

Towards Best Practice in Provision of Health Services for People with Disabilities in Ireland

Foreword

This report is one in a series which presents research commissioned by the NDA in 2002 to provide such baseline evidence on the quantum and range of service provision. In commissioning this series, we found strong concurrence across all the policy areas that there were large data gaps. We have established where those gaps are most evident. We hope that it can assist in setting priorities for data strategies, service planning and policies for the equal treatment and inclusion of people with disabilities in Ireland.

It is clear that much of the policy work to date has been framed from the policy maker's perspective with poor estimations of impact. It is imperative to frame policy from an individual perspective and to aggregate information from the individual to the regional/national perspective so that accurate estimates can be made regarding the potential costs and impact of proposed policy actions on the lives of people with disabilities.

I thank each of the researchers who worked on this series and supported the NDA in undertaking this important work, and the cross functional teams within NDA who had to progress the drafts towards conclusion. The priorities set out in the overview of this document are set to appear in our policy work over the next three year period under the second strategic Plan 2004-2006-
"Progressing the Disability Agenda in Ireland"

I would like to acknowledge the support of the Disability Equality Unit in the Department of Justice Equality and Law Reform, without whose support this work would not be possible. I would also like to mark the encouragement of our Authority members who recognised the value of publishing despite the incomplete picture.

Angela Kerins

Chairperson

National Disability Authority

Table Of Contents

Foreword.....	1
Acknowledgments.....	8
Overview.....	8
Data.....	11
Health service mapping.....	12
Disability policy development and the reform programme in health.....	12
Service provision.....	13
Coordination and integration of services.....	14
Rights and a social model of disability.....	14
Quality developments and standards.....	15
Awareness raising, training and guidance.....	15
Information accessibility.....	16
User involvement and participation.....	16
Equality, equal status reviews and disability proofing.....	16
Conclusion.....	16
Introduction.....	17
CHAPTER I: POLICY AND LEGISLATION UNDERPINNING SERVICE PROVISION, DEVELOPMENT, PLANNING AND MONITORING.....	19
1.1 Introduction.....	19
1.2 The organisation of health services in Ireland.....	19
1.3 The reform programme in health.....	21
1.4 Key legislation.....	22
<i>Mental Health Act 2001</i>	22
<i>National Disability Authority Act, 1999</i>	22
<i>Health (Eastern Regional Health Authority) Act, 1999</i>	23
<i>Health Amendment Act (no 3), 1996</i>	23
<i>Health Act, 1970</i>	23
<i>Health Act, 1947</i>	23
1.5 National health policies and strategies.....	23
<i>Quality and Fairness – A System for You</i>	23
<i>Primary Care: A New Direction, 2001</i>	25
<i>Acute Hospital Bed Capacity: A National Review, 2002</i>	25
<i>The National Health Promotion Strategy, 2000-2005</i>	25
<i>Reports of the Chief Medical Officer, 1999 and 2000</i>	26
1.6 Specific Policies Impacting on Health for People with disabilities.....	26
A Strategy for Equality and Towards Equal Citizenship	26
Specific policy and service developments for people with disabilities	27
<i>People with intellectual disability</i>	27
<i>People with physical and sensory disabilities</i>	28
<i>People with Mental Illness</i>	28
<i>Older People With Disabilities</i>	29
<i>Children With Disabilities</i>	30
<i>Women With Disabilities</i>	31
1.7 Other government policies/legislation impacting on disability and health.....	31
<i>The Strategic Management Initiative and Delivering Better Government</i>	31
<i>Equality Legislation</i>	32
<i>National Anti-Poverty Strategy, Health Working Group</i>	32
1.8 Information and data issues.....	33
1.9 Assuring, monitoring and evaluating quality in health.....	34
1.10 Conclusion.....	36
Chapter 2: The range and quantum of services.....	36
2.1 Introduction.....	36
Mapping exercises in the Midland Health Board and the Eastern Regional Health Authority	37
Disability health services: recent developments	37
Data issues	38
Performance indicators for people with disabilities	40

2.2	Health mapping methodology	40
	Definitions	44
2.3	National data and information	45
	Budget for mental health and disability services	45
	Funding for disability health services, 1997-2002	46
2.4	Mental health services.....	49
	<i>Data on mental health services</i>	49
	Key developments in services	49
	In summary	50
	Numbers in psychiatric care and receiving mental health services: data for 200111	51
	Inpatients	51
	Admissions	52
	Community based psychiatric services: outpatients, day hospitals, day centres and community residencies	55
	Outpatient clinics	55
	Day hospitals	55
	Percentages	61
	Day centres.....	64
	Community residencies	64
	Medical staffing	64
	Inspector of Mental Health Services	65
	Key issues raised by the Inspector of Mental Hospitals (1998, 1999, 2000 and 2001):	68
	Living conditions.....	68
	Standards of care and rights of mental health patients.....	69
	Funding.....	69
	Health status	69
	New services and staffing	69
2.5	Disability services: physical and sensory disability and intellectual disability	70
	Services for people with intellectual disability and autism	71
	Services for people with physical and sensory disabilities	77
2.6	Staffing and personnel issues	79
2.7	Rehabilitative training programmes funded by the DOHC	82
2.8	Community welfare services	82
2.9	Overview of statutory funded provision in a selection of health boards	83
	a) Eastern Regional Health Authority	84
	i) Mental health services	84
	Examples of good practice	87
	b) Midland Health Board	87
	i) Mental health services	87
	Recent service developments	88
	Key policy, auditing and review initiatives impacting on service planning	89
	Key challenges	89
	Emerging issues/unmet needs	89
	Voluntary Sector and Partnerships	90
	ii) Disability support services	90
	Key aspects of the Board's recent activities.....	91
	Recent developments in service	92
	Gaps and challenges identified in services	94
	Core services and staffing.....	94
	Improved quality and range of services	94
	Services for specific groups	95
	c) Southern Health Board	95
	i) Mental health services	95
	Key priorities and plans:	95
	ii) Services for people with physical and sensory disabilities	98
	iii) Services for people with intellectual disability	99
	Key priorities for 2003 include:	99
	d) North Western Health Board	99
	i) Mental health services	100

Recent developments:	100
ii) Services for people with physical and sensory disability	101
Recent developments in services:	101
Priority developments:	101
iii) Services for people with intellectual disabilities	102
Key developments include the provision of the following services:	102
e) South Eastern Health Board	102
i) Mental health services	102
Recent developments in services:	102
ii) Services for people with intellectual disability	104
Recent developments in services	104
Priorities for 2003	104
iii) Services for people with physical and sensory disability	105
Recent developments in services	105
Priorities for the Board for 2003	105
Examples of good practice: initiatives in mental health services and services for people with disabilities	106
2.10 Conclusions	106
CHAPTER 3: INTERNATIONAL GOOD PRACTICE IN HEALTH AND SOCIAL CARE SERVICES FOR PEOPLE WITH DISABILITIES	107
3.1 Introduction	107
Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (adopted by the UN General Assembly in 1993).	110
3.2 International good practice	110
a) United Nations	110
b) World Health Organisation	112
Medical care	114
Rehabilitation	115
Support services	115
Personnel Training	115
3.3 European Good practice	115
a) European Union	115
b) Council of Europe	117
3.4 Case Study: The right to health	119
3.5 National examples of good practice	123
a) Introduction	123
b) The funding of health care	123
c) The organisation and provision of health and social care services in Europe	123
d) Equality, rights to services and legal protection against discrimination	125
Finland	127
Provision of health, social and rehabilitation services	127
Disability legislation	127
Denmark	128
Provision of health, social and rehabilitation services	128
France	129
Provision of health, social and rehabilitation services	129
Disability legislation	130
The Netherlands	130
Provision of health, social and rehabilitation services	130
Disability legislation	131
Sweden	131
Provision of health, social and rehabilitation services	131
Disability legislation	132
UK	133
Provision of health, social and rehabilitation services	133
Disability legislation	133
Australia	134
Disability legislation	134
Canada	135
Disability legislation	135

USA	135
e) The quality of health and social care provision	136
Integrating services for people with intellectual disability	139
Evidenced based service planning	140
Data and information systems	140
Mental health service mapping	141
f) The development of a social model of disability	143
Independent living	143
Assertive Outreach	144
Direct payments and personal budgets	145
Participation of service users in the planning, development and monitoring of services	146
USER INVOLVEMENT	147
3.6 Conclusions	148
Equality and anti-discrimination approaches	148
Social model of disability	149
Good quality services	149
Chapter 4: Conclusions and key findings	150
Key findings from the health mapping research:	151
Data issues	151
Funding	151
Services	151
Data collection and management of data	152
Access to and provision of services	152
Disability Services	153
Mental health services	153
Funding	154
Towards a social model of disability	154
Feedback from service users about the future development of disability health services	155
Equality and disability proofing	157
Chapter 5: Recommendations	158
5.1 Data	158
Department of Health and Children and Health Boards	159
5.2 Health service mapping	160
Department of Health and Children	160
National Disability Authority	160
5.3 Disability policy development and the reform programme in health	161
Department of Health and Children	161
Department of Health and Children, Local Authorities and the National Disability Authority	161
Department of Health and Children, Health Boards and Department of Social and Family Affairs	161
5.4 Service provision	161
Mental Health Services	162
Department of Health and Children and statutory and non-statutory service providers	162
Local authorities and Health Boards	162
Irish College of General Practitioners	162
National Disability Authority, Mental Health Commission and mental health advocacy organisations	163
People with an intellectual disability	163
Department of Health and Children, Health Boards, statutory and non-statutory providers	163
People with a physical and sensory disability	163
Department of Health and Children, Health Boards, statutory and non-statutory providers	163
5.5 Coordination and integration of services	164
Government Departments	164
Local authorities, Health Boards and City and County Development Boards	164

5.6	Rights and the social model of disability	165
	Department of Justice, Equality and Law Reform	165
	Department of Health and Children, statutory and non-statutory providers	165
	National Disability Authority	165
	Comhairle and Advocacy Organisations.....	165
5.7	Quality development and standards.....	165
	Department of Health and Children	166
	Department of Health and Children and the National Disability Authority	166
5.8	Awareness raising, training and guidance	166
	National Disability Authority and the Equality Authority	166
	Department of Health and Children	166
	National Disability Authority and the Department of the Taoiseach	166
5.9	Information accessibility	167
5.10	User involvement and participation	167
	Department of Health and Children, National Disability Authority and Health Boards	167
5.11	Equality, equal status reviews and disability proofing	168
	Equality Authority, National Disability Authority and Health Boards	168
	Bibliography	168
	Appendix 1: List of relevant legislation and policy documents relevant to disability and health	175
1.	Key legislation	175
2.	National health policy statements/documents	175
3.	National policy documents on disability	176
	Mental Health.....	176
	Physical Disability	176
	Intellectual Disability	176
4.	Disability and other groups.....	177
	Children.....	177
	Older people	177
	Women.....	177
5.	Disability, Health and Poverty	178
6.	Strategy Statements/Service Plans.....	178
7.	Other relevant national, European and International provisions	178
	International legal provisions that may impact on disability and health services.....	178
	Appendix 2: Department of Health and Children Performance Indicators for Disability Services	
	Intellectual.....	180
	Effectiveness	180
	Rationale	180
	Source of Information.....	180
	Frequency of Reporting	180
	Specific Questions to be asked:	180
	Commentary required:.....	180
	Health Improvement	181
	Rationale	181
	Source of Information.....	181
	Frequency of reporting.....	181
	Specific Questions to be asked:	181
	Appendix 3: Mental Health Services Mapping Framework.....	182
1.	Day, residential and respite care.....	182
2.	Home and community based supports.....	185
3.	Mental health services for specific groups	187
	Other services	189
	Appendix 4: Services for People with Physical and Sensory Disabilities Mapping Framework....	191
1.	Therapeutic, rehabilitative and medical supports.....	191
1.	Day, residential and respite care.....	193
3.	Home and community based supports.....	195
4.	Other services	197
	Appendix 5: Services for People with Intellectual Disability Mapping Framework	200
1.	Day, residential and respite care.....	200
2.	Therapeutic, medical and other supports.....	202
3.	Services to specific groups.....	203

4. Other services: needs assessment, advocacy, training, transport and housing.....	205
Appendix 6: Descriptions and Definitions of Services	207
Appendix 7: Summary Tables of Health Board Provided and Funded Services.....	212
MENTAL HEALTH: HEALTH BOARD FUNDED SERVICES	212
PEOPLE WITH INTELLECTUAL DISABILITY: HEALTH BOARD FUNDED SERVICES	214
PEOPLE WITH PHYSICAL AND SENSORY DISABILITIES: HEALTH BOARD FUNDED SERVICES	216
Appendix 8: UN Standard Rules.....	218
I. Preconditions for Equal Participation.....	218
II. Target Areas for Equal Participation.....	218
III. Implementation Measures	218
IV. Monitoring Mechanism.....	218
I. Preconditions for Equal Participation.....	218
Rule 1: Awareness-raising	218
Rule 2: Medical care.....	219
Rule 3: Rehabilitation	220
Rule 4: Support services	220
Appendix 9: Non Statutory Service Providers in the Disability Sector	221
A. Organisations Representing Non-Statutory Service Providers.....	221
B. Non-Statutory Service Providers Receiving Health Board Funding	222
Intellectual Disability	222
Physical and sensory disability	224
Mental health	224
All disabilities	225
Housing Associations.....	225

Acknowledgments

Many people cooperated in providing very valuable information and feedback during the preparation of this report. Directors of Disability Services in all of the health boards cooperated in providing information at an extremely busy time of the year. In particular thanks go to Breda Crehan-Roche, Director of Disability Services, David Whelan and Gerry Raleigh from the Midland Health Board for their assistance in carrying out the more detailed mapping exercise and for coordinating and contacting organisations providing disability support services in the Midland Health Board area. These thanks are also extended to Diane Nurse, Service Planner for Physical and Sensory Disabilities, ERHA; John O'Sullivan, Director of Disability Services ECAHB; Violet Hartford, SWAHB; Marion Meany NAHB, Frances Fletcher and Mary O'Reilly at the Department of Health and Children, and Fiona Mulvany and Antoinette Daly from the Health Research Board who provided valuable data for the health mapping. A large number of disability organisations also provided valuable insights and feedback, in particular I would like to thank Deidre Carroll from NAMHI, Donal Toolan, Forum of People with Disabilities, John Dolan and Joanne McCarthy, DFI, John Bosco Comana, IDS, Clodagh O'Brien, Not for Profit Business Association.

Dr Jane Pillinger

November 2003

Overview

The National Disability Authority (NDA) was established in June 2000 as a statutory body under the Department of Justice, Equality and Law Reform with the principal function to advise the Minister and keep him or her informed of developments that concern issues of policy and practice impacting on people with disabilities (NDA Act, 1999). The NDA Act (1999) which underpins the establishment of the Authority defines disability as “a substantial restriction in the capacity of a person to participate in economic, social or cultural life on account of an enduring physical, sensory, learning, mental health or emotional impairment.”

The Act further outlines the core functions for the Authority, including among these:

1. to act as a central national body which will assist the Minister in the co-ordination of development of policy relating to persons with disabilities;
2. to undertake, commission or collaborate in research projects and activities on issues relating to disability and to assist in the development of statistical information appropriate for the planning, delivery and monitoring of programmes and services for persons with disabilities.

In its first strategic plan “A Matter of Rights” for the period 2001 – 2003, the NDA identified its mission as follows “to work on behalf of the State to promote and help to secure the rights of people with disabilities through

influencing public policy and legislation and by working to ensure that services to people with disabilities are of the highest standards and quality.”

One of the major challenges to the successful achievement of our goals to promote quality in service provision is the lack of data on services presently available to people with disabilities. The Commission on the Status of People with Disabilities (1996) identified a number of difficulties regarding the then level of service provision, including a poor co-ordination of services, lack of information around service provision and entitlements, and the absence of an organised and integrated assessment of needs.¹ Monitoring the impact of government policy to promote the equal status of people with disabilities is a key challenge for government in the wake of acknowledged data deficit in Ireland.

In light of these concerns and in line with its statutory duties, the NDA identified the following objective as a priority for year 2002:

[to] “develop baseline quantitative and qualitative data to inform and underpin the planning and development of policy and services for people with disabilities in Ireland” (NDA, 2001a)

The Authority prioritised five key strategic areas for its work during the life of the first strategic plan (NDA, 2001). These policy areas include:

- education
- health
- employment and training
- income adequacy and
- transport

This report “Towards best practice in the provision of health services for people with disabilities in Ireland ” is one in a series of reports which presents research commissioned by the NDA in 2002. This series contributes to our strategic aims by providing much needed baseline evidence on the quantum and range of service provision in Ireland for people with disabilities and a review of international practice in the field against which to measure Ireland’s strengths and weaknesses in the sector. Each report in the series begins by providing an overview of the legislative and policy context for the provision of services and concludes with a discussion regarding gaps in service provision and makes recommendations to bring our service provision in line with best practice.

Dr Jane Pillinger was commissioned to undertake a review of health service provision for the NDA. We acknowledge her important contribution to our programme of work.

Dr Pillinger was asked to identify current and recent research in the field, and collate available information on the quantum and range of services currently available. She also set out to review the literature and survey providers to identify key legislation and policies underpinning the development of health

¹ This finding is reiterated in the recent report of the National Statistics Board (2003) Developing Irish Social & Equality Statistics to Meet Policy Needs, which reported that administrative data sources are limited in usefulness for a range of reasons, including definitional differences and incompleteness.

services in Ireland, and as far as possible, the range and quantum of health services, programmes, and measures available for people with disabilities in Ireland. Finally, Dr Pillinger provides a review of international good practice in relation to the quantum and range of service/programme provision for people with disabilities in this sector. The research involved a range of approaches, including desk research, interviews, surveys and consultation within the sector.

Findings include important successes in Irish health service provision, for example, increased representation of people with disabilities on decision-making bodies and involvement of disability service users in the planning, organisation and monitoring of services. However, there are key gaps in service provision, and critical areas for improvement in our health service system, policies and infrastructure are explored.

Dr Pillinger found broad international consensus on the trend towards provision of services within the framework of a social model of disability, but also difficulty in the speed of this transition due to a widespread historical and institutional reliance on a medical and welfare model of disability.

The NDA uses the World Health Organisation's definition of health:

- 'To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realise aspirations, to satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is positive concept emphasising social and personal resources, as well as physical capacities.' (WHO, 1998)

We recognise that health is determined by a broad range of factors, most of which are outside of the health sector. As acknowledged in the national health strategy:

'Social, economic and environmental factors (are) the main external or structural determinants of health. At an individual level factors *such as age, sex, hereditary factors and lifestyle choices are important.*' (Department of Health and Children, 2001e: 10).

This highlights the importance of social factors, health promotion and public health activity, as well as change in care and treatment services.

Towards best practice in the provision of health services for people with disabilities in Ireland is organised into five chapters:

- 1) Policy and legislation underpinning service provision, development, planning and monitoring
1. Range and quantum of services
2. International best practice in health and social care services for people with disabilities
3. Conclusions and key findings
4. Recommendations

Dr Jane Pillinger has collated and analysed substantial data from a range of sources. This overview is organised according to the eleven headline issues identified in her recommendations. It will provide a commentary on how these can inform the NDA as it enters its second strategic plan period 2004-2006.

As well as informing the NDA, we intend that this report would also be a resource for other agencies and sectors, which are progressing the government's policy of mainstreaming service provision for people with disabilities and reorienting services towards a social model of disability. Dr Pillinger has identified a number of key actors within and without the health sector who have a role in realising the recommendations that she has detailed. These include the Department of Health and Children, Health Boards, Advocacy Organisations, the Equality Authority, Comhairle, Local Authorities, the Irish College of General Practitioners, other government departments including The Department of Justice Equality and Law Reform and The Department of Foreign Affairs, Department of an Taoiseach and the Department of Social and Family Affairs, and statutory and non-statutory service providers.

We welcome the growing awareness of the experiences of people with disabilities and their families, carers and the greater understanding of their rights and health and social care needs. However, there is a very real concern - expressed by Dr Pillinger and shared by the NDA, about the extent to which this is translating into real change in people's lives and health.

Substantial action needs to be taken by all stakeholders to realise the mainstreaming of provision, reorientation of services towards a social model of disability, and inclusion of people with disabilities not only as active participants in their health care but in strategic decisions regarding the funding and planning of services.

Whilst progress has been made in the consultation of people with disabilities, we consider that the health sector needs to develop and resource sustained mechanisms for the involvement of disabled people that give equal respect and value to their expertise. We recognise that this will involve a shift in both organisational cultures and in individual attitudes, awareness and practices.

Data

The health service mapping has underlined the significant data deficit that, in the NDA's view, remains one of the most substantial barriers to progressing the development of provision for people with disabilities. Data collection appears to be a low priority within the health sector. The delayed publication of the National Health Information Strategy is of concern to the NDA. It is hoped that this will be a vehicle to build upon the existing data initiatives such as the Physical and Sensory Disability Database and the Intellectual Database and to address the continuing data deficit.

The mapping research has provided the NDA with useful information about the range and quantum of services and gaps in provision. Perhaps more useful has been the drawing up of an agenda of actions that are required to develop systematic, standardised and compatible data collection. Such data must be effectively utilised in policy development, service provision and workforce planning within and between health board areas. Evidence-based policy and service development in the statutory and non-statutory sectors would promote the strategic and equitable development of services for people with disabilities across the country and support transparent reporting.

Health service mapping

Dr Pillinger concludes that mapping in health boards is undertaken only to fulfil reporting requirements to the Department of Health and Children and for the development of specific strategies, reviews or needs assessment. Health service mapping is not routinely conducted and information is not gathered in a way which supports the development of a comprehensive picture of actual and emerging service needs of people with disabilities across the country.

The NDA considers that service mapping is an essential tool to progress the:

- development of evidence-based planning
- equitable funding of disability and mental health services
- mainstreaming of services for people with disabilities.

A key deliverable from this report is the development of a health service mapping template, that has been piloted in the Midland Health Board and ERHA. This is an important resource, which the NDA is interested in continuing to develop and refine through further pilots.

As well as information about the range and quantum of services, it is essential that accurate and timely information about funding is available. This report highlights the history of chronic under-funding of disability and mental health services, the changing requirements of services (community provision, new needs and the changing age profile of service users) and the increased and changing demands for services.

Service mapping is one way in which a case can be built for increased funding and also a means to promote transparency in how health funding is spent. Are the services that are being provided those which reflect the needs and aspirations of people with disabilities and their families / carers? Is funding being used to develop services including independent advocacy and those which support independent living? Is funding being used to address the significant attitudinal, communications, physical, co-ordination, information, participation and service barriers detailed in the report?

Service mapping is also a vital tool in tracking how the health sector is progressing the mainstreaming of service provision for people with disabilities. Dr Pillinger highlights that education, training, income support and housing services remain under the auspices of the Department of Health and Children. This further marginalises people with disabilities and prevents their full inclusion in society.

Disability policy development and the reform programme in health

In recent years the establishment of national agencies including the National Disability Authority, the Equality Authority, Comhairle, the Mental Health Commission and the Human Rights Commission have provided a number of routes to realising improvements in the lives of people with disabilities.

However, this report highlights that the many progressive policy developments in recent years, including *Strategy for Equality: the Report of the Commission on the Rights of People with Disability*, have yet to be realised in practice. A major challenge for the NDA, as the national statutory body on disability, is to

progress such policy commitments as mainstreaming the social and human rights model of disability.

This report is being published at a time of significant policy and organisational development. The reform programme in health, on foot of *Quality and Fairness*, *A Health System for You*, provides opportunities to:

- Introduce routine health service mapping
- Develop management information systems
- Resource effective participation mechanisms so that people with disabilities are decision-makers at all levels of health care
- Ensuring equitable provision
- Mainstream non-health functions
- Implementing standards and systems of inspection
- Build networks for sharing good practice and building collaboration
- Promote equality proofing of health care policies and provision.

Within health, the establishment of the Expert Group on Mental Health is a long awaited development, to which the NDA looks forward to contributing. We note the Northern Ireland Mental Health and Learning Disability Review 2002-2005 and consider that the simultaneous occurrence of these major initiatives in mental health provides scope for all-Ireland work, under the auspices of the Good Friday Agreement 1998.

Further, the publication of the Disabilities Bill will provide opportunities to progress cross-sectoral action on disability.

Service provision

Whilst the data gathered in the health service mapping is incomplete and has been difficult to validate, it has provided some important information about the diversity of provision in disability and mental health services in Ireland, highlighted through a range of good practice examples internationally and identified gaps in the types and levels of provision.

Concerns are raised about:

- The continued dominance of the medical model,
- The variations in provision across the health boards,
- The lack of choice and control available to people with disabilities,
- Inadequate and inappropriate provision, the poor co-ordination between sections of the health service, for example, between hospital and community.

The extent to which people with disabilities and their families and carers are unable to access health services in the first instance, and the large number of cases in which volunteers, disability organisations and family members / significant others have to plug service gaps is not considered acceptable by the NDA. Dr Pillinger reports that:

‘It is only when substantial care needs exist, or where there is an absence of family or informal care support, that services are provided...there are many people who are outside of the ‘care chain’ for whom no services are provided.’

Independent needs assessment should be available for all people with disabilities and the services, which are required, delivered as a right without being subject to the variables of service organisation or resources, or ability to pay.

Key messages, which will guide our stance on health care, are that people with disabilities want services that are delivered within a social model of disability, which promote independent living, are community based and are provided equitably. The provision of personal assistance and independent advocacy are minimal requirements. Further, services should be modern and informed by international standards of best practice.

While this represents a major task, we recognise that the health service mapping has identified innovative practices such as the piloting of peer advocacy within mental health services, moves towards longer term strategic planning, consultation of service users and the development of services tailored to the needs of particularly vulnerable groups for example homeless people with mental health difficulties.

Coordination and integration of services

Dr Pillinger considers that improved coordination and integration of services is vital if services are to become more community based and organised within a social model of disability. The report identifies the range of statutory and non-statutory service providers that could deliver services.

Rights and a social model of disability

There is government commitment to re-orient services towards a social model of service provision. This reflects calls from the disability sector through consultations including the *Strategy for Equality: Report of the Commission on the Status of People with Disabilities*, the *National Anti-Poverty Strategy*, *Quality and Fairness: A Health System For You: Health Strategy* (2001a) and most recently, the report of the Disability Legislation Consultation Group (DLCG), *Equal Citizens: Proposals for Core Elements of Disability Legislation*, (2003).

The NDA has advocated an understanding of disability based on the social model, articulated in its strategic plans 2001-2003, 2004-2007. The strategic plans state the NDA's core belief in a rights based approach, realised through the pro-active adoption of a civil and human rights perspective in the development of policy and practice for people with disabilities that will:

- Ensure that the needs and rights of people with disabilities are enshrined in all aspects of Irish life
- Promote the empowerment of people with disabilities and their participation in decisions that affect their lives
- Underpin the promotion of an inclusive vision among all constituencies in Irish society.

Quality developments and standards

Health is the first sector in which the NDA has begun to deliver on our statutory remit for the development of standards. In collaboration with the Department of Health and Children (DOHC), we are piloting National Standards for Disability Services that we hope will be finalised and launched in 2004. The NDA welcomes the establishment of the Mental Health Commission and looks forward to working with the Commission on the development of national standards for mental health services.

The report highlights significant concerns, expressed particularly by organisations representing people with disabilities, about the quality, transparency and lack of independent advocacy within services in the statutory and non-statutory sectors. In addition to our own work on National Standards for Disability Services and the anticipated collaboration with the Mental Health Commission, the NDA looks forward to contributing to the work of the Health Information and Quality Authority.

However, the NDA notes the growing number of agencies, which have quality and standards roles. There is a need for dialogue between these agencies to deliver:

- 2) Clarity in each agency's discrete role in order to avoid duplication and territoriality
1. Commitment to collaboration
2. Added value for people with disabilities who are using health services

The efforts of these agencies must deliver service improvements that have a positive impact on service provision, services users' experiences and take-up of services, and ultimately the health of people with disabilities.

Awareness raising, training and guidance

Organisations representing people with disabilities have reiterated the continuing attitudinal barriers in health care including patronising and unaware front-line staff. This was first reported in the *Strategy for Equality: the Report of the Commission on the Status of People with Disabilities (1996)*.

Awareness raising is essential to the building of organisational and individual capacity to deliver the range of services that will enable people to live independently.

The NDA has commenced work on the development of a Code of Practice for disability awareness training and will continue to support the strategic development of good quality disability / equality awareness raising.

This is part of a wider agenda of effecting attitudinal change in Irish society. The NDA has created baseline information through its research into attitudes towards people with disabilities and started to map mental health promotion activity focussing on attitudinal change through its Mental Health Advisory Committee, identifying issues for policy and practice. During its second strategic plan period, the NDA will continue to prioritise attitudinal change through the identification of effective models of good practice.

Information accessibility

Health service information is rarely available in formats that are accessible to people with disabilities. This limits people's understanding of what services are available and how to access them and it raises questions about:

- 3) Whether the uptake of disability, mental health and general services by disabled people is an accurate reflection of real need,
1. The quality of informed consent to treatment that is being secured.

The NDA has developed good guidance on the provision of accessible information and will continue to disseminate this. The Programme for Prosperity and Fairness (PPF, 2000) contained a commitment that each Government Department would undertake reasonable steps to make its services and those of agencies under its remit accessible to people with disabilities. Under this commitment NDA has been given the tasks to develop guidelines, to monitor progress in the achievement of accessible public services and to award an accessibility symbol to compliant public services. The NDA recently issued guidelines in relation to electronically delivered services (IT Accessibility Guidelines, www.accessit.nda.ie) and the built and external environment, entitled *Building for Everyone* (2002c).

User involvement and participation

User involvement and participation remains limited in the health sector, although there is now a greater awareness of the importance of developing effective forms of participation. The NDA has published the *Ask Me* (guidelines for the consultation of people with disabilities 2002). The NDA's vision is that people would be involved in decision-making at all levels of health care both as service users and workers. We support the continued development of innovative practice in this area and seek to learn from international activity. As a relatively new organisation the NDA is both advocating for the inclusion of people with disabilities through resourced, respectful and sustainable mechanisms and learning how it can develop its own practice in this area.

Equality, equal status reviews and disability proofing

The NDA has consistently sought to promote the rights of people with disabilities within the broader equality agenda. We recognise both the diversity of disabled people and the importance of creating solidarity between the equality grounds. Initiatives such as the development of integrated equality proofing, the piloting of Equal Status Reviews and the development of Health Impact Assessment have the potential to systematically assess and address the equality issues within service provision. The NDA will continue to pro-actively contribute to these and other equality developments.

