation. Smoking is addressed as part of the Bamford Review report on Alcohol and Substance Misuse, which makes a number of recommendations in this area.

- 8.8. While life expectancy of people with a learning disability has improved over the last 60 years, mortality rates are still higher than in the general population. Some people are at higher risk of physical ill health arising from problems associated with particular conditions and healthcare professionals need to be aware of these.
- 8.9. There are however more basic healthcare needs which are often neglected in relation to people with a learning disability. Accessibility of information and advice on healthy lifestyles, uptake of screening programmes and other routine physical health checks. Access to appropriate dental treatment is a particular issue for many people with a learning disability. These problems are documented more fully in Equal Lives, the Bamford report on learning disability, and that report makes a range of recommendations for improvement.
- 8.10. The Bamford review's report on Alcohol and Substance Misuse recognises that, as more people with a learning disability are living in the community, they may be exposed to greater social stressors leading to increased use of alcohol and drugs as a coping mechanism. People with a learning disability may also see use of alcohol and drugs as a way of fitting in with their peers. Again the Bamford report on Alcohol and Substance Misuse makes a number of recommendations relating to this issue.
- 8.11. There are concerns regarding the lack of Child and Adolescent Mental Health Services, especially in terms of inpatient beds. Work has started on implementing the recommendations contained in the Bamford review's report "Vision of a Comprehensive Child and Adolescent Mental Health Service".
- 8.12. A growing concern is the number of local suicides and the rising level of self-harm, mainly by young people. To address these concerns a Taskforce was established in July 2005 to develop a regional suicide prevention strategy. Following an extensive engagement and consultation process the final Strategy, "Protect Life – A Shared Vision", was published on 30 October 2006. The Strategy aims to tackle the issues of suicide and self-harm by taking a dual population and targeted approach. The Strategy recognises the fact that, while its primary focus is clearly on prevention, the achievement of its aims will be greatly influenced by the need for its implementation to be taken forward in parallel with progress being made on the delivery of the Promoting Mental Health Strategy and the Bamford Review of Mental Health and Learning Disability.

Qualitative Survey of Users and Carers

- 8.13. The Qualitative Survey of users and carers in a number of voluntary organisations in Northern Ireland identified the following issues:
 - That GPs require better training in mental health issues.
 - A relapse/deterioration in service users' mental health can result in a lack of motivation and drive to attend appointments.

- A negative impact of medication can cause weight problems, which becomes a secondary issue having a further negative impact on their mental health.
 - Smoking alleviates some of the tensions resulting from mental health problems. Government no-smoking policy needs to consider 'outdoor' spaces for clients to smoke.
 - Carers are often unable to attend hospital, dentist and eye care appointments, due to their caring role.
- 8.14. Issues raised in the review reports from people with a learning disability and their carers included:
- General health professionals not having an understanding of how to deal with people with a learning disability and not taking time to listen to them.
 - Waiting times for dental treatment for people with a learning disability.

Where are we now?

- 8.15. The Investing for Health Strategy launched in March 2002 sets out the Executive's views on how the health and well-being of all the people here can be improved, and how the unacceptable inequalities in health can be reduced. Boards and Trusts are implementing this strategy through Health Improvement Plans, adopting a proactive, holistic approach that protects and improve health by implementing action plans being produced in a range of areas, including drugs and alcohol misuse and mental health promotion.
- 8.16. In recognition of the fact that children with learning disabilities are not receiving the necessary dental care and that there are long waiting lists, some of the funding made available from the Children and Young People's Funding Package is being used by the 4 Health Boards to address the waiting lists of children with learning disabilities who are waiting to receive dental treatment.

Recommendations

22. The health and social care needs of people with a learning disability or severe mental health problems need to be identified both at primary care and secondary care level.
23. Any assessment of the needs of people with a learning disability or with more complex mental health needs must include assessment of their physical health needs.
24. The Department of Health, Social Services and Public Safety should produce a Regional Framework for Health Improvement of people with a mental health problem or a learning disability, providing clear direction including targets and timescales. Each HSS Board should review their Health Improvement Plans to ensure that they translate the regional framework at a local level to support improved health outcomes for people with a mental health problem or a learning disability.
25. All generically trained health and social services professionals should receive awareness training on mental health and learning disability issues.