Conclusion

The NDA endorses the goals of the national health strategy, which include "better health for everyone, fair access, responsive and appropriate care, and high performing health services". This report aims to support and inform the current programme of reform of the health services to ensure that new

systems, policies and infrastructure are established, as far as is possible, in line with available evidence on the provision of equitable, effective health services for people with disabilities.

Introduction

This report is based on research to map the range and quantum of disability health services in Ireland. This mapping exercise also identifies the policies impacting on disability health services as well as addressing international good practice. The mapping exercise is intended to help with the development of a knowledge base in the area of disability health services, including a better understanding of the gaps in services and emerging issues. This is intended to contribute to the development of standards in disability services. As part of this mapping exercise two detailed mapping exercises have been carried out in the Midland Health Board and the Eastern Regional Health Authority. These are the subject of separate reports, although some of the issues raised in these mapping exercises that are of relevance nationally are discussed.

This report is organised into five chapters that deal, first, with the national policy context impacting on disability health services, second, an overview of the mapping of the range and quantum of disability health services, third, a discussion of international good practice. A final chapter makes a number of recommendations for the future development of disability health services.

This health mapping research takes place against the backdrop of significant and emerging changes in health services for people with disabilities. This is in the light of rising expectations and increasing criticism of disability services in Ireland marked by the withdrawal of the Disability Bill in 2001 and a number of high profile and critical reports on disability services. The shifting orientation of health service policy is signalled in the health strategy *Quality and Fairness* (DOHC, 2001a) and other key health service policies with a trend towards community based provision and person-centred services. In addition disability organisations in Ireland are looking to international best practice as a way of shifting the focus of disability services into a rights based approach and towards a social model of disability.

Despite the fact that the health mapping shows some progress in health and social care service improvements there are still major gaps in services, inappropriately delivered services and significant gaps in data. For example, despite the shift in orientation towards community based mental health services, recent criticisms of mental health services in Ireland show their failure to provide appropriate residential accommodation and community based services for people with mental health difficulties. A number of recent consultation exercises also confirm the general dissatisfaction with and absence of comprehensive health services for people with disabilities. This includes submissions made to the Health Strategy consultation, to the Working Group on Health for the National Anti-Poverty Strategy, and to the Disability Legislation Consultation Group. Other recent research on disability services (Burke and Pillinger, 2003) highlight many of these problems.

Significant criticisms of conditions in mental hospitals have been made regularly by the Inspector of Mental Hospitals (DOHC, 2001) resulting in the

recent establishment of a project team to draw up plans for a modern forensic psychiatric service that is responding to revelations of hospital conditions that were described by the Minister for Health as “very, very grim”, suffering from “historic neglect” and with “unacceptable” standards of care (Irish Times, 20.2.03). Similarly, a recent high profile report on mental health services in Ireland by Amnesty International (2003) states that Ireland has failed to recognise good mental health care as a human right, that psychiatric services have been seriously under-funded and neglected, and that the treatment of people with mental health difficulties is part of wider discrimination of people with disabilities. In particular there is an absence of services for children, homeless people, prisoners and other vulnerable groups such as Travellers. In particular the Amnesty report is critical of the fact that up to 10% of the population will at any time have mental health difficulties, yet the budget for mental health services is only 7% of the total health budget (with funding falling from 9.4% of total health funding in 1994 to 7.2 % in 2001).

Services for people with physical, sensory and intellectual disability have also been the subject of recent criticisms regarding absence of gaps in home, day, residential and respite services, poor quality services and inappropriate services.

A recent report on the Hospitaller Order of St. John of God Services in St Mary's, Drumcar, County Louth for people with physical, intellectual and mental health disabilities, highlighted the problems of inadequate staffing and inappropriate care provision for people with disabilities including unstaffed provision at night where people are locked and straight jacketed and inappropriate care regimes (Irish Times 27.01.03).

The Health Boards themselves have been through a significant learning phase in recent years by responding to many of the deficits that exist in health services and in developing more person-centred approaches. This is reflected in recent service plans and annual reports and an increasing focus on longer-term disability strategies, reviews and action plans drawn up with and for people with disabilities. The introduction of service planning as a tool for strategic management has helped the process of identifying service needs, reviewing health board positions against the objectives set out in the previous service plan, identifying priorities and key objectives, and putting in place mechanisms for monitoring progress and evaluating effectiveness (Butler and Boyle, 2001).

This is also a significant time of change in health service organisation and provision. The reform programme in health, that follows the Brennan and Prospectus reports, is set to introduce some major changes in the structure and organisation of health services as well as more modern approaches to the planning, management and quality of health services. In addition, the framework set out in the Health Strategy *Quality and Fairness* (DOHC 2001a) for more equitable, people centred, quality driven and accountable services, along with planned new disability legislation, will all impact on disability health services. In addition, at the European and international levels there are moves towards anti-discrimination and civil rights approaches to disability that are driving and shaping new thinking about the social model of disability, user

participation and the mainstreaming of disability. This in turn is impacting on thinking about new ways of delivering services.

CHAPTER I: POLICY AND LEGISLATION UNDERPINNING SERVICE PROVISION, DEVELOPMENT, PLANNING AND MONITORING

1.1 *Introduction*

This chapter identifies the policy and legislation underpinning service provision, development, planning and monitoring. It covers the following:

- The organisation of health services in Ireland
- Key legislation
- Health policy
- National health policies and strategies
- Specific Policies Impacting on Health for People with Disabilities
- Other government policies/legislation that (may) impact on disability and health
- Quality, monitoring and evaluation

Appendix 1 provides a list of legislation and policy documents relevant to disability and health.

The disability policy and legislative framework in relation to health has a number of dimensions to it. On the one hand, there are a large number of general health policies that impact directly or indirectly on health service planning and provision for people with disabilities. On the other hand, there are specifically targeted services for people with disabilities. There are some issues relevant to the broader national policy context, which have relevance to the provision of health services for people with disabilities. These include key issues concerning the coordination and integration of services, policies to tackle poverty and exclusion, and measures to improve the quality and delivery of services. Finally, people with disabilities are also included as one of the nine grounds in the Irish equality legislation (Employment Equality Act, 1998 and the Equal Status Act, 2000). The European (EU and Council of Europe) and international (United Nations and World Health Organisation) drivers that are also shaping disability policy and thinking in Ireland are discussed in Chapter 5 which explores international best practice.

Although attention will be given to issues of access to primary, secondary and tertiary health care services that are accessed by people with disabilities, a specific focus will be given to disability support services provided specifically for people with disabilities.

1.2 *The organisation of health services in Ireland*

Health services include the range of health and personal social services, which are overseen and funded nationally by the Department of Health and Children and provided, funded or enabled regionally by the health boards.

The health boards² provide a range of health services for people with disabilities, including assessment, rehabilitation, income maintenance, community care and residential care. This also includes a range of community, residential and rehabilitative training services that are funded by the Department of Health and Children or the Health Boards and provided by voluntary hospitals and organisations.

Services for people with disabilities include: residential care services (physical and sensory disabilities), support and development services (physical and sensory disabilities), services for deaf people, services for visually impaired people, services for persons with intellectual disability, mental health services (psychiatric hospitals, psychiatric units, community accommodation, day services, personal assistance, bereavement counselling and support, mental health support groups).

Each board must develop an annual service plan, which outlines how the board is planning and delivering health services. This covers areas such as resource allocation, inter-organisation co-operation, multi-sectoral co-operation and implementing government policy. Service plans identify priority areas and needs. The health boards are divided into divisions or programmes that focus on the following main areas of service provision:

- *Primary health care, public health and health promotion* (covering GP services and health centres, public health services, health promotion and information, public health nursing services, dental and ophthalmic services).
- *Community health and personal social services* (services for people with disabilities, mental health services, services for older people, day centres and day care, community care and community services).
- *Special Hospital Services* (Acute Psychiatric Hospitals and Units, Addiction and Alcoholism services, Intellectual Disability Services).
- *General Hospital Services* (Acute hospitals, maternity hospitals, out patient services, ambulance and transport services, pharmacy).

The Department of Health and Children has dedicated units that develop, plan, coordinate, monitor, evaluate and plan services for people with disabilities, including resource allocations and liaison with health boards:

- Physical and Sensory Disability Services Unit
- Intellectual Disability Services Unit
- Mental Health Services Unit
- Services for Older People Unit

In addition, one-off working groups focus on specific issues. At the time of writing a Working Group on Child and Adolescent Psychiatric Services had been established. Specific services have also been developed in areas such

² There are ten health boards which provide a range of health and personal social services. The Eastern Regional Health Authority provides an umbrella for planning and coordinating health and personal social services in three Area Health Boards (Northern, East Coast and South Western), the Voluntary Hospitals and Voluntary Intellectual Disability Agencies in the region. The remaining seven Health Boards (Midland, Mid Western, North Eastern, North Western, South Eastern, Southern and Western) provide and arrange health and personal services at a regional level.

as service for people with autism, suicide prevention and counselling as a result of national working groups.

1.3 The reform programme in health

On 18 June 2003 the Government announced a major reform programme for the Irish health services. This is considered to be the most extensive reform programme in over 30 years. The focus of the reform programme is improved patient care, better value for taxpayers' money and improved health care management. This is considered to be necessary to create modern and responsive health services that are able to deliver on the health strategy (see policy section below) and the increasingly complex demands placed on the health care system. This is particularly important for disability services, which are often fragmented and poorly planned due to a range of management, organisational and resource problems.

The reform programme will cover all areas of the health system and draws on the findings of two reports which recommended the development of a new national management structure and the introduction of new financial accountability procedures. First, is the Commission on Financial Management and Control Systems in the Health Service (the Brennan Commission), which concluded that there is substantial scope for improving the efficiency and productivity of the health system so that there is better value for money and more effective use of resources. It recommended new financial accountability procedures. Second, is the Audit of Structures and Functions in the Health System (Prospectus report), which recommended the development of a new national management structure. The report concluded from its audit of services that there was a need for significant reform of health services and improved planning and management of services.

The two reports show that the current system is ineffective, cumbersome and fragmented. They recommend, first, that rationalisation, standardisation and improved co-ordination are needed to overcome fragmentation. Second, that more clarity is needed about roles and decision-making. Third, effective planning processes must ensure that people are at the centre of care by linking needs assessment, planning of services, funding and activity.

In summary the key reforms are:

- A major rationalisation of existing health service agencies, including the abolition of the existing health board structures and the consolidation and amalgamation of the existing 32 agencies.
- Establishment of a Health Service Executive to manage and deliver the health service as a single national service. There will be three core parts to this. An interim National Hospitals Office will reform the hospital sector; the Primary, Community and Continuing Directorate will manage non-hospital services and there will also be a National Shared Services Care Centre.
- The Primary, Community and Continuing Care Directorate is to deliver regional and local non-hospital services through the establishment of four regional health offices and 32 local health offices.
- Reorganisation of the Department of Health and Children, to ensure improved policy development, oversight and evaluation of service delivery.

- Establishment of the Health Information and Quality Authority to ensure quality and effectiveness of care.
- Devolution of responsibility for budgets to the people in charge of delivering services.
- Modernisation of service planning and management processes to improve planning and delivery of services.

1.4 Key legislation

The following provides an outline of the main features of legislation impacting on disability and health:

Mental Health Act 2001

The Mental Health Act was passed in 2001 and has not yet been fully implemented. It covers a range of issues regarding the detention of psychiatric inpatients and inspection of approved centres. Most significant is the establishment of the Mental Health Commission. In summary it covers the following:

- New rules on admission to psychiatric care and procedures for the involuntary detention of people in psychiatric care and treatment.
- Changes in the legal rights of psychiatric patients.
- An independent review process for all involuntary detentions.
- Establishment of a Mental Health Commission as an independent statutory body to promote high standards and good practices in the delivery of mental health services and to protect the interests of people who are detained for psychiatric care and treatment.
- A Register of Approved Centres (hospitals or other in-patient facilities for the treatment of people with mental illness).
- Establishment of mental health review tribunals.
- Establishment of an Inspector of Mental Health Services.
- The Minister will make regulations on standards in approved centres in consultation with the Mental Health Commission. Standards will cover: accommodation; maintenance, care and welfare; staffing; maintenance of register of residents and records; and information.
- The legislation will be reviewed in 2004.

The Mental Health Commission was established with effect from 5 April 2002; reviews of detention will commence in 2003 and registration of approved centres will be completed by 2004.

National Disability Authority Act, 1999

- Established the National Disability Authority with responsibility for coordinating and developing policies for people with disabilities and advising the Minister of developments in disability policy and practice.
- The Authority is made up of a chairperson and twenty ordinary members the majority of whom are to be people with disabilities, their families or carers.
- Functions include undertaking research projects and activities to

contribute to the development of statistical information for the planning, delivery and monitoring of programmes and services for people with disabilities.

- Development of standards for programmes or services provided for people with disabilities; act as an advisory body for the development of general and specific standards, and monitor the implementation of standards.
- Preparation of codes of practice.
- Development of and provision of disability equality awards system.
- Drawing up of three yearly strategic plans and annual reports.

Health (Eastern Regional Health Authority) Act, 1999

- Established the ERHA as a body overseeing the three area health boards (Northern, East Coast and South Western).

Health Amendment Act (no 3), 1996

- Established the requirement for health boards to draw up and adopt service plans and monitor these.

Health Act, 1970

- Established the current structure of the health service, with the eight health boards that were given statutory responsibility for the delivery of health services in their regions. The Act established the Department of Health's direct involvement in health policy.

Health Act, 1947

- Established the Department of Health

It is likely that additional legislation will be implemented as a result of Quality and Fairness including legislation that defines core specialist mental health services and core disability support services.

1.5 National health policies and strategies

In recent years health policy has been shaped by the following key policy documents relating to the provision and evaluation of national health policy. These are briefly reviewed for their focus and impact on disability services:

- Quality and Fairness – A System for You, 2001
- Primary Care: A New Direction, 2001
- Acute Hospital Bed Capacity. A National Review, 2000
- The National Health Promotion Strategy, 2000-2005
- Reports of the Chief Medical Officer, 1999 and 2000

Quality and Fairness – A System for You

The government's health strategy, *Quality and Fairness*, covers policy, planning and activity and follows the 1994 health strategy *Shaping a Healthier Future*, which put in place a range of initiatives aimed at increasing equity and access of services for disadvantaged groups, including people with disabilities

and older people. The Department of Health and Children carried out a comprehensive consultation process to inform the development of the health strategy and sought views from professionals, users and the public about the future of the health system in Ireland (Department of Health and Children, 2001). *Quality and Fairness* outlines the vision, principles, national goals and frameworks for change necessary to develop and sustain such a health strategy within the following framework: strengthening primary care; reform of acute hospital system; funding; developing human resources; organisational reform; and information.

A large number of recommendations are made that impact on disability, including recommendations for the development of Health Impact Assessment (HIA), a Rehabilitation Strategy, a Cabinet Committee with responsibility for health, measures to address inequalities in health, including inequalities faced by people with disabilities. There are many actions recommended which should lead to better services and greater equality for people with disabilities. The principles of the policy are particularly relevant to people with disabilities and are important to underpinning the setting of standards in health care:

- Equity (people treated fairly according to need and targeting of health inequalities);
- People centeredness (a health system that identifies and responds to the needs of individuals, with co-ordinated planning and delivery, and participation of individuals in decision-making to improve their health);
- Quality (through the creation of evidence based standards set in partnership with consumers and externally validated; and the valuing of continuous improvement);
- Accountability (financial, professional and organisational accountability for better quality, efficient and effective health services).

The goals outlined are equally relevant to people with disabilities and include:

- Better health for everyone;
- Fair access;
- Responsive and appropriate care;
- High performance.

Each goal has a number of objectives and each objective has a range of actions necessary to achieve the objective and goal. These are outlined in an action plan with the deliverables, target date and responsibilities for the implementation of the actions. However, there are no provisions to address the inequalities, raised by many disability organisations, which exist in access to, experience of and outcomes from health service provision resulting from the two-tier health service. *Quality and Fairness* (DOHC 2001a) addresses socio-economic inequalities in health by endorsing the measures outlined in *Working Group on National Anti-Poverty Strategy and Health*.

[Specific recommendations concerning people with intellectual disability, people with physical and sensory disabilities, and people with mental illness are discussed in more detail below under *Specific health policies for people with disabilities*].

Primary Care: A New Direction, 2001

This strategy for Primary Care in Ireland states that primary care is the appropriate setting to meet 90-95 per cent of all health and personal social service needs. It makes the arguments for the centrality of primary care to the health system and why a properly integrated primary care service can lead to better health outcomes, better health status and better cost effectiveness. Twenty actions are proposed for the implementation of the Primary Health Care Strategy, including mechanisms for quality assurance. An implementation plan is also set out. The plan places an emphasis on a new comprehensive model of primary care that meets clients' needs in more integrated ways, including co-ordination between primary and hospital services. An overview of the provision of primary care and specialist services intellectual disability services, physical/sensory disability services, specialist services for the elderly, and mental health is recommended. Disability awareness is to become a core component of staff orientation and training and primary health care centres are to be accessible for people with disabilities.

Acute Hospital Bed Capacity: A National Review, 2002

This policy documents lays out a plan to increase capacity of acute hospital service provision in Ireland. This is a central component of government policy to reduce the current gap in inequality of access to acute public and private hospital services. When achieved it will increase equity of access for all public patients. There are no specific measures in place to ensure that people with disabilities benefit from increased capacity.

The National Health Promotion Strategy, 2000-2005

The National Health Promotion Strategy identifies the specific health needs of men, women, children, older people, and the impact of socio-economic status on health. Emphasis is also placed on developing positive mental health with a strategic aim to "promote positive mental health and to contribute to a reduction in the percentage of the population experiencing poor mental health". Actions in mental health include:

- Research into models of best practice in mental health promotion,
- Research into the development of a national positive mental health strategy
- Partnership work to support the implementation of the recommendations of the Report of the National Task Force on Suicide.

The strategy is important in a disability equality context and has wide-ranging and inclusive principles, approach and recommendations. Recommendations include:

- Multi-sectoral partnerships to contribute to health promotion actions
- Community action in health promotion, collaboration with statutory bodies, local development agencies and the mainstream NGO sector, community capacity building to ensure the participation of marginalised groups
- Health proofing as a key mechanism to ensure healthier public policy development

- An inter-sectoral National Health Promotion Forum is recommended with wide ranging representation.

Reports of the Chief Medical Officer, 1999 and 2000

The First Report from the Office of the Chief Medical Officer (CMO) in 1999 focused on the issue of socio-economic inequalities in health. It concluded that 'commitment to the identification and alleviation of health inequalities must be at the centre of strategic plans in the coming years. It argues that this approach, along with investment in health, will enhance the health and social gain of the population (Department of Health and Children, 2000). This has important implications for people with disabilities. The 2000 Report of the Chief Medical Officer focused on *The Health of Our Children* and highlights the various aspects of the health status of children and the services that have been put in place to serve Irish children's health needs (see below under *Children with Disabilities*).

1.6 Specific Policies Impacting on Health for People with disabilities

A Strategy for Equality and Towards Equal Citizenship

A Strategy for Equality, the report of the Commission on the Status of People with Disabilities (1996) highlights the needs and rights of people with disabilities to co-exist in a framework of independence and support. The report highlighted a number of problems including the inaccessibility of health services, the centralisation of key services in Dublin, the unpredictability and under-funding of community services such as home helps and respite care, as well as widespread lack of disability awareness and of a clearly defined complaints procedure. The Commission proposed a wide range of measures that were necessary to enable people with disabilities to exercise their rights for the fullest participation in economic, social and cultural life, as well as to report on the adequacy of services to meet their needs.

An extensive consultation process took place with people with disabilities. The report was highly critical of many of the social barriers, negative attitudes and poor quality and outmoded services, which created social barriers and marginalisation. The absence of services in the health and social care field were highlighted in the report "...people with disabilities, parents and carers have serious concerns as to the quality of some existing services, and about the lack of some fundamental services" (1996:161).

The Commission's recommendations included the establishment of the National Disability Authority to oversee the implementation of new legislation for people with disabilities and a Disability Support Service providing advice, advocacy and support. Progress in meeting the recommendations is monitored in *Towards Equal Citizenship* (1999). In the area of health issues (chapter 10) that arise for consideration include:

- Accessibility of hospitals and other settings
- Liaison between hospital and community services for children with disabilities

- Disability awareness training for staff, research on technical aids and equipment
- Expansion of the home help scheme and respite care services
- Personal assistance services and peer support for deaf people
- Additional funding for services for people with disabilities
- Special units for continuing therapeutic care
- National standards for services for people with disabilities in the community
- Rights of patients and patient advocacy
- The need for health boards to review services with regard to equity, accountability and quality of services.

The report also details the areas where action has been taken to meet the Commission's recommendations.

Specific policy and service developments for people with disabilities

The Department of Health and Children is implementing the recommendations of the Commission on the Status of People with Disabilities and various other health strategies in a variety of ways. Below are the key policy developments (Appendix 1 provides a more comprehensive list of policy):

People with intellectual disability

- The report *Needs and Abilities* (Department of Health, 1990) outlines the main service developments to enable people with an intellectual disability to live in their local communities with support services to meet their needs.
- Health Board Coordinating Committees for services for people with intellectual disability have been established and they include representatives of the health boards, voluntary agencies and clients/parents.
- The 1994 Health Strategy led to the establishment of the *Intellectual Disability Database*, which was introduced in order to identify unmet needs, provide a service planning tool and a mechanism for monitoring progress. In addition, various services were developed for specific groups of people with intellectual disability.
- *Quality and Fairness* (DOHC, 2001a) goes further in identifying new investment to increase capacity through an expansion of community based services for people with intellectual disabilities and support services for people with autism, including an information database on the numbers of persons with autism and their service needs. By the end of 2002 the following commitments had been made under *Quality and Fairness* (DOHC, 2001a):
 - €38 million for existing services and identified needs
 - €25 million for the development of new services (100 new residential places, 75 new respite places, 600 new day places, support services, transfer from inappropriate placements)
 - €1.27 million under NDP for ongoing capital projects

People with physical and sensory disabilities

- The report of the Review Group on Health and Personal Social Services for People with Physical and Sensory Disabilities, *Towards an Independent Future* (Department of Health and Children, 1996) identifies service developments in this sector in line with the recommendations of the Commission.
- The 1994 Health Strategy led to the provision of extra facilities for day care, respite care, home care and personal support services, as well as additional funding for residential care/ independent living.
- Since 1998 a Coordinating Committee for Physical and Sensory Disability Services has existed in each health board area to advise on the development of services. Voluntary organisations as well as service users are represented on the Committees.
- The piloting of the National Physical and Sensory Disability Database.
- Quality and Fairness (DOHC, 2001a) proposes an action programme of investment in care services, training and multi-disciplinary support services. By the end of 2002 the following commitments had been made under *Quality and Fairness* (DOHC, 2001a) for services for people with physical and sensory disabilities:
 - - €47 million in home support and personal assistance services, therapy services, 100 additional posts, 500 rehabilitative training places (action 55)
 - - Preparation of a national policy for the provision of sheltered work for people with disabilities (action 35)
 - - National Physical and Sensory Disability Database

People with Mental Illness

Mental health policy and activity in the health boards is being shaped by the following key national policy developments

- A Strategy for Equality
- Quality and Fairness – A Health System for You
- Strategy for Primary Care
- Working Group Report on Child and Adolescent Psychiatry (2001)
- Working Group on Psychiatric Services for Adolescents aged 6-16 years
- National Task Force on Suicide

The 1994 Health Strategy placed a particular focus on the development of services that would enable people with mental illness to have “as independent and normal life as possible”. This reflected the objectives set out in the 1984 report *Planning for the Future* on the basis that services should be comprehensive, integrated with other health services, based in the community and organised locally.

A National Task Force on Suicide was established in 1995 in order to make recommendations about how suicide could be addressed. *The Report of the National Task Force on Suicide* (1998) led to the setting up of a Suicide Research Group with funding for suicide prevention programmes in the health boards.

Quality and Fairness (DOHC, 2001a) includes a programme of new investment to increase capacity in community care services and acute psychiatric units; the creation of the Mental Health Commission as part of the implementation of the 2001 Mental Health Act; and a new national policy framework to modernise mental health services. In 2003 a Mental Health Review Committee was established as one of the commitments in *Quality and Fairness* to review mental health services nationally.

In 2002 additional revenue funding of €24.447 million was provided for improvements in mental health services, including community based services, hospital services, child and adolescent psychiatric services, old age services, suicide prevention programmes, and the voluntary sector.

Quality and Fairness also establishes regional advisory panels/co-ordinating committees, with participation of statutory and non statutory service providers and consumers, in all health board areas for people with mental illness to advise on planning, quality and promotion of positive mental health initiatives. By the end of 2002 the following commitments were made for mental health service provision:

- Acute psychiatric units linked to general hospitals had resulted in a total of 18 acute units in place (action 55) and 10 units at various stages of development.
- €10.5 million was allocated to community based services and multi-disciplinary teams (action 55)
- €0.251 million for the mental health advocacy service (action 25).
- €1.11 million for suicide prevention and research (action 25)
- €1.11 million in assistance for voluntary bodies
- €6 million for the Child and Adolescent Psychiatric Service
- €1.8 million for Old Age Psychiatry Service

The *National Health Promotion Strategy* (DOHC, 2000) sets out three objectives in relation to mental health: research into models of best practice in mental health promotion, the development of a national positive mental health strategy and work in partnership to support the implementation of the recommendations of the *Report of the National Task Force on Suicide* (DOHC, 1998).

Overall, *Quality and Fairness* has made provisions for specific disability services and a range of new measures, which are rooted in the principles of fair access, responsive and appropriate care delivery and high performance. These include a statutory framework for the Disabilities Bill that provides for needs assessment and provision of services, an integrated approach to care planning and support for community and voluntary activity. An additional €250,000 has been provided for a one-year pilot awareness programme. Specific additional initiatives are outlined for people with intellectual disability or autism, physical and sensory disability and mental health.

Older People With Disabilities

Policies related to disability in old age can be found in *The Years Ahead – A Policy for the Elderly* (1998). This identified four key objectives for health policy for older people in the provision of coordinated and comprehensive

services that would help to maintain older people in dignity and independence in their own homes and provide a range of home support, hospital and residential care for older people.

Quality and Fairness has recommended an action plan be drawn up to coordinate the needs of ageing and older people. This has been welcomed by older people's organisations as contributing to a more coordinated approach to older people's health needs and is an example of what could be achieved for other groups. User involvement through regional advisory panels is also recommended. Other initiatives include the implementation of an action plan on dementia, the implementation of the 1998 *Health Promotion Strategy for Older People* by the health boards and the promotion of volunteerism for the provision of local support services.

Children With Disabilities

There have been various national initiatives that have touched on the importance of the health of children with disabilities. The issues highlighted in *The National Children's Strategy*, *The Adolescent Health Strategy*, *Best Health for Children* and *the Health of Our Children* are reflected in Chapter 6 and Actions 8, 9, 14, 25 and 27 of *Quality and Fairness*.

- *The National Children's Strategy, Our Children – Their Lives* (Department of Health and Children, 2000) provides an integrated framework as well as the policy context for all new initiatives for children including the priorities and actions outlined in the new health strategy. Emphasis is placed on community based responses, prevention and early intervention and integrated supports and services. The strategy sets out three goals: children will have a voice; children's lives will be better understood; children will receive quality supports and services. For example, the strategy states that "Children with a disability will be entitled to the services they need to achieve their full potential" This reinforces provisions set out in the UN Convention on the Rights of the Child (Articles 23 and 24).
- *The Adolescent Health Strategy* (National Conjoint Child Health Committee, 2001) is based on the national conjoint health committee appointed by the CEOs of the health boards. It highlights the need to tackle inequalities, the need for a whole child perspective, issues concerning mental health and data. It states that adolescent friendly services requires there to be accessibility of services, flexibility in service delivery, appropriate staff skills and training, quality information and partnership working.
- *The Best Health for Children - Developing a Partnership with Families* (National Conjoint Child Health Committee, 1999) also outlines the ways to foster and improve coordination between health boards and parents. Specific emphasis is placed on children with disabilities.
- The 2000 Report of the Chief Medical Officer on *The Health of Our Children* highlights the various aspects of the health status of children and the services that have been put in place. It stresses the need for greater emphasis on prevention and promotion and a more integrated, child centred and holistic approach in order to meet the increasing complex needs of children and adolescents. It prioritises areas for action including

mental health and disability and a number of broader policy issues are identified in relation to the reduction in health inequalities for children. It places the health needs of children and the role of the health sector in supporting children's lives in the context of the *National Children's Strategy* (Department of Health and Children, 2000).

- The *Report of the Review Group on Child and Adolescent Psychiatric Services* recommended new service developments to meet the needs of children in two areas of treatment: Deficit Hyperactivity Disorder and Hyperactivity Kinetic Disorder as part of comprehensive child and adolescent psychiatric services, multidisciplinary teams and closer links between education and community health.

Women With Disabilities

In recent years the greater emphasis on women's health initiatives has resulted from an awareness of women's specific health needs as well as a greater awareness of disabled women's needs. *A Plan for Women's Health* (DOHC, 1997) led to the creation of the *Women's Health Council* and women's health initiatives at health board level. The Plan sought to enhance the health and social gain of women, make health services more women-friendly, and improve the consultation and representation of women in health services. In 1999 funding was earmarked for Health boards to enable them to implement the recommendations of the Plan. Regional Women's Health Advisory Committees now exist in each health board. They are required under the Plan to prepare and implement regional plans for women's health. A review of *A Plan for Women* will be published in 2002. Further recommendations concerning health services and women with disabilities can be found in *A Plan for Women* (Department of Justice, Equality and Law Reform) (2001) drawn up follow on from the Beijing Platform for Action and the Irish *Commission on the Status of Women*, 1993.

1.7 Other government policies/legislation impacting on disability and health

The Strategic Management Initiative and Delivering Better Government

The Strategic Management Initiative and *Delivering Better Government* are important to the broader disability policy context. Government Departments are required to produce Strategy Statements, annual Business Plans and bi-annual Customer Service Action Plans. These plans have been produced by the Department of Health and Children with commitments to improved customer services and a greater focus on equality and diversity and disability access.

The Strategic Management Initiative and particularly *Delivering Better Government* make a strong case for reorientation of services so that they become more responsive to customer needs by improving quality, accountability and efficiency of services. Quality Customer Service now incorporates the principle of Equality/Diversity as one of three new principles, alongside a commitment to improve disability access to public buildings. This

reflects the attention given to providing better quality services for the internal and external customer by taking account of disability within an equality context so that service can become more equal, responsive and inclusive. The development of equal status standards and equal status policies for government services is one way forward for the development of a more integrated equality focus to the delivery of services that could positively impact on equality across the nine grounds in health. Relevant recommendations can be found in *Equality/Diversity in Quality Customer Service* by Jane Pillinger, published by the Department of the Taoiseach, (2001).

Equality Legislation

Disability also sits within an equality policy context. The Equal Status Act (2000) prohibits discrimination in the area of goods and services on nine grounds (gender, marital status, family status, sexual orientation, religious belief, age, disability, race, membership of the Traveller community). Government services, including those provided by health boards, are covered under the Act although certain exemptions apply. The Act also covers disability access and requires an employer, a person providing goods or services, accommodation, educational institutions and clubs to do all that is reasonable to accommodate the needs of an employee or a person with a disability by providing special facilities or treatment. They are not obliged to do this if the special facilities or treatment involves more than the nominal cost. The Act allows for positive action to promote equality of opportunity for disadvantaged persons and to cater for the special needs of persons or a category of persons who may require facilities, services or assistance. The Employment Equality Act (1995) covers the same nine grounds in relation to employment. It covers part-time and full-time workers and includes access to employment, conditions of employment, training, promotion and dismissal in the public and private sectors. The new equality directives from the European Union will further impact on equality.

National Anti-Poverty Strategy, Health Working Group

The Working Group on NAPS and Health placed an emphasis on a rights based approach with an objective of making inequalities in health central to public policy and political development, including equity of access to acute health services; meeting the needs of specific groups; and consultation and participation in decision-making. The Working Group agreed targets for reducing socio-economic health inequalities, promoting equity of access and ensuring that public policy on health is developed through multi-sectoral working and Health Impact Assessment. NAPS is of great importance to people with disabilities since many people with disabilities live in poverty. The targets which seek to improve the health of people who are poor or excluded and improve their access to, experience of and outcomes from health and personal social services is therefore of significance. Target 11 of the new Anti-Poverty Strategy contains a number of recommendations for the introduction of an equality dimension into health and personal services by 2007.

1.8 Information and data issues

A major problem is the availability of reliable and disaggregated information about the health or health needs of people with disabilities. For instance, *The National Health and Lifestyle Surveys* contain information on health and lifestyle behaviour of adults and children by age, gender and social class only (Department of Health and Children, 1999).

The *Intellectual Disability Database* and the *Physical and Sensory Disability Database* go some way to closing this information gap required for service planning. Because of the voluntary nature of the databases the information contained in the databases is not comprehensive of all needs since it relies on those who are in contact with people with disabilities to provide information. The databases are compiled at health board level and these feed into the national databases, which are analysed and operated within the Health Research Board.

Making Knowledge Work for Health, A Strategy for Health Research was published in June 2001 by the Department of Health and Children and provides a framework for the development of health research to enhance health and quality of life and has much relevance to disability. It emphasises a partnership approach to developing a thriving research culture in the health services. The core proposals in the strategy are for a strengthening of support for scientific research for health and the development of innovative research and development function in the health services. It is envisaged that each of these strands are mutually supportive. It outlines that a health research strategy is needed as a key factor in promoting health, combating disease, reducing disability and improving quality of care; that research is vital if health services are to become more efficient and effective; and that more health research can help achieve other government objectives.

Quality and Fairness (DOHC, 2001a) also places a strong emphasis on research and information. One of the frameworks for change is information, which aims at improving performance by supporting quality planning and evidence based decision-making in the health system by:

- Appropriate, comprehensive, high-quality, accessible and timely information on which to plan and organise the health system
- Investment in national health information systems as set out in the forthcoming National Health Information Strategy
- Development of electronic health records to enhance the quality and safety of care.

It also outlines how good information systems will support equity of access. An independent Health Information and Quality Authority will be established on an independent statutory basis and will have responsibility for:

- Developing health information systems
- Promoting and implementing structured programmes of quality assurance
- Reviewing and reporting on a selected set of services each year
- Overseeing accreditation and developing health technology assessment.

Quality and Fairness (DOHC, 2001a) further outlines the role of the National Health Information Strategy, which will be designed to promote:

- Ready access to good quality information about health and personal social services and health matter for the public, patients, health professionals and administrators, managers and policy makers
- Best use of information and communication technology to improve operational service delivery and the responsiveness of services
- Evidence based decision making and planning processes
- Evaluation of real service impact of investment decisions
- A greatly enhanced appreciation of the role of information in improving health, including the importance of healthy lifestyles
- Education and training to ensure knowledge is exploited efficiently to the benefit of all
- Faster more effective communication across all sectors concerned with health.

Other initiatives on data and information include:

- In the area of data, information and evaluation *The Report of the Working Group on NAPS and Health* (2001) details three targets, which were recommended so as to focus on the development of indicators, research, monitoring and review.
- Department of the Taoiseach and Department of Finance Steering Group on Social and Equality Statistics, set up in Spring 2002 with a view to reporting within a six-month time frame.

1.9 Assuring, monitoring and evaluating quality in health

An increasingly important role is now placed on assuring, monitoring and evaluating quality in health service provision. There exist a wide variety of mechanisms for monitoring and evaluation from the monitoring of financial returns (from Health Boards to the Department of Health) to the development of standards and quality in Health Boards and hospitals and developmental work undertaken by the National Disability Authority. There has been a Cabinet committee established to monitor the implementation of *Quality and Fairness* (DOHC, 2001a). Inspectorates have also been established in the areas of children's residential services (under the Social Services Inspectorate) and Inspector of Mental Hospitals.

The most important developments in the area of monitoring, evaluation, accreditation and quality improvement are:

- The *Irish Health Services Accreditation Board* (IHSAB) was created by statutory instrument and is an independent body whose purpose is to establish and continuously review and operate an Accreditation scheme for the Irish health services. The objective is to establish independent assessment against a set of national standards. The accreditation process operates through self-assessment, peer review, and a framework of healthcare standards. It operates on a voluntary basis for hospitals in Ireland and evaluates patient care, support services, leadership and partnership initiatives against the national standards.
- The *Irish Society for Quality and Safety in Healthcare* (ISQSH) has been established to lead the continuous improvement of quality and safety in health care through a network of provision in education, research and

training, dissemination of international models for quality, projects and the development of quality standards. ISQSH is a member based organisation

- The creation of the *Health Boards Executive* (HeBE) is important to the quality and change agenda in health. HeBE was established by statutory instrument and is an independent body. In particular, HeBE will work in networks, collaboratively and across boundaries to support good practice, information sharing and innovation and embed innovation into health services through pilot projects. *Best Health for Children* is an example of good practice established by HeBE to coordinate child health and welfare. No specific collaborative pilot projects have been established on people with disabilities.

Specific disability health service standards have also been emerging in recent years. The development of a more user-focused and quality driven health services for people with disabilities has been driven by *Quality and Fairness* (DOHC, 2001a) and the National Disability Authority's standards project.

Standards are already well established through the Social Services Inspectorate, under the 1991 Child Care Act, and represent good practice that could be established in other residential provision for people with disabilities. Standards developed by the National Disability Authority for disability services in the health sector, FÁS standards for education and training for people with disabilities, and standards of care drawn up by NAMHI are helping to drive the equality agenda. Examples of standards are:

- National Disability Authority has a National Standards pilot project which is implementing and monitoring a set of draft National Standards for Disability Services. The standards were established as a result of an extensive consultation with disabled people and disability organisations. Twenty service providers piloted the standards in 2003. An assessment process and an audit tool have been developed and an evaluation of the pilot will be undertaken in 2003. The standards cover day, residential, training and home support services for children and adults with physical and sensory disabilities, intellectual disabilities and/or autism.
- FÁS has instituted its own standard for the provision of training to people with a disability, the FÁS Standard for Training and Development of People with Disabilities (QA00/01). The standard—which was originally developed by the National Rehabilitation Board (NRB)—allows training providers to measure, and have recognised, the quality of services they offer. Following a decision by FÁS, the Department of Health and Children and the Health Boards, the new standard applies not only to training for people with a disability funded by FÁS but also by the Health Boards. The process of assessing and accrediting organisations providing training to people with a disability against the new standard is the responsibility of the National Accreditation Committee (NAC). The Committee, which was set up in 1996 and which operates under the aegis of FÁS in conjunction with the Health Boards, has produced guidelines for service providers to assist in the process of obtaining accreditation against QA00/01.
- NAMHI Standards of Care (1999) are based on a set of principles that should underpin high quality and person-centred service provision for people with an intellectual disability. The standards cover Service Philosophy and Policy; Admission and Discharge; Administration, Human

Resources; Environment; Medical; Service Delivery; and Complaints and Appeals Procedures.

1.10 Conclusion

This section has shown the legislative and policy context that is shaping disability services. A key issue in the development of policy is that disability health services have largely remained within a medical model, with limited resources being coordinated or provided for independent living and a social model of disability. This is not surprising given the location of disability support services within a health policy framework and despite attempts to deliver more person-centred services and a social model of disability as signalled in the Commission on the Status of People with Disabilities. Nevertheless, the development of more person-centred approaches to policy, a better policy coverage of disability issues and challenges, and a relatively new focus on disability equality under the equality legislation are important to new thinking in disability service delivery. In addition, the development of a more quality focused health service, alongside the development of specific standards for disability services is a welcome development. However, it will be important to ensure that future activities on standards and quality are coordinated between those that are directed towards mainstream health provision and those that are disability specific. This will be particularly important in the context of the health service reform programme.

Chapter 2: The range and quantum of services

2.1 Introduction

This chapter provides an overview of the range and quantum of health services for people with disabilities in Ireland and covers:

- The context within which health boards are operating and a discussion about some of the data and methodological issues in the research.
- An overview of the main national data, including information on the budget for services which can assist in health mapping, that is available nationally covering mental health services, services for people with physical and sensory disabilities and people with intellectual disability. It highlights data gaps and gaps in services where these have been identified.
- An overview of the main disability support health services provided by a selection of health boards. It also outlines strategies, reviews and needs assessments undertaken by health boards to identify gaps in services and areas where services need to be re-oriented.
- Information about non-statutory service providers and reports on mapping exercises that have been undertaken or planned of services provided by non-statutory providers.
- Conclusions from the mapping exercise are checked back against feedback from disability organisations and user organisations. Reference is also made to other consultations that have taken place recently on health care.

Mapping exercises in the Midland Health Board and the Eastern Regional Health Authority

The health mapping research involved a more detailed mapping of disability and mental health services in the Midland Health Board (MHB). A review of relevant health board literature was undertaken and a mapping framework was circulated to health board and non-statutory service providers providing services to people with physical and sensory disabilities and intellectual disability. In order to facilitate this mapping exercise a Steering Group of disability service staff from the Midland Health Board was established to assist with the mapping exercise. A more detailed report of the mapping exercise carried out in disability services has been produced. Some summary issues are presented in this report.

An additional mapping exercise undertaken in partnership with the Eastern Regional Health Authority (ERHA) involved consultations with the Regional Provider Forum, Physical and Sensory Disability Coordinating Committees of the three area health boards, and Disability Federation Ireland. As a result of these consultations further refinements to the mapping questionnaire have been made, particularly concerning non-medical services. The mapping exercise is geared to provide a detailed map of services, as well as an exploration of gaps in services and emerging issues facing the area health boards, voluntary providers, disability support and advocacy organisations. The objective is to have a map of services that can be matched against the service requirements identified in physical and sensory disabilities database. A database has been developed for the data collected in the health mapping exercise and this will help service planners in the ERHA and the three area health boards to effectively identify services, gaps in services and emerging issues in a more coordinated way. In addition, a focus group of disabled service users was held with the ERHA that fed into an EU funded project of the European Social Network on managing diversity and anti-discrimination in health and services across Europe. This focus group sought feedback on disability health and social services. An evaluation of the process involved in establishing a mapping exercise will be undertaken, with the three area health boards, voluntary providers and user advocacy and support groups, when the exercise has been completed. The mapping exercise is utilising the mapping framework that has been developed for this research for the more detailed mapping exercise in the Midland Health Board. □

Disability health services: recent developments

Disability services, including mental health services, have been through some recent and significant changes, most notably:

- The de-institutionalisation of mental health services from acute in-service hospital care to specialist psychiatric care and community based care.
- A shift in emphasis from an exclusively medical model of health to one that recognises the importance of a social model of health.
- The greater inclusion and participation of mental health service and disabled service users in the design and delivery of services and the corresponding emphasis in health service policy on consumer-orientated services.

Further, the principles laid out in *Quality and Fairness* (DOHC, 2001a) concerning equity, people centeredness, quality and accountability have particular relevance to the provision of services in a non-discriminatory and inclusive way. In particular:

- The principle that underpins policy is to enable each individual to achieve his or her full potential and maximum independence, including living within the community as independently as possible (Department of Health and Children, 2001: 141).

Quality and Fairness outlines the following provisions for people with disabilities:

- *People with intellectual disabilities*: expansion of residential care places, more day, community, respite care and support services; complete the programme to transfer people with an intellectual disability currently in psychiatric hospitals to appropriate accommodation not later than the end of 2006, and investment in support services for people with autism.
- *People with physical and sensory disabilities*: a programme of investment in home support services, respite care, day care, residential care, training and other multidisciplinary support services.
- *Mental health*: a new action programme on mental health, expansion of Mental Health Services for children and adolescents, expansion of suicide prevention programmes, investment in Acute Psychiatric Units and Community Care services including community nursing, day centres, day hospitals, training and work programmes and family support.

A review of recent health board Service Plans carried out for this research shows a greater emphasis on these principles in service planning and strategic development. In some cases plans are made against international best practice established by the United Nations and the World Health Organisation.

Data issues

Health mapping is not routinely carried out by health boards and where health mapping has taken place it has tended to be related to existing reporting requirements and/or to the development of board strategies, reviews or needs assessments that have been undertaken on disability services. For this reason this report draws on a variety of data and information sources in order to provide the most comprehensive map of services to date.

A key outcome from the mapping research is the significant data and information gaps that exist regarding services for people with disabilities. This has implications for the planning and commissioning of services and in providing appropriate and timely care. This data is also important to measure the contribution made to the health, social gain, independence and participation for people with disabilities, and, in the light of international best practice, the increasingly important focus now given to rights, autonomy and participation.

The main data issues and problems can be summarised as follows:

- One of the major barriers to conducting a detailed mapping exercise is the lack of accessible, relevant and comparable data. This is exacerbated by

the absence of a national and uniform system for data collection across the statutory and non-statutory providers.

- Most health boards do not have management information systems in place to enable them to draw down relevant data and information. In the majority of cases the data has to be drawn down manually.
- Data collection is not uniform across the health boards. Some health boards collect more data than others and there are difficulties in comparing services where different definitions for services are used by different providers in the non-statutory and statutory sectors. NAMHI (2000) is one of many user organisations arguing for improved transparency of data and information. They also argue that the lack of available information on the current position does raise the issue of the need for standardised information across all health boards.
- During the course of this mapping exercise difficulties in accessing information were compounded by three issues. First, in some cases appropriate data is not held, for example, regarding waiting lists, and admissions and attendances broken down by new and return attendances. Similarly, budgetary information is not desegregated and broken down according to service and function. Second, Directors of Disability Services and Care Managers had limited resources (information, time and human resources) to be able to respond to the requests for information. Third, there was little buy-in with the health boards about the purposes and role of the health mapping exercise and for that reason some health boards saw limited direct relevance of the health mapping to their work. In other cases, however, the framework produced as part of the research generated a great deal of interest in initiating the undertaking of health mapping in the longer term.
- Return of data to the DOHC in mental health is currently provided annually, although in physical and sensory and intellectual disability quarterly returns are now in place. In addition, it is anticipated that more regular reporting of data on mental health services on a quarterly basis to the HRB will have greater impact on service delivery and planning (Daly A and Walsh D, 2002).
- Information collection in hospitals and other community facilities is not a high priority for service providers and medical personnel do not regularly return diagnostic information
- Unreliability of data returned to the DOHC is an issue of concern. For example, the HRB raised the issue of the reliability of data for community psychiatric services in all health board areas, particularly because of the wide variations between the health boards. For example, it is not possible to provide a breakdown of new and return attendances for outpatient clinics or diagnostic information regarding information on people attending outpatient clinics, day hospitals and day centres. The HRB also report difficulties in gaining data from health boards reported in their census and activities report of psychiatric services (HRB, 2002).
- Staffing levels in the mental health and disability health sectors are not disaggregated from total medical staffing levels, except in the cases of staffing in mental health hospitals and hospitals and homes for people with an intellectual disability. The DOHC's personnel census does not

disaggregate personal data into specific disability services. However, research has shown that there are significant gaps in staffing in disability services. This includes an estimated 102% increase in physiotherapists, a 159% increase in occupational therapists and a 328% increase in speech and language therapists required by 2015 (Bacon, 2001). Similarly, there are no agreed statutory guidelines on staff-client ratios as exist, for example, in the UK.

It is anticipated that the quality and accuracy of data collection will improve in the light of the provisions found in *Quality and Fairness*, the forthcoming health information strategy (2003), the reporting on the recently revised (2003) performance indicators for physical and sensory disability and intellectual disability, and the establishment of the Mental Health Performance Indicators Working Group. Health boards and the DOHC are aware of data limitations and recognise the importance of more systematic, comparable and uniform information and data for the change agenda in the provision of quality disability services and in the development of more accountable, consumer-orientated quality services.

Performance indicators for people with disabilities

Despite progress made in the area of equality proofing and in disability specific data collection under the *Programme for Prosperity and Fairness*; (Department of an Taoiseach, 2000) limited impact has been made on the data gaps that exist and their impact in areas such as disability proofing and data on health service utilisation and health status. Nevertheless, there are a number of developments in progressing performance indicators for people with disabilities that are revealing new data requirements.

- The NDA has drawn up a set of equality proofing indicators which “provides a starting point for thinking about this complex issue of data disaggregation and collection in relation to people with disabilities and the further identification of performance indicators for measuring progress in relation to equality” (2002:4). Performance indicators cover six areas, one of which is health.
- In the area of health related support services the DOHC has also, in consultation with health boards, agreed a set of performance indicators for 2003 for physical and sensory disability and intellectual disability. The 2002 performance indicators were poorly reported on and no systematic reporting schedule was put in place by the DOHC. A similar process has been put in place for performance indicators on mental health. These performance indicators can be found in Appendix 2.

2.2 Health mapping methodology

In most cases the health boards have not carried out detailed mapping exercises themselves because of limited data and information resources and low prioritisation of this activity. Moreover, there is difficulty in capturing relevant and comparable information and data in health board published reports, particularly Service Plans and Annual Reports. Some health boards have undertaken needs analysis or gap analysis, others have embarked on

small scale mapping exercises, whilst others have undertaken some mapping as part of the development of regional disability strategies.

The health mapping research revealed the need for, and, in some cases, highlighted the possibilities for undertaking a mapping exercise using the framework developed for health mapping. This framework was discussed with a number of health boards and non-statutory organisations and was considered to be a useful tool that could be adapted to board priorities for future mapping exercises. Many health boards see this as being crucial for identifying future service needs, in undertaking service planning and also gaining more detailed information than is currently required by the DOHC. In the light of the problems and gaps the mapping framework was drawn up to test the extent to which data is available in the different areas for which information was sought and also to test the validity and relevance of the different information sought. The three frameworks developed can be found in Appendices 3, 4 and 5.

The framework served four main purposes:

- To provide a framework for the detailed mapping of the range and quantum of services, including gaps in services, emerging issues and plans for service developments (ERHA and MHB).
- To identify the range of services, by way of overview, in other health boards, including any specific developments in services and gaps in services
- To test and pilot the framework for its usability and relevance to health boards and non-statutory providers, and to ensure that all relevant areas were captured.
- To identify data and information gaps.

The framework attempted to map existing services in the areas of physical and sensory disability, intellectual disability and mental health and sought the following information:

- Is the service provided?
- Service provider
- Location of service
- Budget
- Funding source
- Staffing (whole time equivalents)
- Source of referrals
- Waiting list in place
- Average waiting list times
- Numbers of waiting list
- Numbers using the service (by age group)
- Number of places or sessions (by age group)
- Other services provided
- Gaps in services
- Emerging issues
- Plans for 2003

Three questionnaires were drawn up using this framework and these sought to capture information about the following services.

i) Services for people with mental health support needs

Mental health community based services

- Day centres
- Residential care
- Community Residences / Group Homes
- Respite care
- Psychiatrist
- Community mental health nursing
- Occupational therapy
- Social work
- Community alcohol and drugs service
- Opiate treatment and addiction counsellors
- Counselling for adult survivors of institutional abuse
- Suicide prevention services
- Mental health promotion
- Mental health services for people with intellectual disability
- Mental health services for older people
- Child and adolescent mental health services
- Other services for specific groups
- Needs assessment / individual care plans
- Advocacy service
- Rehabilitative training
- Sheltered workshops
- Vocational training
- Housing support
- Transport services (including taxis)
- Other services

Mental health hospital based services:

- Day hospitals
- Psychiatric hospitals
- Acute psychiatric hospital wards
- Admission / Assessment Unit
- Rehabilitation Services
- Long Stay Residential Services
- Activation and Recreational Therapies Para-medical services

ii) Services for people with physical and sensory disabilities

- Occupational therapy
- Physiotherapy
- Speech and language therapy
- Social work
- Psychology

- Counselling
- Public Health Nurse
- Hospital in-patient
- Day services / day centres
- Residential services
- Planned respite
- Emergency respite
- Planned home-based respite
- Emergency home support
- Summer camps (day/residential)
- Holiday respite placement
- Personal assistance
- Home help
- Peer support
- Sign language interpretation
- Sign language training
- Library support (Braille, large print etc)
- Sighted guide
- Other services
- Individual needs assessment / care plan
- Advocacy services
- Rehabilitative training
- Sheltered workshops
- Vocational training
- Transport services (including taxis)
- Other

iii) Services for people with an intellectual disability or autism

- Day centres / day services
- Residential care
- Psychiatric hospital
- Community residencies / group homes
- Respite care
- Holiday and residential placements
- Crisis and relief care with a family
- Occupational therapy
- Physiotherapy
- Speech and language therapy
- Social Work
- Psychologist
- Counsellor
- Therapy
- Public Health Nurse
- Nutritionist
- Autism services / supports

- Services for people with dementia
- Other services for specific groups
- Individual needs assessment / care plan
- Advocacy services
- Rehabilitative training
- Sheltered workshops
- Vocational training
- Transport services (including taxis)
- Other services

As a result of the piloting of the questionnaire in the ERHA further additional questions were added concerning non-medical supports, information, help lines, home support, family support, peer support, individual support and advocacy. This has helped to ensure that the mapping questionnaire documents social as well as medical supports.

The mapping framework has been used as a framework for the detailed mapping exercise being undertaken for ERHA Physical and Sensory Disability Services (under the aegis of the ERHA's Regional Rehabilitation Forum). During the course of the research similar expressions of interest for a more detailed mapping exercise have been made by other health boards, the Disability Federation Ireland and the Not-For-Profit Business Association. It would be timely for there to be more collaboration on health mapping between service providers, the DOHC and the health boards.

Some methodological issues were raised in developing the framework. These principally concerned the need for clear definitions of services that are uniform and agreed by providers and service users. At times the questions were too simplistic to adequately capture the true range and quantum of services. For example, one question was asked on advocacy services, but did not define the range of activities (including legal advocacy, peer advocacy, professional advocacy, advocacy training for staff or for peers etc). Some services are more complex than at first appears to be the case, whilst some services are only just being developed. This is a particularly difficult issue in capturing new and emerging services. Nevertheless, the framework does represent the most detailed attempt to map services to date and its testing and piloting will be of interest to future mapping exercises and in highlighting existing data gaps.

A key issue is the need for coordination between the various mapping exercises that have been initiated. The NDA could convene a working group of health boards, the DOHC, service providers and disability organisations to agree a framework and protocol for health mapping. This could lead to common definitions of services, for information and data gaps to be highlighted, and for service providers to develop more accountable and uniform reporting.

Definitions

The definitions used of services in this mapping exercise can be found in Appendix 6. Although there are differences in definitions of services between statutory and non-statutory providers and within the statutory services themselves, these definitions tend to be the most widely used. For the

purposes of this study, health services refers to the range of health and personal social services provided for people with disabilities and mental health difficulties, funded by the state and provided by statutory and non-statutory providers, regionally or nationally.

However, it is less easy to define the broader goals and policy outcomes of health, well-being and social gain that are the cornerstone of recent national and international policy on health. The Disability Federation of Ireland (2001) have outlined the impact disability can have on health including: reduced income, the greater demands on that income (extra costs of disability), increased incidence of other disability / disabling condition / illness, lack of early access to acute and rehabilitative services, lack of access to personal social services, worry about the future, stress on relationships, becoming effectively locked out of normal social activities, and a sense of being on one's own. Being aware of these wider dimensions of health and well-being is critical to any future mapping exercises because of the importance now attached to the rights of service users, consumer-orientated and community based provision of person-centred services.

2.3 *National data and information*

This section examines the data and information that is available at the national level that can provide useful background data for health service mapping, first, for mental health services and second for disability support services for people with physical, sensory and intellectual disability. It also identifies information about the range and quantum of services and gaps in services that have already been highlighted from the data.

Budget for mental health and disability services

Funding for disability services has been increasing year-on-year since the 1990s with significant injections of new funding. Up to 2003 there was relatively rapid expansion resulting for new injections of funding to address severe gaps in health funding and provision. An expansion of services, the development of new services and higher levels of funding were recommended in the report of the Commission on the Status of People with Disabilities (1996) in order to develop services within a social model of disability and meet needs.

Funding for disability health services, 1997-2002

In summary, between 1997 and 2001 disability services expanded in the following areas:

- Additional funding of €2.26 million for long term residential care and residential respite care, providing 51 additional long-term residential places and 95 additional respite places.
- €19.68 million revenue funding provided home support and personal assistance services.
- Additional ongoing development funding of €5.785 million has led to the creation of an additional 100 physiotherapy, occupational therapy, and speech and language therapy posts.
- Grants totalling €29.62 million have provided aids and appliances for people with physical and sensory disabilities.
- Additional funding was made available for priorities identified by health boards/regional authority of €3.78 million in 2001 and €6.38 million in 2002.

Between 1997 and 2002, there has been additional capital and revenue funding for intellectual disability and autism services of €327 million resulting in:

- 1,700 additional residential places, mainly community based (including new residential respite places for 1997 and 1998).
- An additional 465 dedicated respite places provided between 1999 and 2002.
- An additional 2,950 new day places.
- Alternative placements, new accommodation or enhanced levels of service for people with intellectual disability or autism residing in psychiatric hospitals or inappropriate placements.³
- Funding of €14.6 million, since 1998, for early intervention, pre-school and multi-disciplinary support services for children with intellectual disability or autism.
- Additional funding of €11.43 million for health boards to provide a range of support services for people with an intellectual disability or autism who present with major behavioural problems.

Table 1 shows the overall upward trend in non-capital funding available for mental health and disability services since 1990. Between 1997 and 2002 this had resulted in a 74.5% increase in funding for mental health services and a 145.7% increase in funding for disability services. As a proportion of overall health funding mental health services have received a declining share of resources from 10.6% of total health expenditure in 1990 to 6.8% in 2003.

³ In October 2002 this figure was 452, down from 571 in 2001 and 970 in 1996.

Disability services have fared better, rising from 9.6% of total health expenditure in 1990 to 12.5% in 2003.

In 2003 health boards were operating in a more uncertain economic climate with the reductions in public finances having implications for the delivery of health services for people with disabilities. This meant that both the range and quantum of services was largely unaltered in 2003. The 2002 Report of the Independent Estimates Review Committee to the Minister of Finance made it clear that the rate of growth of expenditure in health could not be sustained⁴. In the launch of the Book of Estimates November 2002, the Minister of Finance stated that attention should be focussed “on the value we are getting in terms of the quality and quantity of public services” rather than on the creation of new services. For this reason the health boards have been forced to control expenditure and new staffing and deliver “value for money”. In some disability services there have been some moderate increases in expenditure for new service developments and to address immediate service pressures in 2003. Table 2 identifies the levels of additional funding provided for new services such as day, respite and residential places and shows the significant reductions in new funding for this provision in 2003.

Despite an expansion in funding since 1997, the 2003 budget provided for the maintenance of existing levels of service. Between 1997 and 2002⁵ additional funding for health funded support services for people with disabilities has totalled €507 million. The 2000 Budget introduced a significant injection of new funding for intellectual disability services. The three-year plan provided additional revenue funding of £28 million for new services in 2000 and a three-year capital funding programme of £80 million from 2000 onwards. This was a significant increase in funding for new services (which had stood at £7 million in 1997 and £12 million in 1998).

Estimates for non-capital expenditure on all health services totalled €8593.496 in 2003 (representing 7.82% of GDP). The proportion of GDP being spent on health care has risen slightly from 7.72% in 1980, 5.78% in 1990, 6.09% in 2000, and 7.53% in 2002. However, waiting lists continue to grow in part as a result of the changing age profile of people with intellectual disability or autism. The birth rate in the 1960s and 1970s has resulted in a cohort of adults in their 20s and 30s requiring full time residential services, whilst people with an intellectual disability are living longer and using services more. Improved nutrition, health and well-being, the control of infectious diseases, and the move to community living have all contributed to longevity. The HRB conducted a review of waiting lists between 1997 and 1999 and found that while 269 people from the original waiting list of 1,439 had received full time residential care, the list had grown by an additional 238 places (HRB, 1999).

In the area of services for people with autism, the 1994 report *Services for People with Autism* placed an emphasis on early diagnosis, paediatric assessment, provision of mainstream education, regular speech and language therapy, support for families, respite and in-home support, home based

⁴ Health expenditure grew from €3.7 billion in 1997 to an estimated €8.9 billion in 2003.

⁵ Announcement made by Tim O'Malley TD, Minister of State at the Department of Health and Children

programmes, staff training, a national diagnostic centre and regional diagnostic clinics, database for people with autism and coordinated services. A particular issue has been the shortage of speech and language therapists. Between 1998 and 2000 additional funding of €5million was provided for support services for children with autism. A further €3.5 million was provided in 2002 (full year costs) to further enhance services for children with autism and intellectual disability.