9 SOCIAL LIFE

Background

- 9.1. Mental well-being has been defined as the emotional and spiritual resilience which enables us to survive pain, disappointment and sadness. It is a positive sense of well-being and an underlying belief in our own dignity and worth.
- 9.2. A person's social connectedness – activities, relationships, interests, networks – has a significant impact on mental well-being and self-esteem. The reactions of others are often influenced in our social life, our activities, interactions, and our social self. Becoming mentally unwell can profoundly affect both our own social interactions and the reactions of others. It is in such situations that the experience of ignorance, fear and stigma can bring a new dimension of distress to the sufferer.
- 9.3. Mental health problems and the accompanying distress can affect all aspects of one's social life and relationships - within the family, with friends, with work colleagues. The sense of feeling isolated and stigmatised is a very real experience of many sufferers. There is also a sense of disempowerment and the distress arising from this – “my life will never be the same again”. Acknowledgement of these issues and concerns can be of particular importance in promotion of recovery and needs to be recognised by professionals.
- 9.4. The issue of bullying that is commonly reported by advocates can also cause extreme distress and lead to isolation and social exclusion. This issue needs to be proactively addressed both in specialist services and the wider community. People with disabilities should be encouraged to exercise their rights to make complaints to the police or other relevant authority. The Criminal Justice (No. 2) (Northern Ireland) Order 2004 provides protection in that Article 3 extends the protections of Part III of the Public Order (Northern Ireland) Order 1987 to include groups defined by reference to sexual orientation or disability. (Part III currently provides offences and penalties against the use of threatening, abusive or insulting words or behaviour, the display and distribution of written material, and related activities intended or likely to stir up hatred or arouse fear).
- 9.5. The protections, currently provided with regard to religious belief, colour, race, nationality, ethnic or national origins, are extended by Article 3 to include sexual orientation and disability (including mental health problems and learning disabilities). The penalties for stirring up hatred or arousing fear in such cases is: on summary conviction, a maximum of 6 months imprisonment, a fine not exceeding the statutory maximum, or both; on conviction on indictment, a maximum of 2 years imprisonment, a fine, or both.
- 9.6. The relationship between service providers and individuals is of considerable importance in building and maintaining self-esteem, hope and self-worth for individuals with severe episodes of mental illness, experiencing loss of insight, loss of control, in addition to the painful experience of the symptoms of mental illness. This relationship can also provide a role model for family members who themselves may be bewildered and distressed through the experience of an illness episode. The engagement and empowerment of family members

can greatly assist in the recovery and re-engagement of the individual in their social life and relationships.

- 9.7. Access to information has generally been experienced as a problem for individuals in mental health services. It is often difficult to get clear information and this lack of clarity is a problem for users, family and friends. The failure to convey relevant information clearly and in simple terms can cause distress to the user and their families. Information is required about services, choice of services, specific interventions including, for example, medication side effects and crisis arrangements.
- 9.8. In the situation of involuntary admission clarity takes on even greater importance. The sufferer in such situations often experiences a significant intrusion into their personal and family privacy. Involuntary admission procedures should be clearly explained and all involved should identify themselves to the sufferer, family and friends. Difficulties for the user in understanding information at such times requires professionals to pay even greater attention to communication and information sharing.
- 9.9. Within a multi-cultural society, the individual's specific cultural, spiritual and religious needs must be recognised and acknowledged. With the emphasis on community based care and treatment, the religious and spiritual dimension of an individual's life should be considered as part of holistic assessment.
- 9.10. Spirituality, described as "linking the deeply personal with the universal", is inclusive and unifying. In healthcare, spirituality is identified with experiencing a deep-seated sense of meaning and purpose in life, together with a sense of belonging. It is about acceptance, integration and wholeness.
- 9.11. The Royal College of Psychiatrists' leaflet on Spirituality and Mental Health states that service users have identified the following benefits of good quality spiritual care:
 - Improved self-control, self-esteem and confidence.
 - Speedier and easier recovery, achieved through both promoting the healthy grieving of loss and maximising personal potential.
 - Improved relationships - with self, others and with God/creation/nature.
 - A new sense of meaning, resulting in reawakening of hope and peace of mind, enabling people to accept and live with problems not yet resolved.
- 9.12. From a user perspective, spirituality can be an important part of one's personal life and in times of crisis a major source of sustenance. This can be of particular importance in situations where admission to hospital is required with the inevitable separation from family, friends and one's local community. It is a common user experience when in hospital that religious and spiritual needs are not adequately met. Service providers need to be sensitive to the spiritual needs of individuals at such times. It is important that staff working with people with mental health problems or learning disability encourage any helpful inner personal resources and explore what external supports from the community and/or faith tradition are available.