Between 1997 and 2002 an additional €180 million has been provided for services for people with physical and sensory disability. This includes residential, respite and home support services, which include personal assistance, therapy services and day care services. €20 million has been provided for home support services and a further €71 million for capital projects and technical aids and appliances. The 2003 budget for services for people with disabilities resulted in no allocation for new services and places in 2003. On 11 February 2003 a Private Member's Motion (Tim O'Malley TD) called on the government to allocate an additional €35 million for new places in the current year and agreed a plan with national bodies representing people with disabilities to eliminate waiting lists on all essential services within three years.

Overall, services for people with disabilities account of approximately 12% of all health board non-capital health expenditure, whereas mental health services represent approximately 7% of non-capital health expenditure.

Table 1: Non Capital Health Expenditure, 1990, 1995, 2000, 2001, 2002, 2003 (estimated)

	1990 €000m	1995 €000m	2000 €000m	2001 €000m	2002 €000m
Total Health Service Expenditure	2.000.980	3.105.421	5.610.340	7.010.050	8.166.738
Mental Health Services	214.017	289.312	433.654	497.061	563.690
Total Mental Health Services	214.017	289.312	433.654	497.061	563.690
Mental health services as a % of total health expenditure	10.6	9.3	7.7	7.0	6.9
Disability services: intellectual disability					
– Care in special homes	124.709	204.554	378.899	455.629	516.892
– Care in psychiatric hospitals	29.204	40.698	51.713	55.965	63.404
– Care in day centres	12.527	25.405	49.557	59.914	67.966
Disability services: physical and sensory disability	2.552	4.200	6.434	6.523	9.176
– Assessment and care of the blind	787	1.148	2.298	2.369	5.499
– Assessment and care of the deaf	18.465	31.653	95.451	148.471	206.694
– Assessment and care of people with other disabilities	4.660	19.607	67.211	87.038	93.301
Rehabilitation services					
Total Disability Services	192.904	209.405	651.562	815.909	962.932
Disability services as a % of total health expenditure	9.6	6.7	11.6	11.6	11.7

Source: Department of Health: Non-Capital Expenditure 1990-2002; Estimated Non-Capital Expenditure, 2003

Table 2: Capital expenditure in mental health and disability services, 2001

Capital expenditure, 2001	Health board €000	Voluntary €000
Mental health	17,450	441
Disability services	57,658	0

Table 3: Additional funding set out in letters of determination to Health Boards based on service plans, 2002 and 2003, and population in each health board. Non-capital funding (€ million)

	ERHA	MHB	MWHB	NEHB	NWHB	SEHB	SHB
Population 2002	1.401.314	225.588	339.930	344.926	221.376	423.450	580.
Percentage of population in health board	35.8%	5.8%	8.7%	8.8%	5.7%	10.8%	14.8
Mental health services							
2002	7.736	0.590	2.345	2.217	2.214	4.305	3.73
2003	2.235	0.720	0.700	0.760	0.650	0.775	0.79
Services for people with an intellectual disability/autism							
2002	13.408	2.063	2.132	2.243	1.777	2.876	2.75
2003	4.000	0.800	1.130	1.120	0.800	1.600	1.50
Services for people with physical/sensory disabilities							
2002	12.086	1.882	2.505	1.473	2.867	1.982	4.69
2003	6.775	0.948	1.199	1.202	0.897	1.653	1.81
Rehabilitative training and sheltered occupational services,							
2002	3.558	0.874	0.966	0.857	1.038	1.076	1.27
2003	0.277	0.185	0.137	0.136	0.308	0.349	0.42

Source: Letters of determination Health Boards, 2002 and 2003; Department of Health and Children Health Statistics 2002; Central Statistics Office Census 2002 Preliminary Report

2.4 Mental health services

Data on mental health services

At the time of writing the most recent data on mental health services was data up to 31 December 2001. This data can be found in:

- Report of the Inspector of Mental Hospitals, 2001 (for the year ending 31 December 2001)
- Irish Psychiatric Hospitals and Units Census, 2001
- Activities of Irish Psychiatric Services, 2001 (includes National Psychiatric In-Patient Reporting System and In-Patient Census, 2001)
- Annual Reports of health boards, 2001

Key developments in services

There has been a gradual decline in the numbers in psychiatric institutions and a gradual increase in the psychiatric units in general hospitals. For example, general hospital units either opened or were due to open in 2002 at Ennis General Hospital, St Luke's Hospital, Kilkenny, Mayo County Hospital,

Castlebar and Portlaoise general hospital, with other psychiatric units planned in other parts of the country. The general policy in mental health care to shift provision to general hospitals has resulted in an increasing number of admissions (40% of all admissions at the end of 2001) and it is anticipated that the numbers for 2002 will have risen substantially. However, the Inspector of Mental Hospitals 2001 report highlights problems about the uneven development of community-based residential accommodation across the country.

The *Value for Money Audit of the Irish Health System* by Deloitte and Touche (2001) identified a range of factors contributing to and limiting value for money in mental health services. These issues are summarised below:

Contributing to Value for Money	Limiting Value for Money
<ul style="list-style-type: none"> • The development of Guidelines on Good Practice and Quality Assurance in Mental Health Services and the development of the Mental Health Bill • Regular and timely data provision through the Report of the Inspector of Mental Health Hospitals and the National Inpatient Reporting System • The transfer of patients from psychiatric units to dedicated units in general hospitals – although progress has been slower in some regions than originally anticipated, 	<ul style="list-style-type: none"> • The lack of a coordinated approach to measuring quality outcomes and costs which is partly attributable to the lack of a standard methodology for the codification of costs • Limited data on attempted suicide and para suicide • Limited facilities and infrastructure for specialised services. However, deficiencies have been defined and initiatives are being implemented • The inadequate provision of psychiatric services to the criminal justice system (although improvements are planned and are ongoing • A deficit in community residential accommodation resulting in the inappropriate use of acute psychiatric beds • Regional variations in non-residential services and the provision of rehabilitation services.

In summary

- There has been a decline in psychiatric in-patients and a corresponding increase in community mental health services. Psychiatric inpatients fall from 4,331 in 1997 to 3,833 in 2000.
- The number of people attending day centres has risen from 4,992 in 1998 to 5,231 in 2000.
- The numbers attending day hospitals increased from 14,406 in 1997 to 17,516 in 2000.
- Psychiatric out-patient attendances dropped from 230,189 in 1997 to 218,912 in 2000.
- Community residencies grew from 383 residencies providing accommodation for 2,807 to 392 residencies providing accommodation for 2,934 people (a small increase of 104 per 100,000 population in 1997 to

109 in 2000).

There are very few, if any, national measures of mental health or well-being. Admission to psychiatric hospitals and usage of mental health services is used as a proxy in health policy but is in fact just an indicator of acute mental illness rather than mental health and well-being. In 1999, there were 25,062 admissions to Irish psychiatric hospitals of people aged 16 and over which is a rate of 930 per 100,000. More than one in four adults suffer from mental illness at some point in their lives and 25% of families will have a member who suffers mental illness. It is estimated that 10% of the population suffers from depressions and 1% from schizophrenia. (Department of Health and Children, 2001a: 34).

Numbers in psychiatric care and receiving mental health services: data for 2001

Inpatients

4,256 patients were resident in psychiatric hospitals (statutory and non-statutory) and acute psychiatry units (representing a residency rate of 157.9 per 100,000 population aged over 16 years). Figure 1 shows this gradual decline in in-patients from 19,801 in 1963 to 4,256 in 2001. There has been a corresponding increase in community services and community residencies. For example, day services for people with mental health support needs grew from 100 places in 1990 to 179 places in 2000 (Health Research Board, 2002).



Figure 1: Irish psychiatric in-patients 1963-2001.

Source: Health Research Board (2002)

Table 4 provides information about the numbers of in-patients and beds by health board area. Regarding diagnosis: the largest admissions were for Schizophrenia (37%), followed by depressive disorders (18%), and intellectual disability (14%). The highest in-patient rates were found in the SEHB (rate of 237.7, with 271 beds per 100,000 population); lowest in SWHB (rate of 36.1, with 40.0 beds per 100,000 population). 42% of patients were in hospital for five years or more.

Admissions

Figure 2 and Table 4 provide a breakdown of admissions by hospital type; health board hospitals (44%), general hospital psychiatric units (42%) and private hospitals (14%). There has been a gradual increase in the number of admissions to psychiatric units in general hospitals in line with national mental health policy and the plans in place for additional psychiatric units in general hospitals suggest that this trend will increase over the next few years.

Table 4: Health Board Area. In-patients and beds. Ireland 2000-2001.

Numbers with rates per 100,000 population aged 16 years and over.								
In-patients					Beds			
	2000		2001		2000		2001	
	Number	Rates	Number	Rates	Number	Rates	Number	Rates
East Coast Area	139	55.3	129	51.3	182	72.4	182	72.4
Northern Area	508	147.6	463	134.5	554	160.9	534	155.1
South Western Area	150	39.2	138	36.1	153	40.0	153	40.0
ERHA 797	81.5	730	74.6	889	90.9	869	88.9	
Midland	281	188.4	271	181.7	288	193.1	292	195.8
Mid-Western	424	180.6	383	163.1	430	183.2	395	168.3
North-Eastern	197	88.8	194	87.4	241	108.6	221	99.6
North-Western	141	91.2	141	91.2	158	102.2	148	95.7
South-Eastern	770	267.5	684	237.7	827	287.3	782	271.7
Southern	639	156.6	634	155.4	609	149.2	653	160.0
Western	505	193.6	454	174.1	522	200.2	549	210.5
Private Hospitals*	397	-	431	-	702	-	699	-
Central Mental Hospital*	79	-	83	-	81	-	88	-
St Joseph's Intellectual Disability Service*	-	-	251	-	-	-	251	-
Total	4,230	157.0	4,256	157.9	4,747	176.1	4,947	183.6
* Private hospitals and the Central Mental Hospital are not rated to the Census of Population as they receive admissions from throughout the country and do not provide services for a specified catchment area.								

** St Joseph's Intellectual Disability Service is a separate and autonomous intellectual disability service within the psychiatric hospital system. It provides a regional rather than a catchment area service and thus is not rated.

Source: Daly, A and D, Walsh (2002)

Table 5: Hospital type. All admissions. Ireland 2001.

Numbers with percentages.	
Health Board Hospitals	
General Hospital Psychiatric Units	
Private Hospitals	
Total	
	Number %
	Number %
	Number %
	Number %
All Patients	10,793 44.1
	10,343 42.3
	3,311 13.5
	24,447 100.0
Male	5,961 55.2
	5,457 52.8
	1,514 45.7
	12,932 52.9

and shows that there are high rates of admission for people aged over 45 years.

Source: Health Research Board (2002)

Table 9 provides information about discharges and length of stay. Table 10 breaks down health board information about discharges by diagnosis. The lowest rate of admission was in the NEHB (536.4); highest rate of admission MHB (1,189.0 per 100,000 population). 44% of admissions were to health board hospitals, 42% to psychiatric units in general hospitals and 11% to private hospitals. There are also some inter-regional variations in admissions, although the majority receive services in their own health board area. This data can be found in Table 11.

Community based psychiatric services: outpatients, day hospitals, day centres and community residencies

Outpatient clinics

Table 12 shows that there were 237,667 attendances at 254 outpatient clinics (rate of 8,819.0 per 100,000 population). There are considerable variations between the health boards with the lowest attendances in the HWHB (rate of 5,000 per 100,000 population) and highest attendances in the NAHB (rate of 14,000 per 100,000 population).

Day hospitals

Table 13 shows that there were 1,145 places in 63 day hospitals (rate of 42.5 places per 100,000) with big variations between health boards ranging from MWHB with a rate of 84.8, to MHB with a rate of 17.4 per 100,000 population. There were 181,189 attendances at day hospitals ranging from a rate of 1,212 per 100,000 population in the MWHB to 69.9 in the NEHB.

Table 6: All and first admissions. Health board hospitals and units catchment population. * Ireland 2001.

Rates per 100,000 population aged 16 years and over.	
Catchment Population	
All Admission Rates	
First Admission Rates	
East Coast Area	
251,323	
656.5	
183.4	
Northern Area	
344,273	
832.2	
323.3	

South Western Area

382,317

416.7

120.3

Limerick

123,353

702.9

156.5

Clare

68,582

787.4

144.4

Cavan/Monaghan

75,373

270.7

95.5

Donegal

87,109

1,089.4

280.1

Tipperary

98,197

1,264.8

251.5

Waterford

70,578

1,110.8

419.4

North Cork Mental Health Services

53,200

650.4

169.2

North Lee Mental Health Services

106,938

1,076.3

351.6

South Lee Mental Health Services

117,754

551.1

178.3

West Cork Mental Health Services

36,341

759.5

222.9

Kerry
93,859
947.2
272.7

East Galway Mental Health Services
64,942
1,137.9
286.4

West Galway Mental Health Services
73,295
1,140.6
267.4

St Fintan's Hospital, Portlaoise
80,922
949.1
207.6

St Loman's Hospital, Mullingar
68,191
1,237.7
302.1

Our Lady's Hospital, Navan
78,670
392.8
94.1

St Brigid's Hospital, Ardee
67,807
620.9
154.9

Mental Health Service, Sligo
67,507
1,020.6
205.9

St Canice's Hospital, Kilkenny
55,113
745.7
141.5

St Dymphna's Hospital, Carlow
30,469
964.9
223.2

St Senan's Hospital, Enniscorthy
 76,267
 736.9
 178.3

Roscommon County Hospital
 40,809
 1,119.9
 306.3

St Mary's Hospital, Castlebar
 81,742
 814.8
 201.9

Total
2,694,931
779.3
216.9

*Excluding private hospitals and the Central Mental Hospital Dundrum.

Source: Daly A and Walsh D (2002)

Table 7: Children's Centres. First, re-admissions and all admissions. Ireland 2001.

Numbers with percentages.

First
Re-admissions
All admissions
First
Re-admissions
All admissions

Numbers

% (Row)
 % (Row)
 Col %

Warrenstown House, Dublin
 15
 2
 17
 88.2
 11.8
 27.9

St Anne's Children's Centre, Galway
 24
 7

31
77.4
22.6
50.8

Court Hall, Dublin

8
5
13
61.5
38.5
21.3

Total

47
14
61
77.0
23.0
100.0

Source: Daly A and Walsh D (2002)

Table 8: Hospital type by health board area.

	Health Board Hospitals	General Hospital Psychiatric Units	Children' s Centres	Private Hospitals	Central Mental Hospital	Total
East Coast Area	3	1	0	-	-	4
Northern Area	3	2	2	-	-	7
South Western Area	1	3	0	-	-	4
Midland	2	0	0	-	-	2
Mid Western	2	2	0	-	-	4
North Eastern	2	2	0	-	-	4
North Western	2	1	0	-	-	3
South Eastern	5	2	0	-	-	7
Southern	3	4	0	-	-	7
Western	2	2	1	-	-	5
Total	25	19	3	6	1	54

Source: Daly A and Walsh D (2002)

Table 9: Health Board Area. Discharges (including deaths) and length of stay. Ireland 2001. *Numbers with percentages.*

Numbers							
	Under 1 Week	1 - <2 Weeks	2 - <4 Weeks	1 - <3 Months	3 Months - <1 Year	1 - <5 Years	5 - <10 Years 10 -
East Coast Area	622	409	463	599	109	21	4
Northern Area	903	736	640	760	210	44	9
South Western	605	443	480	801	175	26	7
Unspecified ERHA	8	3	-	-	-	-	1
ERHA	2,138	1,591	1,583	2,160	494	91	21
Midland	602	379	355	341	74	12	2
Mid-Western	601	410	405	459	98	12	8
North-Eastern	310	248	256	314	46	3	7
North-Western	556	399	359	341	61	9	-
South-Eastern	944	671	605	590	144	50	10
Southern	888	661	772	934	175	23	15
Western	855	603	538	583	136	39	12
Non-National	44	19	21	20	1	-	-
Total	6,938	4,981	4,894	5,742	1,229	239	75
Percentages							
East Coast Area	27.9	18.3	20.8	26.9	4.9	0.9	0.2
Northern Area	27.3	22.3	19.4	23.0	6.4	1.3	0.3
South Western	23.8	17.4	18.9	31.5	6.9	1.0	0.3
Unspecified ERHA	61.5	23.1	0.0	0.0	0.0	0.0	7.7
ERHA	26.4	19.7	19.6	26.7	6.1	1.1	0.3
Midland	33.9	21.3	20.0	19.2	4.2	0.7	0.1
Mid-Western	29.5	20.1	19.9	22.5	4.8	0.6	0.4
North-Eastern	25.9	20.7	21.4	26.3	3.8	0.3	0.6
North-Western	32.2	23.1	20.8	19.7	3.5	0.5	0.0
South-Eastern	31.0	22.0	19.9	19.4	4.7	1.6	0.3
Southern	25.3	18.8	22.0	26.6	5.0	0.7	0.4
Western	30.3	21.4	19.1	20.7	4.8	1.4	0.4
Non-National	41.9	18.1	20.0	19.0	1.0	0.0	0.0
Total	28.5	20.5	20.1	23.6	5.1	1.0	0.3

Table 10: Health Board Area. Discharges (including deaths) and diagnosis. Ireland 2001. *Numbers with percentages.*

Numbers	
----------------	--

	Organic Psychoses	Schizo- phrenia	Other Psychoses	Depressiv e Disorders	Mania	Neuroses	Personalit y Disorders*	Alcoholic Disorders Dep
East Coast Area	88	497	20	565	258	152	121	453
Northern Area	282	689	57	978	332	151	155	406
South Western	49	589	34	713	406	201	110	312
Unspecified	-	2	-	2	1	2	2	3
ERHA	419	1,777	111	2,258	997	506	388	1,174
Midland	22	341	9	474	141	108	109	478
Mid-Western	28	393	25	512	274	132	68	418
North-Eastern	21	248	27	383	154	107	40	149
North-Western	9	351	48	463	184	95	81	426
South-Eastern	74	544	19	1,014	244	180	174	608
Southern	48	630	56	1,379	477	165	114	470
Western	51	558	21	882	331	112	88	668
Non-National	-	15	6	25	16	6	11	24
Total	672	4,857	322	7,390	2,818	1,411	1,073	4,415
Percentages								
East Coast Area	3.9	22.3	0.9	25.3	11.6	6.8	5.4	20.3
Northern Area	8.5	20.8	1.7	29.6	10.0	4.6	4.7	12.3
South Western	1.9	23.2	1.3	28.1	16.0	7.9	4.3	12.3
Unspecified	0.0	15.4	0.0	15.4	7.7	15.4	15.4	23.1
ERHA	5.2	22.0	1.4	27.9	12.3	6.3	4.8	14.5
Midland	1.2	19.2	0.5	26.7	7.9	6.1	6.1	26.9
Mid-Western	1.4	19.3	1.2	25.1	13.4	6.5	3.3	20.5
North-Eastern	1.8	20.7	2.3	32.0	12.9	8.9	3.3	12.5
North-Western	0.5	20.3	2.8	26.8	10.6	5.5	4.7	24.7
South-Eastern	2.4	17.9	0.6	33.3	8.0	5.9	5.7	20.0
Southern	1.4	17.9	1.6	39.3	13.6	4.7	3.2	13.4
Western	1.8	19.8	0.7	31.3	11.7	4.0	3.1	23.7
Non-National	0.0	14.3	5.7	23.8	15.2	5.7	10.5	22.9
Total	2.8	20.0	1.3	30.4	11.6	5.8	4.4	18.2

*Includes 5 discharges for under 16s with Conduct Disorders. **Source: Daly A and Walsh D (2002)**

Table 11: Inter-regional variations in admissions. Ireland 2001

Numbers with percentages.

Numbers

	Total admissions	Admitted to Health Board Hospital/Unit in own HB Area	Admitted to Health Board Hospital outside area	Admitted to Private Hospital	Admitted to Central Mental Hospital	Admitted to Health Board Hospital/Unit in own HB Area
East Coast Area	2,257	1,523	59	636	39	67.5
Northern Area	3,493	2,802	37	631	23	80.2
South Western Area	2,533	1,550	116	841	26	61.2
Unspecified ERHA	11	-	11	-	-	0.0
Midland	1,773	1,573	25	167	8	88.7
Mid-Western	2,017	1,377	467	166	7	68.3
North-Eastern	1,189	923	40	219	7	77.6
North-Western	1,732	1,606	31	95	-	92.7
South-Eastern	3,038	2,797	34	200	7	92.1
Southern	3,503	3,282	41	172	8	93.7
Western	2,786	2,603	26	152	5	93.4

Source: Daly A and Walsh D (2002)

Table 12: Attendances at outpatient clinics by health board area. Ireland 2000-2001.

Numbers with rates per 100,000 population aged 16 years and over.

	New attendances				Return attendances			
	2000		2001		2000		2001	
	Numbers	Rates	Numbers	Rates	Numbers	Rates	Numbers	Rates
East Coast Area	1,461	581.3	1,218	484.6	26,666	10,610.3	20,550	8,110.3
Northern Area	1,360	395.0	3,587	1,041.9	33,179	9,637.4	45,442	13,041.9
South Western Area	1,555	406.7	1,828	478.1	30,861	8,072.1	32,368	8,478.1
ERHA	4,376	447.5	6,633	678.3	90,706	9,275.5	98,360	10,127.5
Midland	660	442.6	512	343.4	10,325	6,924.3	7,752	5,124.3
Mid-Western	1,192	507.8	971	413.6	15,762	6,714.2	11,299	4,714.2
North-Eastern	971	437.7	1,109	499.9	17,017	7,670.5	18,845	8,499.9
North-Western	628	406.2	442	285.9	9,210	5,956.7	6,988	4,442.6
South-Eastern	1,692	587.9	1,550	538.6	18,456	6,412.7	25,909	9,127.9
Southern	1,292	316.6	1,846	452.3	22,300	5,464.5	22,988	5,646.5
Western	926	355.1	913	350.1	15,839	6,073.5	18,997	7,350.1
Total	11,737	435.5	13,976	518.6	199,615	7,407.1	211,138	7,518.6

**Many hospitals were unable to provide a breakdown of total attendances by new and return attendances. Thus, for most health boards new and return attendances do not equal total attendances.*

Source: Daly A and Walsh D (2002)

Table 13: Day hospitals by health board area. Ireland 2000-2001.

Numbers with rates per 100,000 population aged 16 years and over.

	Places				Attendances			
	2000		2001		2000		2001	
	Numbers	Rates	Numbers	Rates	Numbers	Rates	Numbers	Rates
East Coast Area	165	65.7	150	59.7	10,295	4,096.3	18,696	7,411.0
Northern Area	145	42.1	145	42.1	17,733	5,150.9	17,658	5,111.0
South Western Area	138	36.1	114	29.8	20,701	5,414.6	19,859	5,111.0
ERHA	448	45.8	409	41.8	48,729	4,983.0	56,213	5,711.0
Midland	26	17.4	26	17.4	8,191	5,493.1	8,077	5,411.0
Mid-Western	199	84.8	199	84.8	36,892	15,715.0	38,240	16,211.0
North-Eastern	35	15.8	44	19.8	4,814	2,169.9	6,966	3,111.0
North-Western	118	76.3	115	74.4	18,274	11,819.0	18,671	12,011.0
South-Eastern	139	48.3	128	44.5	18,151	6,306.7	30,723	10,611.0
Southern	84	20.6	149	36.5	25,309	6,201.8	18,129	4,411.0
Western	143	54.8	75	28.8	31,099	11,925.0	14,170	5,411.0
Total	1,192	44.2	1,145	42.5	191,459	7,104.4	191,189	7,011.0

Source: Daly A and Walsh D (2002)

Day centres

Table 14 shows that there were 2,498 places in 104 day centres (rate of 92.7 places per 100,000 population). There are significant variations between the health boards with the highest number of places and attendances are found in the WHB and the lowest number is found in the SWHB. There were 395,868 attendances at day centres overall.

Community residencies

Table 15 shows that there were 3,077 places in 404 community residences (low, medium and high) representing a rate of 114.2 places per 100,000 population. The highest number of places is found in high support residences. Table 16 shows that there were 1,397 admissions to and 1,322 discharges from low, medium and high support community residencies. There are significant variations between the health boards with the highest rate found in NWHB (rate of 200 per 100,000 population) and the lowest in SWAHB (60 per 100,000 population) (Daly and Walsh, 2002).

Medical staffing

In 2001, there were 261 established permanent consultant posts in psychiatry in the public mental health service. Between 1996 and 2001, 57 new consultant posts have been approved, fifteen new posts were approved in 2001. These new posts are increasingly filling new specialities such as psychiatry in later life, child psychiatry, psychiatry of learning disability and

forensic psychiatry. In addition, in 2001 there were 373 non-consultant posts and several areas that had faced recruitment problems. Significant problems exist in recruiting and retaining nursing staff, particularly in the eastern region. In 2001, 156 community mental health nursing posts were approved, many of which had not been filled.

Inspector of Mental Health Services

The Inspector of Mental Hospitals is required to carry out inspections under the Mental Treatment Act, 1945. Under the Mental Health Act, 2001, these functions, including the appointment of the Inspector of Mental Health Services, will be carried out by the Mental Health Commission. In the future the Mental Health Commission will appoint an Inspector of Mental Health Services who will be required to visit and inspect all approved centres, review mental health services and report on the quality of care and treatment of people receiving mental health services.

The inspection process is guided by quality criteria in Guidelines on Good Practice and Quality Assurance in Mental Health Services (Department of Health and Children, 1998) and includes interviews with patients. The Inspectorate covers:

- Community mental health care and day hospital activity
- Day centre activity
- Rehabilitation, residential community placement and recovery services
- Acute in-patient services
- Primary care liaison activity
- Home care programmes

Table 14: Day centres by health board area. Ireland 2000-2001.

Numbers with rates per 100,000 population aged 16 years and over.

	Places				Attendances			
	2000		2001		2000		2001	
	Numbers	Rates	Numbers	Rates	Numbers	Rates	Numbers	Rates
East Coast Area	436	173.5	373	148.4	31,305	12,456.1	52,350	20,456.1
Northern Area	117	34.0	294	85.4	21,687	6,299.4	29,441	8,544.1
South Western Area	134	35.0	110	28.8	15,052	3,937.0	11,141	2,814.1
ERHA	687	70.3	777	79.5	68,044	6,958.1	92,932	9,293.2
Midland	97	65.1	57	38.2	33,149	22,230.8	31,636	20,636.8
Mid-Western	158	67.3	198	84.3	33,727	14,366.8	36,315	16,366.8
North-Eastern	201	90.6	212	95.6	37,473	16,891.1	40,040	16,891.1
North-Western	276	178.5	185	119.7	42,002	27,165.4	35,765	27,165.4
South-Eastern	373	129.6	353	122.7	43,397	15,078.7	42,174	15,078.7
Southern	237	58.1	219	53.7	34,205	8,381.7	32,051	8,381.7
Western	398	152.6	497	190.6	62,775	24,071.1	84,955	24,071.1
Total	2,427	90.1	2498	92.7	354,772	13,164.4	395,868	13,164.4

Source: *Daly A and Walsh D (2002)*

Table 15: Community residences. Places by health board area. Ireland 2000-2001.

Numbers with rates per 100,000 population aged 16 years and over.

2000						
	Low Support		Medium Support		High Support	
	Numbers	Rates	Numbers	Rates	Numbers	Rates
East Coast Area	50	19.9	66	26.3	56	21.8
Northern Area	75	21.8	75	21.8	196	57.0
South Western Area	64	16.7	59	15.4	93	21.8
ERHA	189	19.3	200	20.5	345	30.6
Midland	100	67.1	39	26.2	70	40.7
Mid-Western	86	36.6	78	33.2	76	30.6
North-Eastern	65	29.3	66	29.7	60	21.8
North-Western	123	79.6	6	3.9	170	100.0
South-Eastern	182	63.2	111	38.6	141	40.7
Southern	129	31.6	48	11.8	171	40.7
Western	170	65.2	148	56.8	161	60.7
Total	1,044	38.7	696	25.8	1,194	40.7
2001						
	Low Support		Medium Support		High Support	
	Numbers	Rates	Numbers	Rates	Numbers	Rates
East Coast Area	44	17.5	67	26.7	56	21.8
Northern Area	145	42.1	86	25.0	264	79.6
South Western Area	72	18.8	59	15.4	93	21.8
ERHA	261	26.7	212	21.7	413	40.7
Midland	93	62.4	45	30.2	70	40.7
Mid-Western	56	23.9	72	30.7	105	40.7
North-Eastern	65	29.3	6	2.7	120	57.0
North-Western	131	84.7	6	3.9	171	100.0
South-Eastern	164	57.0	77	26.8	162	57.0
Southern	125	30.6	35	8.6	174	40.7
Western	214	82.1	170	65.2	130	40.7
Total	1,109	41.2	623	23.1	1,345	40.7

Source: Daly A and Walsh D (2002)

Table 16: Community residences. Admissions and discharges by health board area. Ireland 2000-2001.

Numbers.

2000						
	Low Support		Medium Support		High Support	
	Admissions	Discharges	Admissions	Discharges	Admissions	Discharges
East Coast Area	12	13	19	15	49	
Northern Area	9	11	105	98	103	
South Western Area	8	12	15	13	21	
ERHA	29	36	139	126	173	
Midland	15	15	9	10	11	
Mid-Western	25	26	35	32	12	
North-Eastern	11	7	7	5	96	
North-Western	70	74	-	-	247	
South-Eastern	20	14	2	3	16	
Southern	2	4	11	10	16	
Western	47	39	177	160	144	
Total	219	215	380	346	715	
2001						
	Low Support		Medium Support		High Support	
	Admissions	Discharges	Admissions	Discharges	Admissions	Discharges
East Coast Area	12	10	27	19	50	
Northern Area	37	37	119	121	196	
South Western Area	2	4	12	17	7	
ERHA	51	51	158	157	253	
Midland	4	5	7	7	20	
Mid-Western	6	11	36	40	13	
North-Eastern	5	12	0	0	87	
North-Western	74	74	5	5	221	
South-Eastern	14	18	4	3	49	
Southern	6	9	4	4	16	
Western	59	43	105	76	200	
Total	219	223	319	292	859	

- Source: Daly A and Walsh D (2

Key issues raised by the Inspector of Mental Hospitals (1998, 1999, 2000 and 2001):

Living conditions

- Slow rate of progress in upgrading unsatisfactory accommodation and the

provision of alternative community residential accommodation.

- A gradual reduction in the inequalities and disparities in the quality of accommodation between the statutory and non-statutory sectors.
- Health boards and local authorities face problems in providing suitable accommodation.
- Large numbers of psychiatric in-patients who are homeless and accommodated in acute or long-stay hospital wards because community residential accommodation is not available.
- There is a positive development of voluntary housing associations, established by local mental health associations, funded by the Department of the Environment and Local Government.
- The development of community-based centres of psychiatric activity is inadequate. Health professionals are reluctant to locate their activities in community settings. Similar problems face the development of day hospitals.

Standards of care and rights of mental health patients

- A failure to reform the mental health system with criticisms of the conditions of detention in psychiatric institutions, the use of psychiatric institutions for treating people with intellectual disability, the overuse of medication and lack of respect for patient's rights and a failure to inform patients of their statutory rights.
- Despite some transfers of people with intellectual disability into more appropriate services and settings, there are still large numbers in unsuitable accommodation. This is aside from the 300 people in St Joseph's service at St Ita's.
- A high number of alcohol related problems, that should be dealt with in general care services, are dealt with in the mental health services, accounting for one-third of psychiatric hospital admissions.

Funding

- An additional £7 million capital funding provided in 1998 to accelerate the provision of acute psychiatric units in general hospitals and additional capital funds for community based facilities has been inadequate.

Health status

- Around 40% of people in psychiatric units and hospitals are over 65 years of age. Some do not present psychiatric disorders and their needs relate to age rather than mental illness. More appropriate care should be provided in community residencies or suitable residential facilities for older people, and these facilities should be de-designated from the psychiatric register.
- Poorer health and higher mortality of psychiatric patients, compared to the general population is a major area of concern. Physical health examinations are inadequate and described by the Inspector as "infrequent, desultory and superficial in nature" (2002:11). There is a need for participation in health screening and health education programmes.

New services and staffing

- Progress in developing specialist services in the area of psychiatry in later life has resulted in 15 consultants in place, 5 posts to be filled and further posts to be created. The service is usually provided as a sub-unit in general hospitals units. At Tallaght Hospital the six-bed unit had not opened due to difficulties in recruiting staff. Although multi-disciplinary teams and day services are important to psychiatry in later life, these are not in place.
- A growth of forensic psychiatry to reflect the increased prisoner population and the increase in the numbers of prisoners with psychiatric disorders. Five consultant forensic posts have been created in the Dublin region and plans are underway to provide forensic psychiatric services in Cork and Limerick prisons.
- New initiatives include a consultant post specialising in the care of the homeless mentally ill in NAHB, liaison consultant psychiatric posts, and specialist consulting posts in rehabilitation. The need for dedicated multi-disciplinary consultant led teams for patient rehabilitation and services for psychiatry in later life was highlighted in the 1997 report.

2.5 Disability services: physical and sensory disability and intellectual disability

The most recent data sources of information about services for people with physical and sensory disability and intellectual disability are:

- Regional and National Intellectual Disabilities Database, 2002
- Regional and National Physical and Sensory Disabilities Database, 2001
- Health Board Annual reports, 2001
- Individual health board strategies, reviews, assessments and evaluation
- Annual Health Statistics (most recent 2002)

The National Intellectual Disabilities Database (established in 1995) and the National Physical and Sensory Database (established 1998) provide information on the health service utilisation and needs of people with intellectual and physical and sensory disabilities. The disability databases were developed to assist with service planning and cover people currently utilising specialist disability health and personal social services or people who have identified that they need services. They do not provide information about the general living situations of people with disabilities. When completed the databases will cover approximately 63,000 people with disabilities (intellectual disabilities: 25,448 and physical/sensory disabilities: 38,190), providing health related information for about 19% of people with disabilities in Ireland. The data contained in the Intellectual Disabilities Database is now fairly comprehensive whilst the data for the Physical and Sensory Disabilities Database remains patchy and is still in a developmental process.

During the course of this mapping exercise it was found that all health boards had either appointed disability database coordinators or had plans in place to do so. This will assist with the collection of more comprehensive data in the future. Regional databases are held by the health boards and these are collated into national databases by the Health Research Board, who ensure that there is a standardised data collection process, published data from the

databases and verify data accuracy. The databases are monitored by two national committees: Physical and Sensory Database Committee and the Intellectual Disability Database Committee. Each spring there is an annual review process and data records can be updated if a person's circumstances have changed.□

Services for people with intellectual disability and autism

The focus given to services in “Enhancing the Partnership” and “Widening the Partnership” as well as the introduction of the Intellectual Disability Database have been significant developments. Although in recent years there has been the development of new services for people with an intellectual disability and autism, these have built upon an extremely low base of funding and service provision. There still remain significant gaps in services and problems related to staff retention and recruitment.

The *Value for Money Audit of the Irish Health System* by Deloitte and Touche (2001) identified a range of factors contributing to and limiting value for money in services for people with an intellectual disability. These issues are summarised below:

The main areas of health services for people with intellectual disability are as follows:

- Development and Assessment Services (Early Services), including multi-disciplinary assessment services, parental counselling, early intervention services, school and adult support services.
- Pre-school services, to prepare children for school.
- Rehabilitative training, providing training and skills in self-care, personal and social development and work.
- Sheltered work /employment centres, provide sheltered work, usually following on from vocational training.
- Home support services, providing assistance to families through support to carers, assisting with care etc.
- Specialist or intensive services, sometimes necessary for people with profound or multiple needs, for example, people with disturbed behaviour or mental health needs.
- Residential services, provided where a person is unable to live with his or her family. This is available as five-day care, seven-day care, or temporary respite care. Residential services try to be in a home-like environment usually a group home in a residential neighbourhood.

The database captures the following three areas of information:

- Demographic details
- Current service provision
- Future service requirements

The Intellectual Disability Database provides a relatively comprehensive and reliable set of data to inform service planning. The comprehensiveness of the data relates to the high levels of reporting of data from parents/carers and health boards, the lifetime and changing nature of support service needs for

many people with intellectual disability, and the successful piloting and now mainstreaming of the database across all health boards, non-statutory providers.

In 2002, there were 25, 448 people registered on the database, of which 34% were aged 19 and under, 28.5% aged 20 - 34 years, 27.8% aged 35 to 54 years, 9.7% aged 55 years and over. Of these people 37% have a mild intellectual disability, 37.3% had a moderate learning disability, 15.7% had a severe learning disability and 4.2% had a profound intellectual disability. (5.8% were not verified). These figures are considered to be fairly representative of the overall numbers of people receiving intellectual disability services, particularly because reporting levels are high. It is estimated that the prevalence of intellectual disability may increase in coming years due to steady increase in maternal age and recent advancements in neonatal care, which increase the survival prospects of babies at risk of intellectual disability (Department of Health and Children, 2002a:35).

In summary the database shows that the following new places are needed in order to meet need during the period 2003-2007:

- Residential: 1633 places
- Day: 682 places
- Residential support: 1446 places

The 2000 Budget allocated £28-35 million for 2000 and a three-year £80 million Capital Programme for new services for people with intellectual disability. This helped to reduced waiting lists through the provision of additional new residential places, respite places and new day places. In 2000 Minister Cowen also announced the establishment of a National Monitoring Committee to track new service developments.

Evidence from the National Intellectual Disability Database for 2002 shows that there have been increases in the numbers of people accessing services, particularly residential and respite services. Between 2000 and 2002 there has been a 37% growth in the number of people with intellectual disability living in full time residential placements within local communities; a 255% increase in the number of respite places; a 165% increase in the provision of intensive placements designed to meet the needs of individuals with challenging behaviour and a 47% reduction in the number of people with intellectual disabilities accommodated in psychiatric hospitals. This reflects the increased funding allocated in the 2000 development programme and the growing demand for services. For the period of 2003 - 2007, the database indicates that there is a need for 1633 new residential places, 682 new day places and 457 people who had no service at all but require a major element of service in the period. In 2002 there were 515 people with intellectual disability resident in psychiatric hospitals.

Of interest is that the data (both from the Intellectual Disability Database and from the 1974 and 1981 Censuses of Mental Handicap) show a changing age profile with a declining prevalence rate of younger people with intellectual disabilities (0-19 years) and a rising prevalence rate amongst older age groups (35 and above). The changing age profile for moderate, severe and profound intellectual disability, since 1974, has resulted in fewer children and

more adults receiving or needing intellectual disability services. This is explained by increased longevity for people with intellectual disabilities and a gradual reduction in the numbers of moderate, severe and profound disabilities presenting at birth; owing a range of factors including a decline in the birth rate and improved obstetric care. This has implications for service delivery since the rising numbers and prevalence of people with intellectual disability is found in the adult population.

The high incidence rate of intellectual disability in the 1960s is now reflected in the population over 35 years and over. According to Mulvaney's analysis (2002) this has resulted in increased demands for residential services, longer life expectancies resulting in fewer free places, demands for ongoing therapeutic support services for people living with their own families, and increasing demands for more intensive services and services designed specifically to meet the needs of older people with intellectual disability.

More detailed data, broken down by health board, degree of intellectual disability, age, gender and other indicators can be found in the full report of the National Intellectual Disability Database Committee (2002).

Table 17 provides information about numbers of people included on the database in each health board. There are variations in prevalence of intellectual disability with the lowest prevalence found in the Midland Health Board and the highest in the health boards along the eastern sea board.

Table 17: Number of people included on each Regional Intellectual Disability Database.

National Intellectual Disability Database, Ireland 2002. Number of people included on each Regional Intellectual Disability Database.		
	n	%
Eastern Regional Health Authority	8404	33.0
Midland Health Board	1410	5.5
Mid-Western Health Board	2383	9.4
North-Eastern Health Board	1980	7.8
North-Western Health Board	1777	7.0
South-Eastern Health Board	3170	12.5
Southern Health Board	3765	14.8
Western Health Board	2559	10.1
Total	25,448	100.0

Table 18 outlines the main areas of current service provision for people with intellectual disability (2002) and Table 19 breaks this down by health board. A key feature of current service provision (2002) is that 475 people (1.8%) were without services and identified service needs for 2003-2007. For example, significant numbers of individuals currently living at home will also require residential services for the first time.

The database shows that that there is both unmet need and demand for service changes. This includes people requiring day and/or residential

services for the first time, changing service needs for people who require either enhanced or different services and people who are inappropriately accommodated in psychiatric hospitals. In addition, it is anticipated that there will need to be an expansion of adult day services (rehabilitative training, vocational training, sheltered and supported employment) in order to meet the demand for services.

Table 18: Summary of core service provision

National Intellectual Disability Database, Ireland 2002. Summary of service provision in 2002.		
	n	%
Receiving day services	14901	58.6
Receiving 5- or 7-day residential services	7587	29.8
Resident in a psychiatric hospital	515	2.0
Receiving residential support services only	47	0.2
Receiving no service	468	1.8
No identified service requirements		
	1930	7.6
Total	25448	100
Note: 3,619 day attendees and 278 full-time residents receive residential support services in addition to their principal service. 7,542 full-time residents receive a day service in addition to their full-time residential service.		

Table 20 identifies major elements of service that are required 2003-2007 identified by people currently receiving no services and people who are currently availing of day or residential services who require enhanced or different services. This reveals the need for a variety of different and new services to be provided. Table 21 identifies what new residential, residential support and day services are required, 2003-2007. 1633 new residential places, 682 day places and 1446 residential support services are identified. Table 22 identifies the numbers of places and within which services, places need to be changed.

One major area of service need is in the provision of appropriate services for people with intellectual disability residing in psychiatric hospitals. There is now a programme of phased provision of appropriate placement underway and budget allocations have been made for this. Table 23 shows the overall service requirements for people with intellectual disability currently residing in psychiatric hospitals. Table 24 identifies the services needed by those people who require to be transferred to the intellectual disability sector.

The more detailed data from the database can be found in Appendix 7. This provides the data, broken down by health board area, in the following areas:

- Age and degree of intellectual disability
- Number and degree of intellectual disability by health board
- Summary of current service provision
- Summary of current service provision by degree of intellectual disability and age group
- Main residential circumstances

- Principal day service by degree of intellectual disability and age group
- Overall level of residential service provision by degree of intellectual disability and age
- Current service provision by health board area
- Number of people requiring a major element of service 2001-2005
- Number of people requiring residential support services 2001-2005
- Number of places required to meet need 2001-2005
- Future residential service requirements of individuals currently receiving and those not receiving residential service 2001-2005
- Future day service requirements of individuals currently receiving and those not receiving a day service 2001-2005
- Category and numbers of service change required 2001-2005
- Service requirements of people with intellectual disability residing in psychiatric hospitals
- Pattern of full time residential and day service provision required 2001-2005.

In addition, this information has been made available for each health board. For the purposes of this study a number of summary tables and a breakdown of these for the Midland Health Board are presented below and in the Appendix 7.

Table 19: Current Service Provision by Health Board Areas

National Intellectual Disability Database, Ireland 2002.							
	Receiving day services	Receiving 5 or 7 day residential services	Residents in Psychiatric Hospitals	Receiving residential support services only	Receiving no service	No current service requirements	Total
	n	n	n	n	n	n	n
	%	%	%	%	%	%	%
ERHA	4274	2547	258	11	40	1274	8404
	50.9	30.3	3.1	0.1	0.5	15.2	100.0
MHB	874	425	14	3	43	51	1410
	62.0	30.1	1.0	0.2	3.0	3.6	100.00
MWHB	1422	758	22	4	58	119	2383
	59.7	31.8	0.9	0.2	2.4	5.0	100.0
NEHB	1338	495	8	10	61	68	1980
	67.6	25.0	0.4	0.5	3.1	3.4	100.0
NWHB	982	592	1	12	96	94	1777

	55.3	33.3	0.1	0.7	5.4	5.3	100.0
SEHB	2042	812	103	3	98	112	3170
	64.4	25.6	3.2	0.1	3.1	3.5	100.0
SHB	2390	1151	36	3	31	154	3765
	63.5	30.6	1.0	0.1	0.8	4.1	100.0
WHB	1579	807	73	1	41	58	2559
	61.7	31.5	2.9	0.0	1.6	2.3	100.0
All Boards	14901	7587	515	47	468	1930	25448
	58.6	29.8	2.0	0.2	1.8	7.6	100.0

Table 20: Number of People requiring a major element of service 2003-2007

National Intellectual Disability Database, Ireland 2002. Category of service change required 2003-2007.						
	Residential and day	Residential only	Day only	Day and residential support	Residential support only	All service changes
Not verified	6	1	644	31	4	686
Mild	243	80	3366	150	36	3875
Moderate, severe & profound	1745	379	5100	550	181	7955
All levels	1994	460	9110	731	221	12516

Table 21: Number of people requiring new places and year in which new places are required

National Intellectual Disability Database, Ireland 2002. Year in which service needs arise.						
	2003	2004	2005	2006	2007	All years
Residential	1305	105	122	68	33	1633
Day	655	15	8	4	0	682
Residential support	1289	74	44	33	6	1446

Table 22: Number of places requiring to be changed 2003-2007.

National Intellectual Disability Database, Ireland 2002. Year in which service changes are required.						
	2003	2004	2005	2006	2007	All years
Residential	2217	122	71	31	13	2454
Day	10276	790	421	233	133	11835
Of which:						
Health services	7798	497	303	185	92	8875
Education services	1093	138	48	24	6	1309
Employment services	1219	123	45	13	5	1405
Generic services	166	32	25	11	12	246
Residential support	904	11	21	14	2	952

Table 23: Overall service requirements of people with intellectual disability currently resident in psychiatric hospitals

National Intellectual Disability Database, Ireland 2002.									
	No service requirements				Has service requirements				Total
	Not Verified	Mild	Mod-Sev-Prof	All levels	Not Verified	Mild	Mod-Sev-Prof	All Levels	
Resident in a Psychiatric Hospital - no day programme	0	16	41	57	3	36	168	207	264
Resident in a Psychiatric Hospital - with day programme	1	25	37	63	4	60	124	188	251
All residents	1	41	78	120	7	96	292	395	515

Table 24: Residential service requirements of people currently resident in psychiatric hospitals who require to be transferred to the intellectual disability sector

National Intellectual Disability Database, Ireland 2002.				
	Year in which residential service is required			
	2003	2004	2005	2003-2007
7 day (48-week) community group home	3	0	0	3
7 day (52-week) community group home	86	0	0	86
7 day (48-week) residential centre	8	0	0	8
7 day (52-week) residential centre	123	1	1	125
Nursing Home	13	0	0	13
Intensive placement (Challenging Behaviour)	94	0	0	94
Intensive placement (Profound/Multiple disability)	51	0	0	51
All residential services	378	1	1	380

Services for people with physical and sensory disabilities

The Physical and Sensory Disabilities Database is not as comprehensive as the Intellectual Disabilities Database, partly as a result of its recent introduction and ongoing collection of data. Health boards have until March 2003 to provide a comprehensive database in their regions and this information will be coordinated and published by the Health Research Board later in 2003. However, progress in moving towards this objective has been slow.

The Physical and Sensory Disability Database was established by the Department of Health and Children in 1998. It followed from a recommendation in Towards an Independent Future, which identified the absence of reliable information about the numbers and needs of people with a physical and/or sensory disability regarding health and personal social services. The database covers services provided by the Department of Health and Children, health board and voluntary service providers. The database was set up to plan services, prioritise service needs, assist in decisions about resource allocation and prioritising new funding for services at national,

regional and local levels, and to facilitate research. The database includes those people who are currently availing of a specialist disability service or people who require a service. This includes therapeutic, rehabilitative, personal assistance and support, respite, day and residential services. Phase 1 of the implementation of the database carried out the preparation, piloting and evaluation of the database, with pilots in Dublin - Community Care Area 4, WHB-Galway, SEHB South Tipperary/East Waterford, and NEHB Louth/South Monaghan).

The most recent published data, presented in Table 25 for 2000 is based on the piloting of the database in the NEHB, SEHB, SEHB and WHB, this revealed some initial data for 1,683 people with disabilities.

Table 25: Number and Percentage of People in Data Sets from each Phase 1 Area

	N	% of People on Database	% of CCA population
North Eastern Health Board Louth/South Monaghan	249	14.80	$249/92,166 * 100 = 0.2\%$
South Eastern Health Board South Tipperary	829 ^a	49.26	$829/80,612 * 100 = 1.0\%$
Western Health Board Galway	505	30.01	$505/188,598 * 100 = 0.3\%$
South Western Area (ERHA) Dublin – CCA4	100	5.94	$100/143,154 * 100 = 0.07\%$
Total	1683	100.00	

^a Six people were removed from the database sent to the HRB as a result of being ineligible

The most comprehensive data can be found in the SEHB, covering 829 people, whilst the other pilots were less comprehensive. It is anticipated that over 38,000 people will be on the database when it is fully implemented. It is therefore premature to draw on this dataset as it remains at a developmental phase. According to Gallagher:

- ...the database is intended to provide a comprehensive and accurate information base for decision making in relation to the planning, funding and management of services for people with a physical or sensory disability, and for the first time, setting priorities based on an objective evaluation of the needs of the population receiving or requiring physical and sensory disability services. (2001:98)

Although the data is incomplete and therefore not fully representative of the four health boards it is nevertheless useful to reflect on some of the findings from this data. This is broken down by health board area and covers the following:

In summary the disability database provides evidence of the following demand for services:

- **Current Therapeutic Intervention and Rehabilitation Services:** The most commonly received services are physiotherapy, public health nursing and speech and language therapy.
- **Therapeutic Intervention and Rehabilitation Services: Assessments Required.**
The largest demand for assessments are in occupational therapy,

physiotherapy and psychology,
<ul style="list-style-type: none"> • Current Therapeutic Intervention and Rehabilitation Services having been assessed and year required: the most required services are speech and language therapy, physiotherapy and psychology.
<ul style="list-style-type: none"> • Current and future personal assistant and support services: the most often cited services that are required are personal assistant service, home help service and home care assistant services
<ul style="list-style-type: none"> • Current and future respite services: the most commonly received respite services are summer camps (day), planned residential respite with high support and holiday respite placement. Future requirements for respite support include summer camp (day and residential) and holiday respite placement.
<ul style="list-style-type: none"> • Current and future day services: current day services include employment and activation services and the most often cited future day service requirements include resource centre and social and recreational facilities for people with a physical and sensory disability.
<ul style="list-style-type: none"> • Current and future residential services: future residential service needs include dedicated high support with nursing care and therapy services, residential care with nursing care, community homes with high support, and low support independent living units.
<ul style="list-style-type: none"> • Current and future technical aids and appliances: technical aids and appliances include aids to mobility, vision aids, special furniture and other aids, respiratory aids.

2.6 Staffing and personnel issues

Data on staffing levels and gaps is underdeveloped. In particular, data on staffing in the health services is not collected or collated in order to carry out workforce and service planning. This has been raised by the DOHC's (2002) review *Towards Workforce Planning* covering nursing and midwifery and which argues that "...there is an urgent need for a reliable standard mechanism for collection and collation of information by employers and policy-makers at local, regional and national level in order to support effective workforce planning" (DOHC, 2002: 24). *Quality and Fairness* (2001) identifies the need for workforce planning to be integrated into health service planning and the development of a system that anticipates the levels and types of staffing required in order to provide a quality service. The development of a workforce planning tool will be an outcome of this.

In practice the DOHC only categorises staff according to the following categories: management/administration, medical/dental, nursing, health and social care professionals, and general support staff. In 2000 there were a total of 81,513 whole time equivalent staff employed by the health boards and voluntary hospitals, compared to 67,938 in 1997. However, there is no data available to show how many staff are employed by disability services. The only relevant breakdown of figures is for hospital consultants. In 2001, there were 246 posts in psychiatry, 60 of which were vacancies. This represents an increase in staffing compared to 1998 where there were 210 posts, 32 of which were vacancies.

Staffing shortages and difficulties in recruiting and retaining staff in mental health and disability services exist across all health boards. For example, the *St Mary's Drumcar Staffing and Skill mix review* (2002) identified significant staffing shortages at St Mary's Drumcar, a specialist residential home for 256 people with moderate to profound intellectual disabilities. The report concluded that:

- The present shortage of staff leaves the organisation at risk of potential harm to clients and staff due lack of supervision. However, the increase in the staffing levels must be undertaken in conjunction with some fundamental changes to the culture and staff attitudes if the increase in staffing is to make a meaningful difference to the quality of life of the residents. (1066 Consultancy and Healthcare Consultancy Ltd, 2002)

The report found that the total number of clinically based staff required to meet the needs of residents was 287 (WTE). However, there were only 203 WTE funded posts, of which there were 197 WTE in post and six vacancies. The total deficit of staffing was identified as 94 WTE, including an urgent need for 30 WTE nursing staff to cover the night shift. The report also found that a lack of evidence based practice, lack of activation programmes and restraint of patients at night was compounded by high staff turnover, a shortage of nursing staff and reliance on seasonal workers. The study revealed a wide range of management issues as well as issues related to the skill mix of staff. The profiling of residents and staff and the development of a dependency rating based on a methodology developed by Barr in Oxford in the UK was used to identify optimum staffing levels. Given the absence of established staff-client ratios it would be worth exploring this methodology and its wider application to disability health service provision.

There are substantial staffing shortages in services for people with physical and sensory disabilities. Peter Bacon & Associates' (2001) study of staffing in physiotherapy, occupational therapy and speech and language therapy found a significant shortage of staffing in all health boards and this was compounded by the fact that around 25% of all posts in speech and language therapy were vacant in 2000, around 22% were vacant in occupational therapy and 13.8% in physiotherapy.

Not only are current levels of services affected by shortages in staff, there are problems ahead in meeting projected future demands on services. Projections for meeting future demands by 2015 indicate the need for significant increases in staffing for these three therapies, with the need for an estimated 102% increase in physiotherapists, a 159% increase in occupational therapists and a 328% increase in speech and language therapists required by 2015 (Bacon, 2001). The problems of under-supply are particularly acute in the Eastern region where the high cost of living has deterred recruitment, and has created problems in filling posts and retaining staff. In addition, there is an inadequate supply of and recruitment to training courses for these therapies. Table 26 lists the posts in the health boards in 2001.

Table 26: Occupational therapy, physiotherapy and speech and language therapy posts in health boards 2001

Occupational Therapy posts

	Existing	Filled	Vacant	%Vacant
Eastern	85.1	77.1	8	9.4
Mid West	23.1	14.8	8.3	35.9
Midlands	26.5	22.5	4	15.1
North Eastern	22	12.5	9.5	43.2
North Western	29.0	26.5	2.5	8.2
South Eastern	14	7.5	6.5	38.2
Southern	25.9	17.3	8.6	33.2
Western	17.5	12.5	5	28.6
Total	243.1	190.7	52.4	21.6

Physiotherapy posts

	Existing	Filled	Vacant	%Vacant
Eastern	75.7	67	8.7	11.5
Mid West	20	14.5	5.5	27.5
Midlands	20	16.5	3.5	17.5
North Eastern	19	10.5	8.5	44.7
North Western	57.5	52.0	5.5	9.3
South Eastern	11	8.5	2.5	22.7
Southern	37.3	34.7	2.6	7.0
Western	44.5	42	2.5	5.6
Total	285	245.7	39.3	13.8

Speech and language therapy posts

	Existing	Filled	Vacant	%Vacant
Eastern	91.7	85.7	6	6.5
Mid West	40.2	24.2	16	39.8
Midlands	25.4	13.8	11.6	45.7
North Eastern	16	4	12	75.0
North Western	34.3	19.8	14.5	42.3
South Eastern	33.5	26.5	7	20.9
Southern	57	45.8	11.2	19.6
Western	38.5	32.5	6	15.6
Total	336.6	252.3	84.3	25.0

Source: Bacon (2001)

Data exists on personnel in homes for people with intellectual disabilities through the *Mental Handicap Homes - Personnel Census*. The latest figures for 2001⁶ show that there were 9,290 whole-time equivalent staff employed in organisations providing residential services.

⁶ The 2002 Personnel Census will be published in May.

2.7 Rehabilitative training programmes funded by the DOHC

The DOHC is responsible for day activity, rehabilitative training and sheltered work. Vocational training and employment, including sheltered and supported employment is the responsibility of the Department of Enterprise, Trade and Employment. Table 27 lists the number of rehabilitative training places and the number of trainees in 2001. It is also estimated that approximately 7,900 people with disabilities worked in 215 sheltered workshops in 2001.

Table 27: Rehabilitative training programmes funded by the DOHC, 2002

	Number of places	Number of trainees attending
Eastern	924	908
Mid West	134	134
Midlands	202	202
North Eastern	122	90
North Western	209	209
South Eastern	284	284
Southern	336	336
Western	376	376
Total	2.587	2.539

Source: DOHC Health Statistics 2002

2.8 Community welfare services

A range of community welfare services are administered and funded by health boards. Community welfare services available to people with disabilities include a range of allowances: the Rehabilitative Training Bonus, the Blind Welfare Allowance, Domiciliary Care Allowance, Mobility Allowance, Motorised Transport Grant, Long Stay Institutional Spending Allowance and the Respite Care Grant. Other services are the meals services and the home help service. The DOHC collects data from the health boards on the numbers of recipients of these allowances and services. Table 28 lists meals and home help services by health board.

Table 28: Meals and home help services provided by health boards

	Meals service	Home help service For people with physical disabilities
Eastern	N/a	1,015
Mid West	702	137
Midlands	1,134	48
North Eastern	27,069	330
North Western	765	107
South Eastern	822	179

Southern	1,898	433
Western	16,229	204
Total	48,619	2,453

Source: DOHC *Health Statistics 2002*

2.9 Overview of statutory funded provision in a selection of health boards

This section provides a brief overview of a range of mental health and disability services in a selection of health boards (ERHA, Midland, North Eastern, North Western and Southern). It draws on information published by health boards, including Service Plans, Annual Reports, specific disability policies/strategies and reviews of services, and coordinated information provision via web sites and guides to services. The most up to date information is provided, in some cases this dates to 2001. In addition to the information presented in this section it is worth noting that all County and City Development Boards have drawn up ten year strategy and implementation plans for their areas. The Boards are based on local authority areas. Of relevance to health service mapping is that extensive consultations took place during the preparation of the strategies and services in each area were audited. This included audits of disability and health services. The Strategy and Implementation Plans provide useful information about strategies for health service development, including services for people with disabilities.

Health Boards vary in their coverage and provision of services for people with disabilities. Some health boards have developed comprehensive strategies and geographic needs assessments on different areas of disability, whilst others are planning such activities. All health boards have Regional Coordinating Committees for Physical and Sensory Disability and Regional Planning and Consultative Committees for Intellectual Disability to plan and coordinate services. These Committees are made up of representatives of health boards, service users and their organisations and service providers.

Health Boards also vary in the extent to which they provide accessible and comprehensive information about disability services. For example, some health boards provide detailed information on their web sites or provide directories of services that identify services provided, location and contact information. An example of good practice in this regard is the *Directory of Services for Persons with Disability in the Mid West*, published by the Mid-Western Health Board and covering information about the Board's Disability Unit and the services provided including advisory and support services, employment, training and activation services, assessment, diagnostic and treatment services, as well as information about disability organisations and support groups.

A large proportion of disability services are provided directly by non-statutory organisations. This is particularly the case in the area of services for people with intellectual disability where up to 90% of services are provided directly by non-statutory organisations. Health boards provide support to a wide range of disability organisations that provide support and other services for people with disabilities and mental health support needs.

A separate mapping exercise is currently taking place in the ERHA for physical and sensory disability services. A separate report will be produced for this.

In summary, health boards are engaged in:

- A greater emphasis on strategic planning and service planning.
- Service agreements between health boards and non-statutory providers.
- Compliance with nationally agreed performance indicators established by the DOHC.
- Data collection for the Physical and Sensory Disabilities Database and the Intellectual Disability Database and the appointment of regional database coordinators/administrators.
- New service developments including, new services in the areas of advocacy and needs assessment, more multi-disciplinary services, services for specific groups and a shift to more community based provision.

a) Eastern Regional Health Authority

The ERHA is a strategic authority responsible for planning, arranging and coordinating health and personal services for 1.5 million people in Dublin, Kildare and Wicklow. The responsibility for service delivery rests with the three Area Health Boards, the Voluntary Hospitals and Voluntary Intellectual Disability Agencies in the region who are funded directly by the ERHA. The three Area Health Boards are responsible for planning and coordinating services in their areas in cooperation with local non-statutory service providers. The ERHA has nine sectors / community care areas that include disability services. The population in each of these sectors is approximately 60,000, which is double that of most community care areas in other health boards. Mental health services are largely co-terminus with these community care catchment areas.

i) Mental health services

Funding for mental health services has generally been below that of other disability services, although allocations have been increasing since 1999. In 2002 the allocation of €7.736 million in new revenue funding represented a doubling of resources from 2001 and a six-fold increase from 1999. This enabled the Authority to increase staffing with two multi-disciplinary consultant led teams, registrar, nursing, psychology, social work and occupational therapy posts. In addition, capital funding of nearly €9 million enabled the Authority to respond to the recommendations of the 1999 Acute Bed Study in providing community based housing and collaborative social housing projects with the voluntary sector, and a €33 million refurbishment of the Central Mental Hospital in Dundrum. An additional €0.953 million was also allocated through the 2002 Disability Budget for health related support services for children with autism.