- 9.13. Available and affordable transport is a key requirement of a good social life. The introduction by the Department for Regional Development of reduced charges on public transport for people with a learning disability is a welcome development.
- 9.14. People with a learning disability often express dissatisfaction the lack of public transport and the prohibitive costs of taxis, problems with physical access to premises such as cinemas, nightclubs, bars and restaurants and the lack of a companion – a befriender – to accompany them.
- 9.15. Provision of transport within Health and Social Services day services consumes over 25% of the total budget. As a consequence of the locations of many day centres, individuals can spend very lengthy periods being transported to/from centres with only 20% of centres able to transport most of their attendees from home to centre in less than 30 minutes.
- 9.16. A number of services have developed innovative independent travel training schemes, which have increased the capacity of individuals to make fuller use of public transport.
- 9.17. Many people with a learning disability live lonely lives. Most of their free time is spent in home-based pursuits such as watching television and listening to music with few friends of their own age. In a study in 2003, the researchers interviewed the parents of over 50 school-leavers from 2 special schools for pupils with severe learning disabilities in Northern Ireland. Three in five of the young people (58%) were reported to have no friends of their own. In all, 90% of parents would like their son or daughter to be more involved with friends of their own age and they mentioned the need for more clubs and for more sports and leisure activities.
- 9.18. A similar picture emerges for adults. In a 2002 study, over 2 in 5 people reported having no friends outside of the day centre they attended and 4 was the most that anyone reported. The most common activities undertaken with friends were going to discos and social clubs, but most of these were organised specifically for people with a learning disability.
- 9.19. A study of 65 persons resettled from a long-stay learning disability hospital in Northern Ireland into nursing home and residential care found that only 14 people (21%) had regular or frequent contact with friends outside of the residence.
- 9.20. Overall people with a learning disability tend to lead more sedentary lifestyles than the general population, performing significantly less than the minimum levels of physical activity recommended by the Department of Health. Levels of obesity appear to be rising among adults with a learning disability in Northern Ireland.
- 9.21. People with a learning disability often express dissatisfaction with their community, recreation and leisure activities. They mention in particular the need for more evening and weekend activities and greater opportunities to take part in community events.
- 9.22. Many family carers are also concerned about the lack of leisure opportunities. Among the suggestions they made were:

- Drop in centres and more social clubs.
 - Weekend or short breaks away.
 - Befriending schemes with long-term commitments.
 - Education of the general public about learning disability.
 - Community Access/Support Workers to allow individuals to attend events/concerts rather than depending on their ageing parents/carers to take them.
 - Day centre facilities utilised in the evenings.
 - Relatively little monies have been expended by social services in promoting the social and leisure lives of people with a learning disability. Often this has been left to charitable groups (often led by parents and relatives) and they continue to be the main provider of leisure opportunities outside working hours with a heavy reliance on volunteers.
 - The main service innovations in this area have revolved around the concept of befrienders; ideally a person of similar age, background and interests recruited to share some of their leisure time with a chosen partner. A Northern Irish survey identified this as the fifth most popular form of voluntary activity with an estimated 80,000 people involved across all client groups.
 - A range of agencies in Northern Ireland has set up a number of dedicated befriending schemes mostly in the non-statutory sector although as yet there has been no evaluation undertaken of their impact and sustainability.
- 9.23. Few resources are spent in encouraging access to social and leisure opportunities by people with mental health problems or a learning disability. Greater attention to developing people's social networks could pay dividends in other ways by reducing the possible consequences of social isolation including challenging behaviours and depression.
- 9.24. Meaningful relationships, including marriage, and expression of one's sexuality contribute greatly to people's quality of life. The sexual expression and developing sexuality of people with a learning disability is often seen as problematic and not a normal part of growth and development. This ignores the person's rights and the benefits to be gained.
- 9.25. The subject of relationships and sexuality and the social skills required in forming appropriate relationships receive insufficient attention at home, at school and in other service settings.
- 9.26. The changes in the life stages of people with a learning disability are often not recognised. There is a marked lack of sex education for men and women with a learning disability and lack of guidelines for staff who provide sex education.
- 9.27. Life stages and general sexual and reproductive health care is not provided. For women in particular issues are not adequately addressed in relation to premenstrual syndrome, cervical and breast screening, sexual health screening and the menopause.
- 9.28. Sexual orientation and preferences often go unnoticed and undetected or attributed to lack of experience, choice or environmental influences.
- 9.29. Staff members who participated in a consultation exercise highlighted a number of issues

pertinent to supporting sexual expression that they feel unable to resolve because of lack of clear legislation, policy and guidelines. These included:

- Participants working in residential care settings who expressed feelings of frustration around being willing to support clients in their sexual expression but being hampered by how current legislation is interpreted and implemented through policy.
- A perceived need for greater clarity between the Mental Health (Northern Ireland) Order 1986, Sexual Offences Act 2003 and Human Rights Act 1998, in relation to individual's rights around sexual expression and the process used to assess capacity to consent.
- A need for ongoing training, supervision and support to develop understanding and competencies at different levels of intervention, mostly around inappropriate touch/abusive behaviours.
- Policies are now more likely to acknowledge the rights of people with a learning disability around their sexuality and sexual expression, however, there is a lack of clarity around whether individual's rights are prioritised above parents' rights and the legal position regarding parents' rights i.e. if there is a clash between the individual's wishes and parents' wishes, who should be prioritised?
- Balancing rights, responsibilities, vulnerabilities and risk in this area is complex and hampered by apparent lack of clear direction as to the parameters within which staff should work at a practice level. e.g., what kind of information staff should be giving relevant to their role if a man or woman with a learning disability asks for information about contraception or wanting to be sexually active.

9.30. There is a lack of support, education and training for parents, to enable them to identify emergent issues and gain knowledge and skills in supporting their children. Many parents struggle with their own values and beliefs around sexual expression and the desire of young people and adults with a learning disability to form sexual relationships. The following issues have been expressed by parents:

- Fears and concerns around lack of support for children particularly when during times of transition from primary to post primary education, where they are seeking to keep their children in mainstream education.
- Education around appropriate sexual expression. Parents often feel unable to discuss problems with others and are unable to identify appropriate means of support.
- Accessing affordable information to support them to do sex education work with their sons or daughters.

Recommendations

26. The limitations posed by existing transport provision have curtailed access to educational, employment and leisure opportunities. A determined effort is required to ensure that these barriers are removed. There is scope to more actively promote independent travel on public transport and on foot. This should be planned with the support of the family and must feature in schools and higher and further education establishments. In addition, those charged with responsibility for public transport must ensure that the particular needs of men and women with a learning disability are incorporated in their strategies.

27. Leisure and recreation schemes should be promoted and co-ordinated at District Council level. An audit should be commissioned of leisure and recreation facilities, societies and clubs within their area that serve the wider community as well as people with disabilities. This Directory should be maintained by District Councils and widely circulated to all service-providers (including residential services) and family carers. A central point should be created or identified for recruiting volunteer helpers and drivers. Different schemes within District Councils should have shared access to a minibus or people-carriers. Seed monies should be available to initiate new schemes.
28. Now that all services are expected to have policy guidelines in place on sexuality and personal relationships, there needs to be a concerted effort across all services to make available opportunities for education on these issues and on sexual health. This should be done with the knowledge and support of family carers, but they should not have a sanction on their relative's participation if that is his or her wish.
29. The issue of bullying that is commonly reported by self-advocates needs to be proactively addressed both in specialist services and the wider community.
30. The Office of the First Minister and Deputy First Minister should take a leadership role developing people's social networks with central and local Government, the voluntary and private sectors to help reduce social isolation.