The ERHA has carried out an initial mapping exercise of mental health services by catchment area. The Catchment Area Service Map lists the name and location of service provider, the treatment provided, the capacity of the

facility and the number of places offered. This exercise has taken two years and is still not complete.

Gaps in services have been identified by both the ERHA and service user groups as:

- The lack of a comprehensive and modern service; hospital psychiatric services are still provided in an outmoded physical infrastructure and in old buildings, whilst community care and housing services remain inadequate.
- An absence of services for homeless people with mental illness.
- Poor throughput of people in need of acute beds and particularly intensive psychiatric care beds.
- Inadequate services and gaps in coordination and moving people between hospital and community care.
- Assertive outreach and out of hours services
- Early intervention and children's services with new models of practice.
- Prevention and an educational model for prevention working with children and families whose parent or sibling has mental health support needs.

The development of mental health services in the ERHA is currently focusing on two key areas. First, to enhance and develop services for people with milder and more moderate forms of mental illness and distress in a primary health care setting. This is based on evidence that GPs deal with and are treating substantial and growing numbers of people who are mentally ill. However, GPs are not always equipped to tackle these complex issues and work with the Irish College of General Practitioners is being developed to identify training needs in this area. A related priority is that of promoting positive mental health.

The second area is to ensure that there is a comprehensive range of services provided for individuals who require specific and dedicated psychiatric support. This is part of a re-orientation of psychiatric services away from large institutions towards what the ERHA describe in their 2002 Service Plan as "a dynamic, responsive, community orientated service" (2002:113). It also addresses a major problem concerning acute bed capacity in the Eastern Region resulting in inappropriate bed management and high bed occupancy resulting from the lack of provision of core services and high support community residential accommodation (ERHA, 1996). This area also includes the need to integrate more systematic outcome measurement, needs assessment and user involvement.

In the light of the growth of new demands recent good practice in the ERHA has led to the development of the National Forensic Service, the homeless programme for the mentally ill and the appointment of Health Promotion Officers with responsibility for suicide prevention. Other key service developments include the commissioning of a peer advocacy training programme in mental health, a review of psychological and psychiatric conditions within GP practices, a pilot training programme for GPs in suicide prevention, a regional training programme on dialectical behaviour therapy, a pilot project for training and support for the treatment of eating disorders and a plan for the development of child psychiatry services. Funding was also

allocated to Schizophrenia Ireland and Mental Health Association of Ireland for advocacy and other work.

A new monitoring system is currently being piloted in the ERHA region in order to provide information about patterns of service utilisation and service users and will cover age, gender, diagnosis and length of stay. This will be part of the Mental Health ICT strategy that is currently being developed. In addition, reporting on the national performance indicators will take place for 2002.

There are also evaluations of mental health services currently being carried out that will contribute to the mapping of services and gaps in services in the ERHA:

- Mental health needs assessment
- Consumer appraisal study
- Study of catchment area management teams
- Homelessness and mental health
- Autism services
- Psychiatric of old age services

The priorities for the development of services are based on key principles that underpin the commissioning of services that have been established with reference to WHO recommendations (WHO, 2001).

These priorities⁷ include the development of:

- A Mental Health Strategy for the Eastern Region. A review is currently being developed, with user organisations, in each of the three health boards and will set out the priorities for service development that will in turn feed into the national review of mental health signalled in Quality and Fairness.
- A primary care infrastructure for the development of accessible local services.
- Community psychiatric treatment infrastructures.
- Information and education programmes for a balanced mental health lifestyle.
- Partnership model between providers and advocates.
- Psychiatric services to have the capacity to respond to need with adequate in-patient and community treatment.
- Human resources and intellectual capital.
- ICT in the Mental Health Service and for use by professionals
- Effective monitoring and evaluation of service demand, service use, performance indicators and outcomes from treatment.
- Legal advocacy training for psychiatrists and GPs and advocacy systems for peer and user advocacy.
- Mental health promotion approach that incorporates suicide prevention.
- More community based housing provision rooted in a social model as well

⁷ These priorities are established from the 2002 and 2003 Service Plan and from interviews with Breda Lawless, Service Planner for the ERHA in Mental Health and Martin Rogan, Director of Mental Health Services, SWAHB.

as alternative housing solutions, for example, with local authorities and housing associations in order to overcome the current costly solutions that are being sought within the ERHA.

Examples of good practice

- Advocacy training for nursing staff and training for peer advocacy
- Clubhouse Day and Employment Service run by and for people with mental health support needs (Clondalkin and Newbridge)

b) Midland Health Board

i) Mental health services

Mental health services are organised into sectors based on the geographic catchment areas of Laois/Offaly and Longford/Westmeath. In the Laois/Offaly catchment area services are organised into three sectors Portlaoise, Tullamore and Birr and inpatient services are provided at St. Fintan's Hospital Portlaoise. In the Longford/Westmeath catchment services area are organised into three sectors Athlone, Mullingar and Longford and inpatient services are provided at St. Loman's Hospital, Mullingar.

Mental health services are provided by a multi-disciplinary team with a Consultant Psychiatrist providing clinical responsibility for both the sector and wards in St. Fintans Hospital, Portlaoise and St. Loman's Hospital, Mullingar. A senior nurse, at ACNO level, in each sector plays a lead role in the management and co-ordination of service delivery. Each Sector Team comprises of a variety of health care professionals including: medical staff, nursing staff, psychotherapists, psychologists, para-medical support staff, occupational therapist, administrative staff and social workers.

Total revenue funding for 2001 was £22.336m (€28.36m), an increase of 13.45% on the previous year. In 2001 £1.297m was allocated from National Development Plan capital funding for the construction of a new 50 bed acute in-patient unit at the Midland Regional Hospital, Portlaoise and the renovation of existing acute in-patient unit at St Loma's Hospital. Despite an increase in funding for mental health services in recent years, the shortfall in funding for new service developments in 2003 of €0.395 million has resulted in no financial support for some adult psychiatric and substance misuse services which have to be met from the Board's own resources.

Table 29: Summary of funding for disability support services provided directly by the Midland Health Board, 2002 and 2003

Budget and Planned Service Developments, 2002 and 2003			
€m	2001 €m	2002 €m	2003 €m
Total revenue funding	28.36	32.20	34.641
Total revenue funding includes:			
Development funding	0.1.001	0.250	
On-going initiatives	0.871	0.470	
Total	1.872	0720	

Core services are provided in school, home and community settings and provide for prevention of mental illness and promotion of mental health, assessment, treatment and rehabilitation for people with mental illness and support for families. Core mental health services include:

- Mental health promotion in schools, workplaces and community groups
- Suicide prevention and community supports
- Children and adolescent community based out-patient assessment and treatment services
- Counselling for adult survivors of institutional abuse
- General adult psychiatry provided by six Community Mental Health Teams for people between the ages of 16 and 64 years
- Psychiatry in later life provided by consultant led teams for people over 65 years old
- Substance misuse counselling services

Strategic Direction for Mental Health Services 2003

The 2003 Service Plan sets out the strategic direction for mental health services, as outlined in *Quality and Fairness (DOHC, 2001a)*, which aim to:

- Ensure provision of a responsive people centred service
- Maximise the individual's ability to lead as fulfilling a life as possible, supported by a range of existing and new services available within the community
- Provide a range of in-patient and residential care facilities in a modern and appropriate environment
- Provide more flexible and open pathways of referral to services
- Have a uniformly high standard of clinical facilities and working environments
- Continue the professional development of staff
- Build on work carried out in substance misuse education, prevention, treatment and rehabilitation
- Create a mechanism for inclusion of service users in service planning, monitoring and evaluation.
- Break down stigma.

Source: Midland Health Board, Service Plan 2003

Recent service developments

- The development of a comprehensive integrated mental health service for the region.
- Additional allocations for funding in 2001 for the continuation of service developments (£0.637m), for the development of new mental health services (£1.14m), and for the substance misuse prevention and treatment programmes (£0.301m).
- Construction of a new 50-bed acute in-patient unit at the Midland Regional Hospital, Portlaoise, began in 2001 and plans were put in place for a 36 bed acute psychiatric unit for Longford-Westmeath General Hospital.
- Planning for alternative residential accommodation, including two high support residential care facilities, two extended care units and a regional Intensive/Special care unit, and partnerships with voluntary organisations

for the provision of social housing. These developments result from the closure of old institutions and the opening of new acute units in general hospitals.

- Creation of 51 wte posts (medical, psychology, social work, occupational therapy, nursing and non-nursing, audit and research, risk management, substance misuse counselling and administration).
- Implementation of a number of quality initiatives and initiatives to improve the quality of services. In the in-patient psychiatric services quality improvement initiatives have been implemented arising from recommendations in reports of the Inspector of Mental Hospitals.

Key policy, auditing and review initiatives impacting on service planning

- Commencement of a Mental Health Strategy, in order to contribute to and in line with the commitments to develop a new national framework policy for mental health services nationally.
- Report of the Review Group on the Board's Child and Adolescent Services, 2002
- Audit of admissions to hospital due to alcohol related disorders, 2001
- Annual report of the Inspector of Mental Hospitals
- Strategic Review of Substance Misuse and Prevention, 2002
- Data gathering on self-harm and attempted suicide episodes in A&E departments in the Board's area to identify prevention strategies (with the National Suicide Research Foundation).

Key challenges

- Increased demands for day centres, day hospital and community residences.
- Lack of community residential accommodation
- Need for a specialist multi-disciplinary rehabilitation service
- No additional funding has been given to roll-out successful pilot projects on needs assessment and care planning and an integrated clinical pathway for persons attending psychiatry in later life.
- Difficulties in recruiting staff in some areas. In 2001 posts not filled included team leader in the drug and alcohol services and consultant psychiatrist with an interest in substance misuse.
- Difficulties in data collection owing to limited human resources.

Emerging issues/unmet needs

- Lack of access to in-patient facilities for children under 15 years and suitable places for 16-18 year olds. This impacts on care outcomes. In 2002 the MHB sought additional funding for a consultant led team in the region to provide community based services and for the development of a service for children with attention deficit disorder.
- Unmet needs in the area of individual and group therapy, which need to be met through additional psychologists.
- A psychotherapy service is needed in the region.
- Growing waiting list for assessment and treatment for the opiate treatment

service and growing costs of care for individuals attending the service (transport, medicines and GP services). In addition, service targets set out in the implementation of the 2002 Local Drugs Task Force could not be met without additional funding.

- Continuing difficulties in reducing overall hospital beds.
- The need to carry out a population based mental health needs assessment, in line with targets set out in Quality and Fairness.
- The importance for local authorities to meet demands for housing and accommodation for people leaving institutional care.
- Increase in requests under freedom of information for medical notes and information.
- Investment and funding required for modern integrated IT systems to provide timely reports; for a budget for locum consultant cover and for meeting the increasing costs of prescribed drugs with less side effects.

Recent good practice in the health board include:

- Suicide prevention and the Midland Suicide Bereavement Support Service
- Community Drug and Alcohol Services
- Establishment of a peer advocacy service and training in peer advocacy with the Irish Advocacy Network
- Principles in The Prevention of Homelessness in Persons leaving Institutional Care, led to the development of a protocol for the Board in working with local authorities and community welfare offices.
- An individualised needs assessment and care planning project was piloted, audited and implemented in two sectors.
- Integrated care pathways in Psychiatry of Later Life initiative

Voluntary Sector and Partnerships

Grant aid is given to the following mental health voluntary organisations who provide contact and support for persons with a mental illness and their families, particularly in the area of mental health promotion and suicide reduction: Mental Health Association of Ireland; AWARE; Schizophrenia Association of Ireland; GROW and the Irish Advocacy Network.

ii) Disability support services

The Midland Health Board organises its services for people with disabilities within a disability care group, which covers people with an intellectual, physical and/or sensory disability. The disability care group has three main elements:

- Services for people with an intellectual disability and people with autism
- Services for people with a physical and/or sensory disability
- Rehabilitative training, sheltered work and allowances

The aim of the Board is to ensure people with an intellectual, physical and/or sensory disability receive a quality service delivered locally and responsive to their individual needs. The board regards partnership to be key to the delivery of high quality services and there are good working arrangements between the partners in the provision of services to persons with an intellectual

disability. Childcare and family support services are an important aspect of the Board's activities which have resulted from the 1999 Review of Child Care and Family Support Services.

Key aspects of the Board's recent activities

- Emphasis on independent living and community based care, with a programme to transfer people with intellectual disabilities from large residential centres and psychiatric hospitals into the community.
- Further development of respite services to support carers and families.
- Training service providers in person-centred planning and continuous quality improvement.
- A programme of quality improvement.
- Consumer panels so that people with disabilities have a voice in service planning and monitoring.
- A project team has been established to develop a methodology for client satisfaction across all disabilities.
- Service planning is utilising both the outcomes of needs assessments and the disability databases
- Disability Strategy, 2002-2007

Midland Health Board Disability Strategy 2002-2007

The Disability Strategy 2002-2007 was drawn up by the Midland Health Board, service providers, services users and their families in order to more effectively plan services to meet the needs of people with physical and sensory disability in Laois, Offaly, Westmeath and Longford. This is also to ensure that services are coordinated between the different service providers and areas of Health Board activity that impact physical and sensory disability in order to avoid duplication and ensure resources are used effectively. The Strategy is set in the context of the four core principles of equity, people-centeredness, quality and accountability, underpinning *Quality and Fairness*, as well as within a rights-based approach found in *A Strategy for Equality*. The plan states that:

- “The purpose of services for this client group is to facilitate the development of each individual to their full personal and social potential and to maximise their independence, choice and participation in society. This is achieved by advocating, promoting and developing ‘person-centred’ services of the highest quality” (2002:1)

The Strategy identifies gaps in services and sets out a plan for the development of services in the following areas:

- Information, access, counselling and advocacy
- Assessment and therapy services
- Aids and appliances and assistive technology
- Respite and personal support services
- Residential services
- Rehabilitation services
- Education, training and employment
- Health promotion

Recommendations for services in the future concern the coordination of services between different providers; person-centred and partnership approaches to delivering services; and improved strategic planning and implementation.

Recent developments in service

- Development of an advocacy service in the Board’s area. This will be based on the results of an exploration of different advocacy models for people with disabilities. A mentoring model will also be developed for people with intellectual disabilities as part of the development of an advocacy system. This is being carried out jointly with APT and the Midland Health Board.
- The development of training in person-centred approaches is being provided for people with disabilities, parents, family members and service providers.
- A policy and monitoring system, developed by the Board, relevant stakeholders and voluntary providers for the provision of sheltered work for people with disabilities.
- Five year strategy for rehabilitative training.
- Consumer panels to provide feedback on quality of services.

Emerging issues identified by the Board and service users include increasing demands being placed on the system for:

- Information on services and entitlements for people with disabilities.
- Dependent population of older people with intellectual disabilities.
- Respite care and community homes.
- Services for people with challenging behaviour.
- Residential and day services for people with autism.
- Speech and language therapy, occupational therapy and physiotherapy.
- Adults with mild intellectual disability requiring ongoing support from the health board.
- Services for people with head injury (identified as a priority).
- Personal assistant services for people with physical and sensory disabilities.
- Services for older people with physical and sensory disabilities.
- Multidisciplinary team for people requiring psychosexual assessment and follow-up.
- The absence of an educational psychology service has led to difficulties for health related supports and multidisciplinary teams.
- Insufficient therapeutic pre-school places.
- Increasing referrals of school age children with language disorder, poor literacy skills and post cochlear implant.
- Increasing referrals of neo-nates/infants with swallowing/feeding problems to speech and language therapists.

Staffing and management issues:

- Need to involve government departments and agencies in service provision.
- Difficulties in recruiting staff including carer relief, nursing and therapy staff.
- The need to develop a sector team approach and link into Regional Coordinating Committee for Physical and Sensory Disability.
- IT resources for therapy staff.

Other recent service and staffing developments:

- Additional staffing of health professionals and a community worker, although some posts were not filled because of difficulties in recruitment.
- Pilot project on head injury in partnership with Headway Ireland (one wte liaison).
- Funding for respite break for people who have post-polio.
- Summer camps organised for children with physical/sensory disability.
- National Council for the Blind of Ireland (NCBI) (1 wte equivalent IT training officer)
- National Association for the Deaf (NAD) (1 wte aural rehabilitative technician and 1 wte text translator for deaf and hard of hearing).
- Irish Wheelchair Association (IWA) (an additional 48 people took up assistive living services).

- Two temporary resource workers employed to develop and implement the National Physical and Sensory Disability Database.
- Central Remedial Clinic Outreach Clinics (CRC) (Mullingar and Abbeyleix).
- Residential services for people with significant disability: project team established to advise the Board on residential services for people with significant disability and the purchase of a site in Tullamore for six people. In partnership with the Cheshire Foundation.
- Health promotion training to key staff in signing, advocacy and lifestyles.
- Waiting times for therapy services: Speech and Language Therapy services in Longford/Westmeath developed software to capture waiting times
- Audiology: project team established to advise the Board in relation to audiology services.

Gaps and challenges identified in services

Although the Midland Health Board mapping exercise was not fully comprehensive (owing to gaps in the data provided by service providers) the additional research carried out for this mapping exercise has shown that there remain significant gaps in services in the Midland Health Board region. The no additional service development principle underpinning services in 2003 does not help to resolve this.

The mapping exercise addressed the issue of gaps in services and some service providers provided detailed information about these gaps. The main gaps in services and challenges facing the services exist in the following areas:

Core services and staffing

- Staffing for therapeutic and other support services including physiotherapy, occupational therapy, speech and language therapy, and counselling services (this includes overcoming the problems of recruiting speech and language therapists).
- Day services.
- Home help and home support services.
- Respite services.
- Community residencies.

Improved quality and range of services

- Overcoming fragmentation in services through better coordination and integration of services.
- Development of new services that encompass independent needs assessment, advocacy, independent advocacy services, independent living for people with disabilities, and personal assistance.
- Extension of standards to all statutory funded services in the non-statutory sector (using NDA model).
- Inspection of all residential and day facilities using the model of the Social Services Inspectorate and the Inspector of Mental Hospitals.

Services for specific groups

- Services for challenging behaviour, including policy and guidelines
- Services and coordinated assessment procedures for people with dual-diagnosis.
- Services for people with mild intellectual disability.

c) Southern Health Board

The Southern Health Board has a total population of 580,605 people, which is growing. Services are organised on the basis of five catchment areas in North Lee, South Lee, North Cork, West Cork and Kerry.

i) Mental health services

Mental health services are organised through multi-disciplinary teams in each of the five areas, led by a Clinical Director and with a Director of Nursing and Principal Psychologist in each area. There are 26 Consultant Psychiatrists, including one with a special interest in intellectual disability, one old age Consultant Psychiatrist and one Liaison Psychiatrist. In 2003, €0.790 million was allocated to the Board for the continuation of ongoing services in child and adolescent psychiatry, suicide prevention, support to voluntary agencies, adults services, and education and training schemes.

In 2002, *Focussing Minds...Developing Mental Health Services in Cork and Kerry*, was developed in consultation with users of services and user organisations, with a framework for developing services in the near future. The change agenda that the report presents is focussed on a community-orientated approach that is supported by hospital services and the establishment of Community Mental Health Teams, Community Rehabilitation Teams and the development of associated services and infrastructure to support the work of the teams.

Key priorities and plans:

- To develop services in line with *Focussing Minds*, particularly concerning a shift from hospital based to community based services.
- Develop advocacy services
- Development of housing projects, day hospitals and day centres.
- Development of the Board's suicide prevention strategy Targeting Suicidal Behaviour.
- Develop a mental health promotion strategy.
- Develop a mental health advocacy service and develop the advocacy network in the mental health service.
- Consolidate work with homeless people.

Focussing Minds...Developing Mental Health Services in Cork and Kerry

The strategy document *Focussing Minds* is rooted in the Southern Health Board's *Caring for People* mission. This is set in values of excellence, integrity and openness, respect and support, loyalty to organisation, caring and commitment, efficiency and effectiveness, communication and leadership.

Focussing Minds represents a change in Board policy on mental health services towards a new model of care based on primary care, health promotion, public health and community based services. As part of the development of the strategy the Board carried out a consultation process with users, which was undertaken on the Board's behalf by the Irish Advocacy Network, a user run and led organisation. A separate booklet *What We Heard During Our Consultation* has been published with quotes of the key issues that were raised in the consultation. The main issues and gaps raised were:

- Additional services needed in the community
- Involvement of service users and carers in planning
- Care Plans and Discharge Plans essential
- Key workers required and more staff needed
- Ombudsman for Mental Illness
- Policy on acute units within general hospitals needed
- More information and education on mental health issues needed, to continue de-stigmatisation of mental illness
- Information on services is required
- Less medication and where medication is provided information on what is being prescribed is needed
- Respite beds needed
- Alternative therapies required – holistic approach needed
- Training for staff
- Condition of out-patient departments is poor
- Need additional day care services
- Range of residential accommodation essential which provide rehabilitation
- Many facilities need to be upgraded
- Multi-disciplinary team working is necessary
- Over reliance on medical model of provision

As well as mapping existing services and gaps in services the review looked at models of mental health service provision nationally and internationally and expert opinions were sought from the Chair of the Mental Health Commission and the Inspector of Mental Hospitals. The report of the review states that "...the current service model does not match the expectation of our users and other stakeholders. Our staff wants to deliver modern, high quality, person-centred services. Research suggests that by reorientating mental health services, there is a better quality of life for users, greater job satisfaction for our staff and overall, better outcomes". It goes on to stress that there is a need "to change the way we deliver our service...The outcome of this review proposes the introduction of a new model of mental health service provision" (2002: 23). The new model of service provision is based on the development of community Mental Health

Teams and Rehabilitation Teams. An action plan sets out the strategic actions, targets and timeframes.

ii) Services for people with physical and sensory disabilities

The Board is organised around six Care Groups: services for children, services for older people, services for people with physical and sensory disabilities, illness prevention services, community health services and drug and alcohol treatment services. In 2003, funding of €1.818 million was provided for funding of core services, with additional funding of €0.422 million for the rehabilitation and sheltered occupation services. The Board is currently in the process of developing a three-year action plan for the development of services for people with physical and sensory disabilities in line with *Towards an Independent Future* (1996) and *Quality and Fairness (DOHC, 2001a)*.

Key priorities and plans concerning people with physical and sensory disabilities:

- To work with non statutory organisations in identifying gaps in core services and develop a consumer panel system.
- Implementation of the Accommodation Services Project which identified the accommodation and respite needs of adults with physical and sensory disabilities. The project team are identifying best practice and solutions to housing needs for people with physical and sensory disabilities.
- To develop Assisted Living Services / Home Support Out-of-Home Services within available resources.
- Establishment of a multi-disciplinary group from the Physical and Sensory disability sector, Intellectual Disability Services and Acute Services to review assessment, diagnosis and early intervention procedures for children with disabilities.
- The further development of community therapy, psychology and nursing services within the care group structure and within a coordinated and multi-disciplinary approach.
- The development of a regional Audiology Service Plan 2003-2007 in coordination with hospital, health board aural service providers and voluntary groups.
- Review of rehabilitative training and sheltered occupational services in order to identify current and future needs.

The tables below summarises the main service objectives for 2003

Table 30: 2003 Disability Service Objectives. Southern Health Board

2003 Service objectives	Actions to achieve objectives	2003 Funding
Priority services, respite, home supports, paramedical services, aids and appliances etc.	The funding will be applied to address service pressures as identified locally	€1.515,000
National Physical and Sensory Disability Database	To facilitate the continued roll out of the database	€257,000
Regional Coordinator	The provision of a regional coordinator for the Disability Federation of Ireland	€46,000
Rehabilitative Training and Sheltered Occupational Services	To assist the Board in maintaining existing levels of service	€422,000

iii) Services for people with intellectual disability

Services for people with intellectual disabilities are planned and organised in line with national policy and the Board's objective of providing care in appropriate settings. In 2002, funding of €2.270 million was provided for services for people with intellectual disabilities, including additional residential, respite, day, home support and specialist support services. Additional funding of €0.127 million in 2002 enabled the Board to develop a specialist service for people with challenging behaviour. Revenue funding of €0.317 million was also provided to enhance support services for children with intellectual disability and autism, including additional therapy in schools. In 2002 a Regional Autism Spectrum Disorder (ASD) Team was set up. Additional funding of €1.500 million has been provided for 2003 to enhance support services for children with an intellectual disability or autism and to meet the full year costs of the 2002 development programme.

The Board, in partnership with the non-statutory sector, is currently drawing up a Five Year Regional Development Plan 2002-2008 for Intellectual Disability and Autism Services. This will guide the future development of services.

Key priorities for 2003 include:

- Development of specialist high support respite services
- Support to voluntary agencies in continued development of community supports and day services.
- Review the operation of home support services and develop an integrated model of service.
- The Regional Planning Committee is to carry out a research project to establish the number of people with ASD and to inform a new development plan based on a regional assessment of need.
- Development of services, particularly children's health support services and an expansion of the regional assessment team, multidisciplinary supports to children in mainstream schools, and residential, day, home support and respite services for ASD.
- Development of specialist services to people with intellectual disabilities and major challenging behaviour in partnership with the DOHC, Brothers of Charity and the COPE foundation, including a new 8 place regional short-term therapeutic unit for adults with major challenging behaviour at COPE Foundation.

d) North Western Health Board

The North Western Health Board (NWHB) has a population of 211,000 people. The region has the lowest population density compared to other boards and an older population than other parts of the country. The region is divided into two areas Sligo/Leitrim (population of 81,956) and Donegal (129,435). Disability services have been developing towards more community based provision, with a significant expansion of community and home based services in recent years. In the Intellectual Disabilities Services, a projected increase in spending of €10 million from 2000 for the following decade is based on a comprehensive plan for services resulting from an in-depth

consultation and needs assessment in the region. Training and employment support services are provided for 700 people with physical, sensory, intellectual or mental health disabilities across the region in four training centres. 42% are people with learning disabilities, 41% have mental illness and 17% have physical and sensory disabilities.

i) Mental health services

Mental health services in the NWHB are informed by the Board's strategy for mental health *Into the Millennium and Beyond – A Strategy for Mental Health in the North West* and the NWHB response to the *National Report on Suicide*. In addition, a major review of mental health services was initiated in 2003 and is being carried out by the UK based Sainsbury Centre for Mental Health with plans for reporting in November 2003.

Recent developments:

- Reorientation of services from institutional care to acute units, day and community provision has resulted in infrastructural developments. Development of Acute Admissions Units in Sligo General Hospital and Letterkenny General Hospital. Purchase of community based units to meet the needs of remaining patients in the St Conal's Campus and purchase of community accommodation for a Supervised Residential Unit in Dungloe and commissioning of a similar Unit in Manorhamilton. New day centre in Letterkenny. Other services include a range of accommodation options with the Sligo Mental Health Association.
- An emphasis has been placed on promoting positive mental health. This has been achieved through health promotion activities in post primary schools and as part of the Underpressure Project run at junior level. This programme has been evaluated by NUI Galway. A survey of health professionals and voluntary and community services was carried out to assess attitudes and practice in the area of mental health promotion. This will be used for the strategic development of mental health promotion. Consultations have also taken place regarding suicide prevention and positive mental health for young men. A steering group has been established to assess factors impacting on the positive mental health of older people.
- The development of a suicide prevention programme has resulted in the appointment of a suicide coordinator in the Board's trauma and loss service, the development of new services, training, research and information and training for staff on suicide prevention.
- Enhanced service provision has resulted in the appointment of two new Consultants in Old Age Psychiatry, Consultant Psychologist and Consultant Psychotherapist, improved coordination with Primary Care Services through the appointment of a GP liaison worker, additional management staff, day centre staff, nursing staff, counsellors and doctors. A particular emphasis was placed on services for post-natal depression, a review of day services and new day services in the region, sheltered housing, and the provision of motorised transport vehicles.
- Other service developments include the development of consumer advocacy in the region and improved IT capacity.

ii) Services for people with physical and sensory disability

The NWHB has developed *Progressing the Partnership: A Multi-Annual Plan for People with a Physical and Sensory Disability, 2002-2006*. This resulted from an extensive consultation process with users, carers, voluntary groups and service providers. The Plan states that the focus of services and the underpinning values “now concentrates on the rights of people with disability in terms of full participation and full inclusion in community life, individualised services, increased choices, localised services and ‘living at home’” (NWHB, 2002:1).

Recent developments in services:

- A reorientation of services resulting in increased home support (66% increase). This has resulted in 279 people in receipt of home support services (compared to 111 one year previously); 50 people in receipt of the Home Care Attendance Scheme; 75 people in receipt of a Personal Assistance Service, covering 47,608 personal assistant hours, and the creation of Home Support Referral Committees in each area to coordinate home support service provision.
- Appointment of key workers to assist people with high dependency needs and Brain Injury and additional Physiotherapists, Speech and Language Therapists and family support workers.
- Cooperation with Cheshire Homes in providing high dependency residential and respite services for people with high levels of need.
- The Assistive Technology Support Unit established in Sligo in 2001 provided assistance to over 100 recipients. This Unit provides access to technology for people with disabilities and has video conferencing facilities that link with the Central Remedial Clinic in Dublin and centres around the world. This has reduced the number of trips that people have had to make to Dublin.
- A new Personal Opportunities Training Programme established in Donegal Cheshire Apartments for ten people.
- Wide dissemination of information packages jointly funded by Comhairle and the Board.
- Support to various non-statutory organisation in provision of services, for example, National Association for Deaf People provided six outreach programmes with support to 30 families; MS Ireland provided a carers break for Donegal carers; as well as grants for specialised aids and appliances for the NADP and NCBI. .
- Establishment of a personal support service for 17 children with disabilities, including respite for families.

Priority developments:

- *Accommodation, respite and additional therapy support and training.* A particular need is for accommodation for people with high support needs in community settings with personal choice. This is being developed with Cheshire Homes for 20 people. An independent living skills house is planned in Donegal to support confidence and skills for independent living. Increased home and personal support services are needed to enable

people to have the choice to live in their own homes. A respite team has been developed in Donegal to provide a range of options for respite and a Family Support Work Programme is supporting children and adolescents with a disability to participate in daily activities and develop friendships.