10. WAY AHEAD

- 10.1 During the review it was noted that there is a lack of local research in Northern Ireland in promoting social inclusion for people with mental health problems or a learning disability.
- 10.2 Implementation of the recommendations will be the key to delivering social inclusion for people with mental health problems and/or a learning disability.

Recommendations

- 31. There is a need to gather further information on the social inclusion needs of people with mental health problems or a learning disability.
- 32. The inter-departmental taskforce needs to address the recommendations of this report by addressing the implementation issues including: an action plan, timetables, targets, resources, budgets, research, evaluation and monitoring.

CONCLUSION

- 11.1 Many people with a learning disability or a mental health problem have not always been included as full and equal members of society. The effective implementation of this Report's recommendations will help people with a learning disability or mental health problems to reach their full potential, as equal members of society.

MEMBERSHIP OF THE PROMOTING SOCIAL INCLUSION GROUP

The Promoting Social Inclusion (PSI) Group was established within the Social Justice and Citizenship Committee (which is part of the overall Bamford Review of Mental Health and Learning Disability), to take forward the review of social inclusion. Membership of the PSI group included representation from Office of the First and Deputy First Minister (OFMDFM), Department of Health Social Services and Public Safety (DHSSPS), Department for Social Development (DSD), Social Security Agency (SSA), Department for Employment and Learning (DEL), Department of Education (DE), Department for Regional Development (DRD), the Law Centre, the voluntary sector, carers and users.

QUALITATIVE SURVEY OF SERVICE USERS AND CARERS

The Qualitative Survey of Users and Carers was performed by DHSSPS. Two staff met with users affiliated to various mental health and learning disability voluntary organisations throughout the province in early 2004 to establish difficulties they had with social inclusion for people with a learning disability or mental health problems. The organisations visited were Newry and Mourne Mental Health Forum, Rethink, Aware Defeat Depression, S.T.E.E.R. and the Down's Syndrome Association.

RECOMMENDATIONS

1. There is an ongoing need to monitor negative stereotypes within the community and to change the attitudes that reinforce these negative stereotypes. Communities need to be educated to ensure the successful social inclusion of people with a mental health problem or a learning disability in their community.
2. There is a fundamental need for a campaign to challenge the images that communicate negative stereotypes. The campaign needs to directly involve people with first-hand experience of discrimination, target specific audiences and monitor and evaluate its effectiveness.
3. All service providers must be encouraged to provide information in a form that is understood by people with mental health problems or a learning disability.
4. There is a need to establish a group to address the stigma associated with mental health problems and learning disabilities.
5. The Labour Force Survey (2002) indicated that only 21% of people with a mental health problem or learning disability are in employment yet research from the US found that with effective rehabilitation support, up to 58 % of adults with severe and enduring mental health problems are able to work using the Individual Placement and Support approach. Therefore the Northern Ireland target should be at least 50% of people with mental health problems or a learning disability should be in full time employment.
6. Employment Advisors should work with community mental health teams and community learning disability teams to provide pathways to employment.
7. European monies have funded a number of supported employment positions and Departments should mainstream this funding, where it has been shown to achieve positive outcomes.
8. Permitted work rules for Incapacity Benefit and Severe Disablement Allowance should be further improved, simplified and promoted effectively to reduce the barrier from moving from benefit to work. Returning to work should be on a voluntary basis and people should not be disadvantaged if their condition changes and prevents them from continued working.
9. DSD and housing providers should develop a housing strategy to ensure people with mental health problems and learning disabilities can, where possible, live in the accommodation of their choice, subject to normal financial constraints.
10. People with mental health problems or learning disabilities should have the choice to live independently but the use of specialised group housing has a role to play, for example as step-down accommodation after leaving hospital.

11. DSD should ensure participation of people with mental health problems or a learning disability in the planning of housing services.
12. Independent advice and advocacy services should be embedded in mental health and learning disability services to help support and enable people with mental health problems or a learning disability to live independently with dignity and a good quality of life, both in and out of work.
13. There should be partnership schemes between Government, commercial companies, housing associations and credit unions to extend insurance cover and other financial products and services to financially excluded people with mental health problems or a learning disability.
14. The Social Security Agency should work with the voluntary sector and other relevant organisations to examine customer service issues for people with mental health problems and/or learning disability.
15. Social Security Agency decision-makers, Medical Referee staff, front line benefit staff and the Appeals Service (NI) chairpersons and tribunal members should receive more in-depth mental health and learning disability awareness training.
16. Financial institutions should review their policies to ensure that they treat people with mental health problems or learning disabilities no less favourably than they treat others in order to comply with the Disability Discrimination Act 1995.
17. Education and Library Boards should continue to develop their policies and services to provide support to children with mental health problems or a learning disability to enable them to receive the most appropriate education.
18. Education and Health and Social Services bodies should continue to collaborate to ensure that all the needs of children with a mental health problem or a learning disability are met.
19. Schools should be pro-active in identifying pupils with possible learning disabilities or mental health problems and in getting professional help. Where that help needs to be provided by Health and Social Services, a timely response should be provided.
20. Schools and Health and Social Care providers should make arrangements to ensure that, as far as possible, a child's education is not allowed to suffer during an episode of mental health problems including people with a learning disability.
21. The principle of equal access to the full life of the school should be pursued by statutory and voluntary organisations.
22. The health and social care needs of people with a learning disability or severe mental health problems need to be identified both at primary care and secondary care level.
23. Any assessment of the needs of people with a learning disability or with more complex mental health needs must include assessment of their physical health needs.

24. The Department of Health, Social Services and Public Safety should produce a Regional Framework for Health Improvement of people with a mental health problem or a learning disability, providing clear direction including targets and timescales. Each HSS Board should review their Health Improvement Plans to ensure that they translate the regional framework at a local level to support improved health outcomes for people with a mental health problem or a learning disability.
25. All generically trained health and social services professionals should receive awareness training on mental health and learning disability issues.
26. The limitations posed by existing transport provision have curtailed access to educational, employment and leisure opportunities. A determined effort is required to ensure that these barriers are removed. There is scope to more actively promote independent travel on public transport and on foot. This should be planned with the support of the family and must feature in schools and higher and further education establishments. In addition, those charged with responsibility for public transport must ensure that the particular needs of men and women with a learning disability are incorporated in their strategies.
27. Leisure and recreation schemes should be promoted and co-ordinated at District Council level. An audit should be commissioned of leisure and recreation facilities, societies and clubs within their area that serve the wider community as well as people with disabilities. This Directory should be maintained by District Councils and widely circulated to all service-providers (including residential services) and family carers. A central point should be created or identified for recruiting volunteer helpers and drivers. Different schemes within District Councils should have shared access to a minibus or people-carriers. Seed monies should be available to initiate new schemes.
28. Now that all services are expected to have policy guidelines in place on sexuality and personal relationships, there needs to be a concerted effort across all services to make available opportunities for education on these issues and on sexual health. This should be done with the knowledge and support of family carers, but they should not have a sanction on their relative's participation if that is his or her wish.
29. The issue of bullying that is commonly reported by self-advocates needs to be proactively addressed both in specialist services and the wider community.
30. The Office of the First Minister and Deputy First Minister should take a leadership role developing people's social networks with central and local Government, the voluntary and private sectors to help reduce social isolation.
31. There is a need to gather further information on the social inclusion needs of people with mental health problems or a learning disability.
32. The inter-departmental taskforce needs to address the recommendations of this report by addressing the implementation issues including: an action plan, timetables, targets, resources, budgets, research, evaluation and monitoring.