- *Implementation of the Multi-Annual Plan for People with a Physical and Sensory Disability, 2002-2006*, which requires an additional €35 million over five years to implement. This will be developed “in a coordinated and innovative way with service providers working together in partnership arrangements [and an] integrated approach to care planning for individuals will become a consistent feature of the system”. This will be achieved through greater communication and liaison between clinicians and services, the development of care management approaches, and the appointment of key workers for care planning with children with disabilities.

iii) Services for people with intellectual disabilities

Services for people with a learning disability are currently being guided by two needs assessment surveys in Sligo/Leitrim/West Cavan and Donegal. These needs assessments have been important in mapping services and identifying gaps in services.

Key developments include the provision of the following services:

- Development of community supports, including Counselling for Special Needs Service, Community Support Facilitator Service, Early Intervention Service
- A substantial increase in carer support through home help services.
- Increased respite care provision, which in 2001 provided 119,951 hours of respite, of which 32,610 are respite nights. An average of 91 people per month receive respite services.
- The development of pre-school facilities and classroom assistants as well as assistants to support children in mainstream schools.
- There was also a further development of community based residential services with the provision of new community group homes and a review was carried out of services.
- Autism services were further developed to provide high support to children, family support, home help, carers support, weekend respite and summer camps.

e) South Eastern Health Board

SEHB has a population of 391,046 (based on the 1996 Census). The SHB is organised in four community care areas (Wexford, Waterford, South Tipperary and Carlow/Kilkenny), which also cover services for people with disabilities

i) Mental health services

Recent developments in services:

- Building of acute admissions unit at St Luke's hospital in Kilkenny; providing 45 beds and transfers were completed in 2003.

- Upgrade and extension of high support hostels.
- 21 bed residential unit completed in Kilcreene Hospital, Kilkenny, developed in partnership with the Mental Health Association, for people with intellectual disability who were previously in St Canice's Hospital.
- Consultant psychiatrist with special interest in old age appointed for Wexford Mental Health Services; a second post was waiting approval from DOHC.
- Community child care and adolescent services were enhanced through the provision of two additional teams.
- New day centre completed in 2001 at St Vincent's, Tipperary.
- Family therapy services established in Coolgreaney House, Clonmel.
- Community focus to mental health services enhanced through additional posts: family therapists, nursing staff, care assistants and social workers. An outreach service was established for home support services.
- Community mental health centre established in Enniscorthy.
- Review of Industrial Therapy Units attached to the mental health services.
- Developments within the Regional Suicide Resource Office include initiatives to reduce the incidence of suicide and parasuicide including training, support to local suicide bereavement support services, including the introduction of a lo-call number for people wanting to receive bereavement support, funding for pilot liaison psychiatric nursing post to deal with self-harm, development of *Mental Health Matters* resource pack in partnership with Mental Health Association, and the development of a *Directory of Services for People in Distress* and wide dissemination of information cards *Help and Health for You*.

A service map has been produced by SEHB that provides some basic information about mental health services. Mental health services are provided by sector teams at community level and by five county based hospitals (in Clonmel, Kilkenny, Carlow, Enniscorthy and Waterford).

- St Dymphna's Hospital: A 115 bed psychiatric hospital. Acute and long stay care, out-patient, addiction counselling, respite, community hostel facilities and day care facilities.
- St Canice's Hospital: A 138 bed psychiatric hospital: acute and long stay care, out-patient services, addiction counselling, respite care, community hostel facilities and day care facilities.
- St Luke's Hospital: Provision of 168 long stay beds and a 50 bed acute psychiatric unit, outpatient services, addiction counselling, respite care, community hospital facilities and sector headquarters for day hospital and day care facilities and vocational training.
- St Otteran's Hospital: 118 bed psychiatric hospital, acute services are provided at Waterford Regional Hospital (45 bed unit). Services include out-patient services, addiction counselling, respite care, community hostel facilities and day care facilities.
- St Senan's Hospital: 213 bed psychiatric hospital providing acute and long stay care, out-patient services, addiction counselling, respite care, community hostel facilities and day care facilities.

The 2003 Service Plan identifies the following objectives:

- Implementation of the 2001 Mental Treatment Act
- Continue to provide a high standard of care to inpatients, hostel residents, day patients and people receiving services in the community.
- Develop mental health services at primary health care level.
- Develop acute psychiatric services in acute general hospitals.
- Develop patient care plans for rehabilitation, vocational training and activation.
- Health promotion and awareness of mental health in the community
- Promote good working relations with health care staff and voluntary organisations
- Build on work on substance misuse education, prevention, treatment and rehabilitation.
- Maintain existing levels of service and consolidate 2002 developments.
- Establishment of a review group for the development of a comprehensive strategic plan
- Development of a consultant led team for Psychiatry of Old Age
- Raise public awareness and develop advocacy schemes
- Further development of the suicide prevention strategy
- Further development of Child and Adolescent Psychiatry Service

ii) Services for people with intellectual disability

There are three residential homes for people with intellectual disabilities (in Clonmel, Enniscorthy and Wexford).

Recent developments in services

- New day and residential places for adults and children. For example, in 2001, 67 people benefited from funding allocated for new or additional residential services, 77 people benefited from new or enhanced day services and 15 emergency needs were met through unplanned service requirements. Continued upgrading and development of premises for day and residential care.
- New funding in 2001 also enabled 303 children and adults to benefit from day or residential respite services; additional numbers received home based respite support.
- Enhanced guidance / assessment service for the provision of rehabilitative training for people with intellectual disability.
- Continued relocation of people from inappropriate psychiatric institutions to appropriate residential settings. In 2001, 21 people were transferred from St Canice's Hospital to purpose built accommodation.
- Collection of data to prepare for the signing of service agreements with voluntary agencies.
- Joint training with staff in the non statutory and statutory sector on autism and challenging behaviour.
- Development of standards of care for services in the region.
- Service reviews on Autism and Challenging Behaviour.

Priorities for 2003

- To continue to develop the full range of services and develop and enhance services in a number of priority areas.
- Establish a permanent service response to meeting the needs of clients who presented with emergency needs in 2002.
- Provide emergency responses only to those who present with crisis.
- Services for children with Learning Disability and Autism.
- Training front line staff and managers to assist in dealing with people with Challenging Behaviour.
- Development of service agreements with non statutory organisations.
- Strategic review of Autism.
- Continued development of capital projects under the National Development Plan

iii) Services for people with physical and sensory disability

The Board aims to “assist persons with physical and sensory disabilities to achieve their full potential through the development of appropriate and responsive services, which enable people to live with dignity and with the greatest independence possible”. This includes the objective of providing high quality, customer friendly services.

Recent developments in services

- Extension and development of day, respite and residential services.
- Additional home support and personal assistance services for 58 people for the first time and 40 people were provided with an increased service.
- Additional specialist services for people with visual and hearing disabilities.
- Additional specialist therapeutic services, multi-disciplinary teams, and the development of a Regional Assessment Centre in partnership with the Central Remedial Clinic.
- Development of a Regional Acquired Brain Injury Assessment and Advisory Team
- Enhanced guidance / assessment service for rehabilitative training for people with disabilities.
- Review of home support services in the SEHB region.

Priorities for the Board for 2003

- Continuation of the planning for the full range of day services and new services in Waterford and Carlow.
- Enhancement and development of Personal Assistants and Home Care Attendant Services.
- Skills enhancement of Multidisciplinary Therapeutic Services
- Specialist services for children
- Enhancement of services for people with Acquired Brain Injury.
- Further enhancement of residential and respite services with Cheshire facility in Waterford and other agencies.
- Complete the database for the region.

Examples of good practice: initiatives in mental health services and services for people with disabilities

There exist some good examples of consulting and involving people with disabilities in the planning and development of services:

- *St Lomans Mental Health Service* Commissioning Group commissioned a piece of research to gain the views of community-based service users who had been patients at St Lomans Hospital to inform the relocation and development of acute hospital services to a Unit in a general hospital. The research outlines the main arguments and a process for including service users in the planning and development of health care services (Elliot, 2000).
- *Experiences of Mental Health Services from a User-Led Perspective (2002)*. The *Pathways* research project explored service users experiences of mental health services in Galway city and was conducted by a team of mental health service users, in collaboration with a member of staff from the mental health services and Schizophrenia Ireland. The project was funded by the Western Health Board. Mental health users were at the center of the research, both as researchers and interviewees. A key recommendation from the research relates to communication between service users and service providers. The report concludes that: "It is clear from this study that mental health service users have expertise and desire to be active participants and not passive recipients of treatment in the mental health services" (2000: 23).

2.10 Conclusions

The review of health boards in this section shows that there have been some positive service developments in recent years, not least in orientating services towards a social model of disability and the development of community based services. However, this section has largely reviewed the new developments taking place and has not dealt with some of the fundamental problems facing health boards, including chronic under-funding of services and poor quality of services. Indeed, many of the developments in recent years have yet to be realised in practice.

In mental health services there is a general absence of a modern service and inadequate provision of community based services to meet the demands for services in the community as part of the general shift away from institutionalised care. There continues to be inappropriate placements of people with intellectual disabilities in mental hospitals because of a lack of appropriate day and residential accommodation. The development of mental health services for homeless people, people in prison, young people and older people are an indication of services being developed to meet needs in more effective ways. However, there remain significant gaps in the provision of advocacy and assertive outreach programmes, and a need for the further development of involvement of service users and carers in planning. In the ERHA, the problem of acute bed capacity is directly related to the inadequate provision of community based and appropriate residential accommodation. Services for people with an intellectual disability and autism are also being developed to address shortfalls in services, including gaps in services that

provide community based residential accommodation, high support respite, home support services, counselling services and the development of specialist services to address challenging behaviour. Similarly, the development of needs assessments and strategies for the development of services for people with physical and sensory disability is resulting in a greater emphasis on the provision of more appropriate and quality services.

CHAPTER 3: INTERNATIONAL GOOD PRACTICE IN HEALTH AND SOCIAL CARE SERVICES FOR PEOPLE WITH DISABILITIES

3.1 *Introduction*

This chapter identifies international good practice in disability health services that provides some useful learning and direction for disability health services in Ireland. It looks first at International and European instruments that are increasingly framing good practice developments in Ireland. It then goes on to look at a range of good practice at the national level in a selection of countries. A key focus of this survey is to identify good practice that can be used to inform service developments and the commissioning of services in Ireland. The methodology is based on a literature review of primary and secondary sources, including reports of European and international organisations and national governments.

This review of international good practice is particularly relevant to developments taking place in Ireland, notably regarding the development of new disability legislation. The report of the Disability Legislation Consultation Group (2003) makes reference to the importance of international good practice. In particular, policy developments in the European Union and the United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities have been important in framing future developments in disability health services and the parallel shift internationally to the introduction of rights based approaches to disability services. The DLCCG report states that:

- New legislation on disability in Ireland is part of a broader process of change internationally and nationally that is shaping a new social model in Ireland. This is based on changing values, rights and principles, with equality, participation, quality and inclusion being increasingly regarded as key values and principles underpinning Irish social policy. Ireland has also contributed to and benefited from the development of the European model of social rights rooted in social cohesion and social inclusion. (DLCCG, 2003: 1)

The greater interest in rights-based approaches in legislation, giving access to legally enforceable rights to services, has been an important part of the development in thinking in this area. This was first recommended by the report of the Commission on the Status of People with Disabilities. The DLCCG argues that the rights of people with disabilities need to go beyond those found in the anti-discrimination legislation to ensure that appropriate economic

and social supports are available to enable people with disabilities to exercise those rights in practice.

In the review of international literature, the following common themes come up:

- Health, social care and rehabilitation are provided in and for non-disabled environments. Programmes are often ongoing with few clearly focussed and community based goals.
- Support services are often controlled and allocated by health service professionals and with limited participation of disabled service users.
- Health personnel lack expertise in the provision of general health care for people with disabilities, health information and health advice is often limited and negative assumptions abound.
- Medical services are orientated towards prevention and acute treatments rather than long-term supports, particularly for mental health system users.
- Medical services do not empower people to live independently in the community.
- Services are poorly coordinated and integrated and this has a major impact on the planning of quality health and social care services.
- The shift to a social model of disability has been hindered by a historical and institutional reliance on a medical and welfare model of disability.

However, there have been some very positive developments in the provision of health services for people with disabilities, notably:

- The provision of services by people with disabilities for people with disabilities, for example, based on the Clubhouse model for people with mental health difficulties.
- The representation of people with disabilities on decision-making bodies and the involvement of disability service users in the planning, organisation and monitoring of services.
- The growth of more targeted health services for people with disabilities with a greater emphasis on the coordination of services and the development of multi-disciplinary teams.

Piastley (2003) argues that disability, like age, has been an administrative category in social policy. In contrast to the medical model of disability, the social model of disability has been the basis upon which people with disabilities have promoted disabled people's autonomy and control in their own lives and as a civil rights issue. As Vic Finkelstein argued in 1980:

- Once social barriers to the re-integration of people with physical impairments are removed, the disability itself is eliminated. The requirements are for changes in society, material changes to the environment, changes in environmental control systems, changes in social roles, and changes in attitudes to people in the community as a whole. The focus is decisively shifted on the source of the problem – the society in which disability is created.

The changing perceptions and attitudes to people with disabilities has resulted in a shifting policy focus on inclusion rather than exclusion, on rights rather than charity and on independence rather than dependence, independent living rather than institutionalised living. This has resulted in a rejection by people

with disabilities of policies that promote care and management. Many service developments are aspiring to good practice located in community-based interdisciplinary approaches with the maximum participation of disabled person and his/her family in decision-making. The social model of disability has stressed the need for attitudinal changes and on the basis that it is attitudes that disable more than the disability itself. Similarly, care policies can be disabling and as Helen Meekosha (2001) argues "Care" sits at the point of intersection between the social management of disability and the politics of personal autonomy.

In their survey of comparative anti-discrimination disability law Degener and Quinn (2000) argue that the paradigm shift from the medical to the social model of disability has enabled disability to be seen as a human rights issue. This is a reflection of a corresponding shift from welfare law to civil law whereby equal opportunities for disabled people could be used to challenge disabled people's segregation, institutionalisation and exclusion. At the time of their survey 40 of the 189 UN Member States had adopted anti-discrimination legislation for people with disabilities. In particular, the American with Disabilities Act (ADA) of 1990 has impacted on the development of anti-discrimination legislation globally. These developments have particularly important implications for health and social care services in Ireland.

New thinking about service delivery includes the need to both decouple support services from medical services and also integrate the full range of services required for independence and participation. As Finkelstein (2001) argues this includes the development of new skills and training and community-based professionals who can deliver recipient requested services whereby the service user requests assistance to meet his or her own aspirations. This is compared to care services which are 'deliverer determined' whereby the service provider assesses the needs of the disabled person and then decides which services can be provided.

In the area of health services for people with disabilities there are three related areas of good practice that are discussed in this report.

- Equality and legal protection against discrimination
- The development of a social model of disability through community-based, integrated and independent living
- The quality of health and social care provision
- *International Covenant on Economic, Social and Cultural Rights*, includes rights to the highest attainable standard of physical and mental health. The Covenant contains a number of provisions that impact on people with disabilities: Article 12 includes the right of everyone to the enjoyment of the highest attainable standard of physical and mental health; Articles 23 and 24 concern rights for all children; and Article 15 covers the right of everyone to participate in cultural life. Although the Covenant is not binding it does make a clear statement of principle and obliges 'contracting states' to take steps to the maximum of their available resources and progressively to achieve their full realisation.
- Various international Conventions which have articles and provisions that are of relevance to people with disabilities including: *Convention on the Rights of the Child* (1989); *Convention on the Elimination of All Forms of*

Discrimination Against Women (1979); and *Convention on the Elimination of All Forms of Racial Discrimination*. All have various references to non-discrimination in areas such as health and disability.

- Various Declarations including the *Declaration on Social Progress and Development* which includes the rights and assuring the welfare of children, older people and disabled people (Article 11c). Declarations have also been agreed on the *Rights of Mentally Retarded Persons* and the *Rights of Disabled Persons*. The *Declaration of the Rights of Mentally Retarded Persons* includes a right to proper medical care and physical therapy, participation in community life, and where residential care is necessary that this should be in circumstances as close to those of normal life. The *Declaration on the Rights of Disabled Persons* sets out norms related to human dignity, equal civil and political rights, measures to promote independence, the right to medical, psychological and functional treatments and to medical and social rehabilitation, vocational training and rehabilitation, aid, counselling and services to promote social integration or reintegration. It also includes the right to economic and social security and community participation and living.

Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (adopted by the UN General Assembly in 1993).

A significant outcome of the Decade of Disabled Persons was the adoption, by the UN General Assembly, of the *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* in 1994. Although not legally binding, the Standard Rules represent a strong moral and political commitment by Governments to take action for the equalisation of opportunities for people with disabilities. The rules serve as an instrument for policy-making and as a basis for technical and economic cooperation. The Standard Rules consists of 22 rules summarising the message of the UN. The 22 rules cover four chapters - preconditions for equal participation, target areas for equal participation, implementation measures, and the monitoring mechanism - and cover all aspects of life of disabled persons.

3.2 International good practice

International good practice on disability can be found in legal and other measures that are increasingly shaping the development of disability policies at the national level. At the international level this has been established principally by the United Nations and the World Health Organisation; whilst at the European level this has been established by the Council of Europe and more recently the European Union.

a) United Nations

The international policy agenda is important in both reinforcing and establishing good practice regarding national disability policies. Disability is now part of the mainstream international human rights agenda the emergence of which was marked by the 1975 UN General Assembly Declaration on the Rights of Disabled Persons. This was followed by International Year of Disabled Persons in 1981 and the development of a World Programme of

Action. In 1985 the Universal Declaration of Human Rights was extended to include disabled people and in 1993 the UN *Rules on the Equalization of Opportunities for Disabled Persons* addressed participation in eight specific areas: accessibility, education, employment, income maintenance and social security, family life and personal integrity, culture, recreation and sports, and religion. Similarly the importance of the social model of disability was reinforced by the UN in 1994 in that "...society creates a handicap when it fails to accommodate the diversity of all its members" and "People with disability often encounter attitudinal and environmental barriers that prevent their full, equal and active participation in society" (United Nations, 1994, paragraphs 3 and 4). By 1995, the implementation of the Standard Rules had led to the reformulation of thinking on disability issues at the national level in a large number of countries, where they have been used as a benchmark to guide good practice in a social model of disability (Michailakis, 1997; Priestly, 2003).

The main instruments of the United Nations are:

- *Universal Declaration of Human Rights (1948)*, covering fundamental political and civil rights, contains fundamental human rights such as the right to life, liberty and free speech.
- *International Covenant on Civil and Political Rights, 1966*, which came into force in 1976, upholds the rights set out in the Universal Declaration concerning the right to life, liberty, equality before the courts, peaceful assembly, marriage and having a family, freedom of association, conscience, thought and religion. Article 26 guarantees equality of treatment without unfair discrimination, including discrimination on the basis of disability. Various articles are relevant to people with disabilities in the broad area of health, residential and social care, including inhumane or degrading treatment and consent to medical or scientific treatment (Article 7), institutional abuse (Article 9), privacy (Article 17), the right to marry and found a family (Article 23) and equality in access to public affairs, voting and public services (Article 25) (Quinn, 1995).

The UN Standard Rules were originally intended as a statement of principles and values rather than legal rights and although States are not legally forced to adopt them they have been used widely. According to Degener and Quinn (2000) there is "No doubt the UN Standard Rules of 1993 provided the key moral imperative for change on a worldwide basis. There can equally be no doubt that the enactment of the Americans with Disabilities Act (ADA) showed that change was possible and practicable". Rule 15 of the Standard Rules states that "States have a responsibility to create the legal basis for measures to achieve the objectives of full participation and equality for persons with disabilities". Degener and Quinn (2000) go on to say that the "...history of disability discrimination law in a number of countries reveal that either the ADA and/or the Standard Rules served as a model law for the domestic legal development". Three global surveys have been carried out to date by the United Nations Commission for Social Development and the impact has been felt positively in a large number of countries.

The first four *Standard Rules on the Equalisation of Opportunities for Persons with Disabilities*, concern the provision of awareness raising, medical care, rehabilitation and support services.

The Standard Rules place responsibilities on government bodies in evaluating and implementing national programmes. Many countries have taken the Standard Rules as their explicit frame of reference. The Finnish Government was the first country to adopt the Standard Rules in its legislation in 1993 and in 1998 the Greek government incorporated the Standard Rules into national law. In Norway, UN Standard Rule 3 on Rehabilitation is based on the rights of individuals to define their own goals and that services shall assist and stimulate the responsibilities and efforts of the individuals to gain well-being. This is in a framework of community based provision, local community involvement and coordination of services. An Action Plan for disabled people is based on a social model of disability which recognises the limitations on the local environment and which places responsibilities on local authorities and other bodies to ensure the full participation of disabled people (WHO, 2000a).

Appendix 8 lists the main provisions of the Standard Rules and provides the full text of the provisions related to *Preconditions for Equal Participation* covering the provision of awareness raising, medical care, rehabilitation and support services.

Other relevant instruments include the Proposed new UN *Convention on the Rights of People with Disabilities* which is being discussed by the UN Ad Hoc Committee set up by UN Resolution 56/168 to “consider proposals for a comprehensive and integral international convention to protect and promote the rights and dignity of persons with disabilities”. The proposed UN Convention on the Rights of People with Disabilities aims to give legal protection to rights for people with disabilities by building on the UN Standard Rules which have been the principal international instrument designed to protect the rights of people with disabilities. However, the Standard Rules are voluntary and there is little scope for recourse where violations or non-application occurs. In other areas the UN has adopted legally binding conventions to protect against human rights violations for disadvantaged groups, for example, covering women and refugees. An international Convention on the Rights of People with Disabilities is proposed to form the central component of this international legal framework, providing in amongst other areas the right to a decent education, the right to vote, the right to due process, the right to participate in the life of the community. There appears to be growing international backing for the introduction of the Convention, including backing from the European Union.

b) World Health Organisation

The World Health Organisation, established as the health arm of the UN in 1948, has the objective of the attainment by all peoples of the highest possible level of health. Health is defined in WHO's Constitution as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. According to the WHO the limited participation of disabled people in school, work and social activities is no longer viewed as a result of their impairments, but as a result of societal barriers to their

participation. The rights of people with disabilities to have the same opportunities as others in their communities and societies are now well recognized. Despite the increased awareness about the community participation of people with disabilities and the developing policies and legislation related to disability, there are still many disabled people who do not have adequate opportunities to access rehabilitation services to attend school, to achieve income producing work, or to participate in activities characteristic of their communities.

The WHO has also established a classification for the functioning, health and disability of people. The ICF (International Classification of Functioning, Disability and Health) was established in order to focus attention on quality of life, health and social policies to improve access and treatment, and take account of social aspects of disability by focussing on the impact of the social and physical environment on a person's functioning.

Initiatives in the WHO impacting on the development of good practice include the 2001 campaign on mental health, and annual report 2001 focused on "*Mental Health: New Understanding, New Hope*", includes recommendations about what states should do to improve mental health care.

Recommendations set out in the WHO's *Mental Health: New Understanding, New Hope* should be used to inform service developments and the commissioning of services. The ERHA Service Plan for 2002 refers to the recommendations from *New Understanding, New Hope* to guide its commissioning principles.

In addition, the WHO programme on disability and rehabilitation (DAR) provides support to Member States for policy development with special focus on chronic conditions and support for integrating rehabilitation into Primary Health Care through Community-Based Rehabilitation (CBR). Based on UN and WHO guidelines, the objective of DAR's programme is to enhance the quality of life and equality of opportunities for all people with disabilities by supporting Member States in framing policies, developing appropriate services, and strengthening community participation.

WHO has also been monitoring the implementation of the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities concerning government responses to the implementation of the rules on medical care, rehabilitation, support services and personnel training (WHO, 2001b).

Not surprisingly health and health services are areas where a great deal of work has been carried out in establishing quality initiatives and standards. This includes the development of policy concerning health systems and financing, human rights, service provision, health promotion and research (WHO, 2001c). WHO has set a wide range of targets and standards in relation to *Health For All* and in relation to areas such as air quality, public service reforms and health personnel, mental health quality policy and service provision, quality child health etc. A key issue in many of these documents is the importance of well-trained staff, continuous education and capacity building for health staff; information and technology resources.

The WHO also sets out standards regarding different aspects of care, including access to health care and the development of primary health care

and community-based models. It argues that good quality care services are cost-efficient, equitable, they improve staff morale and they save lives. There are many examples of quality improvement and quality assurance systems being developed using a range of tools and instruments that have been developed by WHO to test the quality of care (Brown, undated; WHO, 2001c).

According to the WHO "Health and rehabilitation can no longer be understood solely in terms of orthodox medical interventions and conventional notions of 'care'. These centre almost exclusively on the perceived limitations of individuals rather than on society's failure to accommodate the needs of people with disabilities. Thus, there is an urgent need for an approach that cares not only about disabled people but also about society and its structures" (WHO, 2001:1c) Recommendations made by the WHO include:

- *A holistic approach: access, legislation and funding.* This includes the development of community-based services, accessible services, anti-discrimination laws, and support.
- *Medical services.* This includes the provision of high quality medical services as a basic human right, participation of disabled people in allocation of resources, fully accessible services in both mainstream and targeted services, recruitment and training of disabled people as doctors, nurses and other medical service personnel.
- *Rehabilitation services.* This includes the removal of barriers to full participation and where necessary appropriate education, training and skills to secure meaningful participation in economic, social and cultural life of the community.
- *Support services.* Access to support services should be a basic human right and that provision should be free, participation of disabled people and their families and disabled representatives of disability organisations should be a key feature and programmes should be community based and controlled by people with disabilities.
- *Awareness-raising.* Awareness-raising targeted to all sections of the community with the participation and involvement of disabled people.

In evaluating the UN Standard Rules on medical care, rehabilitation, support services and personnel training the WHO has provided a number of good practice examples that are helpful to service developments and the commissioning of services. These include:

Medical care

- The provision of programmes of early detection, diagnosis, assessment and treatment,
- Full involvement of people with disabilities and their families in the planning and monitoring of services and programmes.
- Provision of medical care for children and adults with disabilities in the general medical system.
- Awareness raising for health and medical personnel.
- Provision of disability programmes in multi-disciplinary teams of professionals and the full participation of people with disabilities and their families in the planning and evaluation of these programmes.

- Free provision of medical care for people with disabilities.
- Trained medical and paramedical staff who are equipped to provide medical care to people with disabilities.
- Primary health care model.
- Provision of information and communications about services in Braille/tape, sign language, easy readers etc.

Rehabilitation

- Provision of rehabilitation services to enable all people with disabilities, including people with severe or multiple disabilities to reach their optimum level of independence and functioning.
- Local community based provision of rehabilitation services.
- Involvement of people with disabilities and their families in the design, organisation, provision and evaluation of rehabilitation programmes.

Support services

- Access to assistive devices, provided free of charge or affordable.
- Development, production, distribution and servicing of equipment and dissemination of information about them should be undertaken by the State.
- Provision of personal assistance, interpreter services and equipment by the State in order to achieve equalisation of opportunities.
- Community based and home based support.
- Financial support to carers and to families with children with disabilities.
- Involvement of people with disabilities and their families in the planning, organisation, provision and monitoring of support services.

Personnel Training

- Human resource planning to ensure the optimum mix of health professionals in order to provide the best quality service.
- Disability awareness training for health personnel.
- Training programmes should stress the importance of the principle of the full participation and equality for people with disabilities.
- Training programmes to be developed in consultation with people with disabilities and people with disabilities should be involved as teachers, instructors and advisors in staff training programmes.

3.3 *European Good practice*

a) European Union

Good practice is also being established at the European level in a variety of ways to promote equality and the European social model. A key shift in European policy has been to develop mechanisms for the exchange of good practice through the open method of coordination in European policy established at the Lisbon Council in 2000. The European mechanisms include:

- An emphasis on the social model of disability can be seen in recent policy statements and the Charter of Fundamental Rights agreed at the Nice Summit in December 2000. The Charter recognises the importance of the prohibition of discrimination and the right of people with disabilities “to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community” (Article 21).
- In the area of anti-discrimination Article 13 of the Treaty on European Union explicitly refers to disability discrimination. This has led to the introduction of a new generation of directives focussed on anti-discrimination. This covers various legal provisions concerning disability, including the new framework directive on employment. The bulk of these legal provisions, however, concern employment opportunities and non-discrimination in access to employment and training. Issues concerning health and social care, for reasons of subsidiarity, remain the competence of the member states.
- The Community Action Programme to Combat Discrimination (2001-2006) aims to support member states in developing legislation and policies for combating discrimination. It covers seven grounds of discrimination. The programme aims to strengthen the capacity to address or prevent discrimination through exchanges of information and good practice, and through awareness raising. Anti-discrimination measures are further developed under the *Social Policy Agenda* and through the inclusion of provisions for the respect for fundamental social rights ‘as key components of an equitable society and of respect of human dignity’ (European Commission, 2000:22). One example of a good practice initiative funded under this programme is a European project on anti-discrimination and managing diversity involving directors of health and social services across Europe. The project, run by the European Social Network, is establishing good practices across Europe in relation to health and social care services for people with disabilities, minority ethnic groups and older people.
- Disability is also an important theme related to EU policies to combat social exclusion. The agreement at the Nice European Council for a new impetus for the development of actions to combat poverty and social exclusion has resulted in an open method of policy coordination, national action plans on social inclusion, and an action programme designed to strengthen member states efforts in developing indicators, benchmarking, improved statistical information, research, networking and exchanging of good practice.
- A Community Action Programme (2001-2006) to encourage cooperation between member states to combat social exclusion aims to further promote good practice across the Member States in the field of social inclusion through innovative approaches, networking and exchanges of information and good practice. The Programme is intended to complement the national action plans by developing “...a better understanding of mainstreaming the combating of exclusion in Member States and Community policies and measures, and the development of priority actions chosen by Member States in accordance with their particular situation” (2000:8). The operation of the Open Method of Coordination in the

development of the National Action Plans Against Poverty and Social Exclusion (NAPincl) which have a wider impact on disability and services, including access to quality services, health care etc.

- Programme of transnational measures as part of additional funding allocated for *European Year of People with Disabilities* (including a €12m budget for national and transnational meetings, events, information, surveys and studies).
- The EU has the competence to increase its role in the promotion of good mental health through prevention-orientated initiatives as part of the obligations on public health in the Treaty on European Union.

European Disability Forum: The Madrid Declaration

The Madrid Declaration represents a vision developed at the European Congress on Disability welcoming the proclamation of 2003 as European Year of People with Disabilities. The Declaration sets out a framework for action at European Community level, national, regional and local level.

The preamble includes the following principles:

- Disability is a human rights issue
- Disabled people want equal opportunities not charity
- Barriers in society lead to discrimination and social exclusion
- Disabled people: the invisible citizens
- Disabled people form a diverse group
- Non-discrimination + positive action = social inclusion

The Programme for Action includes the following:

- 1. Legal measures including comprehensive anti-discrimination legislation.
- 2. Changing attitudes
- 3. Services that promote independent living
- 4. Support to families
- 5. Special attention to disabled women
- 6. Mainstreaming of disability
- 7. Employment as a key for social inclusion
- 8. Nothing about disabled people without disabled people.

Various actions are suggested for the EU, local authorities, disability organisations, employers, trade unions, media, education institutions, disabled people to implement.

b) Council of Europe

The Council of Europe was established to protect human rights in 1949 and has 41 member countries. It has been important in establishing a range of civil, political, social and economic rights in the European region. The implementation of human rights legislation in the UK and Ireland and the incorporation of the European Convention on Human Rights and Fundamental Freedoms into European Union law has the potential to impact directly and significantly on the human rights of people with disabilities. In the UK the Human Rights Act has particular relevance in that people with disabilities now can litigate against the withdrawal or restriction of medical services and the

abuse and degrading treatment of disabled people in institutional care (Daw, 2000).

The most important instruments impacting on disability are:

- *European Convention on Human Rights and Fundamental Freedoms (ECHR)*. The European regional equivalent to the International Covenant on Civil and Political rights and the judicial enforcement of civil and political rights exists through the European Court of Human Rights. The Convention has been important in developing case law in a key number of areas impacting on disability, under liberty, fair trial, inhuman or degrading treatment and mental disability. A non-discrimination clause fails to explicitly cover disability.
- *The European Social Charter of 1961 (amended in 1996)*. Most of the principles in the European Social Charter have relevance to disability. They include the opportunity to earn a living in an occupation freely entered into (principle 1), the right to just conditions of work (principle 2), the right to appropriate facilities for vocational training (principle 10), the right to benefit from measures enabling the person to enjoy the highest possible standard of health attainable (principle 11), the right to benefit from social services (principle 14). Principle 15 states that disabled people have the right to vocational training, rehabilitation and resettlement. This requires States to take a range of measures concerning employment, including measures “To promote their full social integration and participation in the life of the community in particular through measures, including technical aids, aiming to overcome barriers to communication and mobility and enabling access to transport, housing, cultural activities and leisure”.
- *Council of Europe Convention on the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Biomedicine and Human Rights (1997)*. Although the Convention has a number of shortcomings it states that there should be protection for the dignity and identity of all human beings and [to] guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine.
- *Council of Europe Convention on the Prevention of Torture and Inhuman and Degrading Treatment (1987) and Disability (CPT)*. This Convention has been important in the context of people with disabilities who reside in a mental institution or other residential care.
- *Partial Agreement in the Social and Public Health Field*. This has led to the discussion of a range of disability matters (including discrimination based on disability) by the Committee on the Rehabilitation and Integration of People with Disabilities (CDPRR).
- *Recommendation of the Committee of Ministers on the adaptation of health care services to the demand for health care and health care services of people in marginal situations (2001)*. This includes people with disabilities along with other groups who live in marginal situations and advocates the development of integrated and coherent social and health policies and measures to reducing inequalities in health. This is based on principles of human rights and patient's rights, human dignity, social

cohesion, democracy, solidarity, equality, participation and freedom of choice.

- *Recommendation on a Coherent Policy for Persons with Disabilities 2001.* This recommendation aims to implement the principle of equal opportunities and non-discrimination principles found in the UN Standard Rules regarding prevention, active participation in community life and independence. This includes a number of aims, for example, involvement in the planning and implementation of rehabilitation and integration processes, full citizenship and access to all institutions and services in the community, independence and self-determination and particular attention to the situation faced by women and older people with disabilities. It covers general policy, prevention and health education, identification and diagnosis, treatment and therapeutic aids, education, vocational issues, employment, social integration, protection, training of personnel, information, statistics and research.
- *Recommendation Concerning the Legal Protection of Persons Suffering from Mental Disorder Placed as Involuntary Patients and Subsequent Developments.* This recommendation results from the 1997 White Paper on the protection of the human rights and dignity of people with mental disorder, especially those placed as involuntary patients in an institution. At the time it was recommended that Member States review their legislation and administrative rules on the confinement of the mentally ill by reducing to the minimum the practice of compulsory detention. The Recommendation was agreed in the light of a number of important cases in the European Court of Human Rights. The Recommendation covers the grounds for involuntary loss of liberty and the rights of those subjected to this power. A further Recommendation in 1994 on psychiatry and human rights updated the principles within a human rights context.
- *Recommendation on A Charter on the Vocational Assessment of People with Disabilities 1995.* This recommendation argues for ‘the greatest possible measure of social and economic participation as well as independence’.

3.4 Case Study: The right to health

This section looks briefly at various instruments on the right to health. It gives a more detailed discussion of Article 12 of the UN’s International Covenant on Economic and Social Rights. The right to health is recognised in a large number of international instruments, including:

- Article 25.1 of the *Universal Declaration of Human Rights* affirms: “Everyone has the right to a standard of living adequate for the health of himself and of his family, including food, clothing, housing and medical care and necessary social services”.
- The *International Covenant on Economic, Social and Cultural Rights* provides the most comprehensive article on the right to health in international human rights law. Article 12.1 of the Covenant, requires States parties to recognise “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health”. Article 12.2 illustrates a number of “steps to be taken by the States parties ... to achieve the full realization of this right”.

- The right to health is also referred to in anti-discrimination conventions including Article 5 (e) (iv) of the *International Convention on the Elimination of All Forms of Racial Discrimination* of 1965; articles 11.1 (f) and 12 of the *Convention on the Elimination of All Forms of Discrimination against Women* of 1979 and in article 24 of the *Convention on the Rights of the Child* of 1989.
- Regional human rights instruments also recognize the right to health, such as the European Social Charter of 1961 as revised (art. 11).
- The International Bill of Rights includes amongst other areas rights to equality and non-discrimination; health can be seen as one component of the realisation of human rights.

According to the WHO “..societies should organise their resources for health equitably, so as to make them accessible to everyone” (WHO, 1999:5). WHO targets for health include addressing inequalities in health by tackling poverty and the particular risks faced by women, children, the elderly and those suffering from mental illness (WHO, 1999b). Equity in health means that “everyone should have a fair opportunity to realise his or her full health potential and that no one should be prevented from achieving this potential” (WHO, 1999a:5).

In Ireland the issue of human rights and health has been of recent significant concern to the disability movement who are critical of the absence of a rights based framework for disability services. The recent political interest in health care has also raised the issue of how a rights based approach to health care could be developed to ensure that there is equity of access and rights to services. The United Nations Committee on Economic, Social and Cultural Rights (2002) recently concluded that Ireland needed to address human rights issues in the context of a wide range of areas, including, health services and disability services. The right to health care is seen as fundamental to human rights. The Committee recommended that the State incorporate economic, social and cultural rights in the proposed amendment to the Constitution as well as domestic legislation, a human-rights approach to the Disability Bill and to health services. In relation to health the Committee recommends that the State:

- ...revisit the recently published National Health Strategy with a view to embracing a human rights framework in that strategy, in line with principles of non-discrimination and equal access to health facilities and services...The Committee furthermore urges the State party to introduce a common waiting list for treatment in publicly funded hospitals for privately and publicly insured patients. (2002:4)

Article 12 of the International Covenant on Economic, Social and Cultural Rights (United Nations)

The right to the highest attainable standard of health is set out in article 12 of the International Covenant on Economic, Social and Cultural Rights. In this respect “Health is a fundamental human right indispensable for the exercise of other human rights. Every human being is entitled to the enjoyment of the highest attainable standard of health conducive to living a life in dignity” (United Nations, 2000). Article 12.1 covers the right to “the highest attainable standard of physical and mental health”. This includes the right to health,

which includes a wide range of socio-economic factors and underlying determinants of health (article 12.2). This right to health has both freedoms and entitlements. The freedoms include the right to control one's health and body, including sexual and reproductive freedom, and the right to be free from interference, such as the right to be free from torture, non-consensual medical treatment and experimentation. Entitlements include the right to a system of health protection, which provides equality of opportunity for people to enjoy the highest attainable level of health. The interpretation of the right to health in article 12.1 includes the right to timely and appropriate health care, the underlying determinants of health, as well as the participation of the population in all health-related decision-making at the community, national and international levels.

This also includes availability, accessibility, acceptability and quality of health care and other related goods and services. Under, quality it states that "As well as being culturally acceptable, health facilities, goods and services must also be scientifically and medically appropriate and of good quality". Under accessibility Article 12.1 states that health facilities, goods and services have to be accessible to everyone without discrimination. This covers:

- *Non-discrimination* so that health facilities, goods and services are accessible to all, particularly the most vulnerable and marginalized people
- *Physical accessibility* whereby health facilities, goods and services are within safe physical reach for all sections of the population, especially vulnerable or marginalized groups. Accessibility further includes adequate access to buildings for persons with disabilities.
- *Economic accessibility (affordability)* whereby health facilities, goods and services must be affordable for all. Payment for health-care services, as well as services related to the underlying determinants of health, has to be based on the principle of equity, ensuring that these services, whether privately or publicly provided, are affordable for all, including socially disadvantaged groups. Equity demands that poorer households should not be disproportionately burdened with health expenses as compared to richer households.
- *Information accessibility*, which includes the right to seek, receive and impart information and ideas concerning health issues. This should include the right to have personal health data treated with confidentiality.

In the area of *Acceptability*, health facilities, goods and services must be culturally appropriate, i.e. respectful of the culture of individuals, minorities, peoples and communities, sensitive to gender and life-cycle requirements, as well as being designed to respect confidentiality and improve the health status of those concerned.

The requirement to promote the right to health requires States, to ensure that "health services are culturally appropriate and that health care staff are trained to recognize and respond to the specific needs of vulnerable or marginalized groups". Similarly, this requires that "medical practitioners and other health professionals meet appropriate standards of education, skill and ethical codes of conduct" and that "there is provision of "appropriate training for health personnel, including education on health and human rights". Regarding the provision and funding for health services "States have to ensure the

appropriate training of doctors and other medical personnel, the provision of a sufficient number of hospitals, clinics and other health-related facilities, and the promotion and support of the establishment of institutions providing counselling and mental health services, with due regard to equitable distribution throughout the country”.

Article 12.2 (d) covers the right to health facilities, goods and services including the provision of equal and timely access to basic preventive, curative, rehabilitative health services and health education; regular screening programmes; appropriate treatment of prevalent diseases, illnesses, injuries and disabilities, preferably at community level; the provision of essential drugs; and appropriate mental health treatment and care. This also includes the participation of the population in the provision of preventive and curative health services and participation in political decisions relating to the right to health taken at both the community and national levels. Specific provisions are recommended regarding non-discrimination and equal treatment, gender, older people and people with disabilities. Articles 2.2 and article 3 of the Covenant also prohibits discrimination in access to health care and underlying determinants of health on a number of grounds including physical or mental disability and health status (including HIV/AIDS). In this respect “equality of access to health care and health services has to be emphasized” (Economic and Social Council, 2000).

The Economic and Social Committee states that the core objectives of Article 12 require States to adopt measures:

- To ensure the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalized groups;
- To ensure equitable distribution of all health facilities, goods and services;
- To adopt and implement a national public health strategy and plan of action, on the basis of epidemiological evidence, addressing the health concerns of the whole population; the strategy and plan of action shall be devised, and periodically reviewed, on the basis of a participatory and transparent process; they shall include methods, such as right to health indicators and benchmarks, by which progress can be closely monitored; the process by which the strategy and plan of action are devised, as well as their content, shall give particular attention to all vulnerable or marginalized groups.

Finally, the Committee states that national health strategies should identify appropriate right to health indicators and benchmarks and that these should be disaggregated on the grounds of discrimination. Benchmarks should also be set in relation to each indicator and these will be used as the basis for monitoring the implementation of Article 12.

States that ratify the Covenant agree to an international obligation to submit reports to the United Nations on the measures that have been adopted and the progress made through five yearly reports. The Committee on Economic, Social and Cultural Rights reviews these. However, major problems exist with the reporting and monitoring of the Covenant by States. Suggestions for a

new approach to monitoring women's right to health include providing funding to NGOs to monitor their governments (Chapman, 1995).

3.5 *National examples of good practice*

a) Introduction

This section explores a number of national good practice examples covering both health and social care service provision for people with disabilities as well as disability rights. It begins with a discussion of health care funding and the organisation of services, and then considers examples under the three main themes: equality, rights to services and protection against discrimination; quality of services; and the provision of services within a social model of disability framework.

b) The funding of health care

There are a variety of different models of health service financing. These include tax based models, social insurance models, controlled market insurance and private insurance. Table below provides an international comparison of health care funding. The most equitable systems are found in those that are based on funding through direct taxation and social insurance.

Table 31: Health Care Financing: International Comparison

Health Care Financing: International Comparison		
Financing mechanism	Main revenue raising mechanism	Supplementary revenue raising mechanism
Tax based financing	Ireland UK Canada Australia Sweden New Zealand	USA (elderly/children) Belgium Germany France
Social insurance based mechanisms	Belgium Germany France The Netherlands	-
Controlled market insurance	Switzerland	
Private insurance: free market	USA	UK New Zealand Canada (pharmaceuticals)
Out of pocket payment	-	All

Source: Deloitte & Touche (2002) Value for Money Audit of the Irish Health System: Executive Summary, Page 18

c) The organisation and provision of health and social care services in Europe

There is a wide diversity of models of services provision in the Member States of the EU. A brief comparative analysis shows that services are relatively well developed in the Nordic countries, where universal entitlements to services exist. In sharp contrast, services remain rudimentary in Spain, Greece and

Portugal, and to a lesser extent in Italy and Ireland, where family and charity based systems of care have been relied upon. However, there is now more evidence of coordinated services through multidisciplinary approaches to providing services for people with disabilities in recognition of both a social model of disability and the multi-faceted problems and needs that extend beyond health and social services to housing, transport, training, employment and so on. This has resulted in some evolving methods of internal and external coordination, of multidisciplinary teamworking and a greater understanding of the service needs of users across Europe.

Nevertheless, the structure, funding and organisation of the health and social care services varies significantly across the EU. In summary, four main welfare regimes exist in Europe (Pillinger, 2001, Esping-Anderson, 1990).

- *Continental Europe (Germany, France, Belgium, Austria, the Netherlands and Luxembourg)*. Welfare systems have developed based on the relationship between social needs and merit/work performance, funded from employer and employee contributions to social or national insurance schemes and some direct taxation. The provision of insurance-related social benefits outweighs the provision of services. This model has particularly facilitated direct payments for people with disabilities. Health care is financed from social insurance.
- *Social democratic model or Scandinavian model*. This has developed from a principle of the individual as part of a social collective, whereby universal services and the entry of women into the labour market became the mechanism for fulfilling social needs, financed through direct taxation. The model is based on principles of social rights derived from citizenship, universalism, redistribution, social partnership and a strong public sector. Although this model is based on production and financing by the public sector and institutionalised welfare, the recent trend has been towards more private sector solutions in social security systems; the introduction of charges for services, and contracted-out care and welfare services. Nevertheless, there are a wide range of entitlements and in some cases rights to services, including high levels of support services and funding for the promotion of independent living. Health care is funded from a combination of central taxation and social insurance.
- *The UK and Ireland*. A model of welfare rooted in the Beveridge principles of universalism, although benefits are at lower levels and have a higher degree of selectivity than in the social democratic model. It was predicated on the assumption of women's role in the home and full employment. However, in the UK in the last two decades the model has been shaped by a policy of a reduced role for the state, an increasing welfare mix focused on market competition, and a focus on selectivity and targeting rather than universalism. In the UK health care is funded through national taxation, whereas in Ireland there is a unique mix of national taxation and private insurance.
- *Southern Europe*. Portugal, Spain, Italy and Greece have developed rudimentary welfare systems based largely on family and voluntary systems of support and limited state involvement. Portugal, Spain and Greece are characterised by increased levels of state intervention in recent years. Nevertheless the family remains the main instrument of

solidarity between the generations, and employment in the social public services remains relatively low (Pillinger, 2001). Health services are funded by insurance.

d) Equality, rights to services and legal protection against discrimination

There has been a noticeable change in disability policy in recent years with an increasing emphasis on a social model of disability and the adoption of anti-discrimination legislation in a large number of countries. According to Degener and Quinn (2001) this is reflected in the "...paradigm shift to the human rights perspective is now nearly universal. Most countries are beginning to view disability as a human rights issue".

Different approaches to the rights of disabled people are in evidence. In Germany, Finland and Canada provision is made in constitutional law, whereas in Britain, Sweden and Ireland provision is made in civil law, and in France in criminal law. A particular role is played by human rights legislation in the USA, UK, Canada, New Zealand and Australia.

Anti-discrimination legislation: international comparison of different legal approaches				
Country	Constitutional law	Civil law	Criminal law	Human rights legislation
Australia		✓		✓
Canada	✓			
Denmark		✓		
Finland	✓			
France			✓	
Germany	✓			
Ireland				
Netherlands		✓		
New Zealand		✓		✓
Sweden		✓		
UK		✓		✓
USA		✓		✓

Waddington and Diller (2001) suggest that disability activists in both North America and Western Europe have argued for a re-evaluation of the concept of disability and the thinking behind disability policy through:

- ...a recognition of the role which physical and attitudinal barriers play in excluding people with disabilities (a key tenant of the civil rights model of disability), and a rejection of the assumption that medical impairments automatically result in disadvantage and exclusion (an assumption inherent in the social welfare model of disability).

They argue that despite the recognition of anti-discrimination legislation as part of the civil rights model this has not resulted in a complete overhaul of disability policy, rather newer policy instruments, inspired by the civil rights model, have been added to existing and older instruments, such as the long-established social security schemes, segregated education and housing programmes, and employment quotas which were originally inspired by the social welfare model. The tension between the social welfare model and the civil rights model is particularly important in Ireland and suggests that consideration should be given to a new conception of disability policy. Similar tensions can be identified when discussing good practice at the national level.

For example, in Canada and the Nordic countries, access to high quality health and social care sits alongside positive developments in disability rights and anti-discrimination policies. In this respect, it is important to recognise the importance of the dual impact of a well-funded, universal system of health care that provides a wide range of health and social supports for people with disabilities, alongside a civil rights framework that provides for a social model of disability and a rights based framework. A key issue is the extent to which health services are organised equitably. According to the World Health Organisation (WHO) “..societies should organise their resources for health equitably, so as to make them accessible to everyone” (WHO, 1999a:5).

Although a large number of countries have outlawed discrimination against disabled people at work, this is more limited in relation to rights to health and social care services for people with disabilities. There are some rights based approaches to health and social welfare provision and some interesting examples of the right to certain services have been established in Sweden, Finland, the USA, Australia and Canada.

In Sweden and Finland, there is a right to named services, including personal assistance and support. In Germany legislation introduced in 2002 on equality of treatment (Behindertengleichstellungsgesetz, BGG) has the goal of eliminating discrimination of disabled people to ensure their participation in society, the elimination of barriers and the provision of sign language. The legislation contains a right to action for associations/organisations of disabled people (who are significant service providers in Germany) if rights are violated, but not the right to action for individuals.

The emergence of disability policies to promote equal opportunities has been related, on the one hand, to the development of civil rights for disabled people across Europe, and on the other, to the importance governments now attach to integrating disabled people into work and reducing welfare dependency. In mental health, models of care have shifted away from health care into social support, education and work-related activity. I have argued elsewhere that these developments are rooted “in new notions of user empowerment, new ethics of care based on empowerment, and principles of independent living, which stress personal assistance rather than care. They have had the effect of challenging disabling professional attitudes and disabling services by problematising dependency within the context of social relations that excludes and depersonalises disabled people” (Pillinger, 2001).

Even in those countries that suffer from inadequate funding and service provision, there exist new discourses regarding the needs of adults with severe disabilities, and the need to integrate health, welfare, psychology, education and other services in order in order to maximise the potential for independence. There is no doubt that families and service users who are articulating the need for a broad mix of services favour this focus. The greater articulation of users’ needs is having an impact on new investment programmes to improve community, institutional and group care for adults with learning disabilities.

The examples that follow have been selected to reflect good practice in the provision of disability and health services as well as civil rights approaches. This covers the European countries of Finland, Denmark, France, the

Netherlands, Sweden and UK, as well as Australia, Canada and the USA. They cover the provision of health and social care services, rights to services and equality and legal provisions.

Finland

Provision of health, social and rehabilitation services

Finnish health and social care services are based on a Nordic model of welfare with roots in Protestantism and democracy and a political tradition of social democracy. This has emphasised the role of the state in providing universal services and a basic minimum income for all. The main features of the Finnish model are comprehensive policies, social rights derived from citizenship, the public sector as the main provider, earnings-related and flat-rate income benefits, public provision of services financed by taxation, equality, and the redistribution of income. In recent years there has been the introduction of income-related charges and eligibility conditions for some services. Health and social services are decentralised to Finnish municipalities.

Since the 1970s there has been a policy shift away from institutional to open care for adults with learning disabilities and mental illnesses. This led to the introduction of a five-year plan, instigated by the National Board of Social Welfare, to develop community care services and make home care services compatible with other services. As a result the 1984 Social Welfare Act required municipalities to develop services for adults with learning disabilities that are generally available to other municipal residents. In practice, the bulk of care is provided at home by families, and as a result the introduction of home-care services has been highly important in enabling this target group with learning disabilities to be cared for in their own family settings.

Although the organisation and provision of care services varies across the Finnish municipalities, there is evidence of improvements in services, resulting from increasingly effective collaboration between localities and different administrations, and better information about services. This is particularly the case where specialist services are required, and collaboration has been introduced for the purchase of these services from specialist care circuits. For instance, in the Padasjoki municipality, the provision of services for adults with learning disabilities among general municipal services, and the integration of services for disabled people with other welfare services, are considered to be positive developments by relatives and personnel. The coordination and integration of services for people with learning disabilities and people with mental illnesses has become more necessary in the light of these principles.

Disability legislation

In Finland health care is provided at the local municipal, district level, provincial, and national levels and people with disabilities are included as part of the general medical system. This includes general practitioner, specialised doctors, paediatrician, nurse, psychologist, primary health care worker, physiotherapist, speech therapist and occupational therapist. A primary health care model enables services to be provided in rural areas. Medical care is

provided free of charge through the government's social insurance scheme. The health care system provides for a range of prevention, early detection, diagnosis and treatments; in some cases people with disabilities are involved in the planning and evaluation of services. A national rehabilitation programme exists and programmes are provided at local, district, provincial and national levels. Social care and home-based supports are provided by municipalities. This includes personal assistance, assistive devices and interpreter services.

A number of principles have been developed in Finland as a basis for organising services for adults with learning disabilities. These include recognition for the person's potential to participate as an equal member of the community and society; normality and integration; integration and client-orientation; thinking in terms of life as a whole; quality of life and the right to self-determination.

The *Act on Services and Assistance for Disabled People* promotes independent living and equal opportunities and provides for services to be provided irrespective of financial or social status. The Act of 1987 provides an individual right to independent living services for severely disabled people, including transportation, housing, interpretation services and personal assistance services. Because the Act's main purpose is to enable disabled persons to live as a member of society on equal footing with others the Act is also called the *Disabled Person's Equality Act*. Of interest is that the Act suggests that inequalities can result from the provision or non-provision of services, for example services which are dependent on municipal funds. The *Act on the Status and Rights of Patients* of 1992 has a clear anti-discrimination clause in relation to health care. Furthermore, the Finnish Constitution has been amended to include social and economic rights alongside traditional political and civil rights. This requires equal opportunities to be applied in all areas, including health, housing and education on the basis that "everyone who is incapable of securing the necessities of life with human dignity has the right to the necessary income and care". A new provision includes the rights of people using sign language and the need for interpretation and translations services, the rights to which are now guaranteed in the law.

Finland was the first country to adopt the UN Standard Rules in 1993, resulting in a disability policy programme in 1995. In 1995 the Constitution Act of Finland was amended to include the equal treatment of people with disabilities. A Toolkit has been developed by the Finnish government providing guidance to local authorities on how they can implement the Standard Rules at the local level.

Denmark

Provision of health, social and rehabilitation services

Denmark provides health, social, and rehabilitation services through a universalistic social democratic model that is primarily public sector led and provided, and funded through taxation. It is based on principles of universalism, equality and redistribution. This model has been open to

criticism and scrutiny in recent years for its financial burden, inefficiency and paternalism. There are increasing problems of waiting lists, concerns about a growing number of unsupported vulnerable groups, concerns about the legitimacy of the model, and a breaking of the consensus over the welfare model that has dominated the post-war Danish welfare system. In contrast to other Scandinavian countries the Danish model places a higher priority on social services than on social security benefits. The majority of services are provided at the local level (social services) or the regional level (health).

The Danish health care system provides a range of prevention, early detection, diagnosis, rehabilitation and treatment programmes for people with disabilities within the general medical system. People with disabilities and their families are sometimes involved in the planning and monitoring of services. Medical care is provided free of charge through the Danish social insurance system. A national programme of rehabilitation is provided through community based programmes provided by local, district and county governments. People with disabilities are also involved in the design and provision of rehabilitation programmes. Support services are provided by local municipalities and personal assistance is provided at home, school, work, and leisure. Interpreter services (provided through sign language and speech interpretation) are provided at home, school, work, leisure and at health and social service provision is provided free of charge by the municipalities.

Disability issues are included in the training of professionals and staff training programmes are developed in consultation with people with disabilities and directly involve people with disabilities as teachers, instructors and advisors.

Denmark has a long tradition of social and rights based legislation that includes the rights of people with disabilities to participate fully in public life. Denmark has a highly devolved system of social provision and resources are provided at local levels for this.

France

Provision of health, social and rehabilitation services

The French model is based on two principles: insurance and assistance. Health and social care services are provided through a complex structure of state provision with a large number of services decentralised to local authorities, departmental authorities, and social and socio-medical institutions. The operation of assistance and insurance has led to problems with a dual system where responsibilities are divided between the government, regional and local authorities. An increasing number of services are now delegated by the government to the private sector and non-profit associations. The French Government is responsible for the approval and regulation of these organisations.

The French health care system operates at local, regional and national levels and is funded through a social insurance system which provides free health care. People with disabilities are treated as part of the general medical system, which provides for a range of prevention, early detection, diagnosis, treatment and rehabilitation services. A national rehabilitation programme exists and community based rehabilitation services are provided by NGOs.

Support services are provided by local municipalities which are part funded by social insurance, local municipalities and NGOs. A range of personal assistance and interpreter services are provided. People with disabilities tend not to be involved in the planning and monitoring of services. In France recent reforms are marked by a shift from models of care assistance to models of support and the development of autonomy, self decision-making, independent living and integration into the labour market. In particular, education for young handicapped adults outside of the family has been developed in order to facilitate their integration into society, their autonomy and independence.

Disability legislation

The French Penal Code makes it unlawful to discriminate against a person with a disability on the grounds of health or impairment when providing goods, services or employment.

The Netherlands

Provision of health, social and rehabilitation services

The Netherlands is characterised by a social democratic model with high levels of welfare spending and access to universal and comprehensive benefits, although influenced by Christian Democratic ideology and a social insurance model. The social partnership model between government and interest groups have introduced wage moderation, control of public spending and control on social security and has had some successes. This led to an agreement to trade off wage moderation for an increase in jobs between the social partners, a reform of the social security system, including cost containment, cuts and measures to reintegrate people into work. The 'polder model' also led to new systems of consultation, discussion and consensus building activities that were also applied to the health service through systems of self-administration at local levels, alongside the introduction of marketisation of services. The Netherlands has highly decentralised services and a high level of provision and its services are universal. The bulk of services are provided by non-profit organisations that are funded by the state, local authorities and social insurance. These organisations have moved from being charities to professional service providers. The emphasis is on public funding and private provision of care and the development of a market-orientated and needs-led service. A high priority is given to client empowerment and local user forums.

The Dutch health care system operates at the district and national levels and is funded by a national social insurance scheme and provided free of charge by a range of statutory and non-statutory organisations. Services include a range of prevention, early detection and diagnosis, treatment and rehabilitation programmes. People with disabilities and their organisations are regularly involved in the planning and monitoring of services. A national rehabilitation programme exists and community based provision is provided at local levels. Support services are funded by the national and local government (municipalities) and a range of personal assistance and interpretation services are provided and financed through social insurance. People with disabilities and their families are involved in the planning and monitoring of services.

Direct payments schemes exist for the provision of home based care and personal assistance for people with physical and sensory disabilities and people with intellectual disability.

Disability legislation

The rights of disabled people are protected by a combination of special and general legislation. The law allows for legal remedy through courts and there are a number of non-judicial mechanisms that exist to promote non-discrimination. The general legislation applies to all categories of disabled persons with respect to education, employment, the right to marriage, the right to parenthood/family, political rights, access to court-of-law, right to privacy and property rights. There are also a number of guarantees to services in law including the right to medical care and other health care, training, rehabilitation and counselling, financial security, participation in decisions affecting them. The Netherlands has adopted the UN Standard Rules and implemented them through the Act on Facilities for the Disabled (WVG) which was adopted and came into force in 1994. Since the adoption of the Rules the Government has been active in their dissemination and has sought to integrate the basic principles of the Rules through a programme for an intersectoral policy on the disabled, 1995-1998.

Sweden

Provision of health, social and rehabilitation services

Sweden has a long social democratic tradition of universal services for its citizens that continue to be at one of the highest levels across Europe. The Swedish social democratic model is based on full employment, women's participation, active labour market policies and universal benefits based on notions of citizenship and entitlement, and social corporatism typified by social partnership approaches to policy making and bargaining. A high priority is now attached to the reform of welfare to reduce its abuses and adverse effects and to improve the effectiveness and efficiency of services. This has led to decentralisation of services to the local level, the greater involvement of user and community participation, and a partnership approach to service planning.

Swedish health and social services are governed under the provisions found in the Social Services Act and the Health Care Act. Sweden was the first European country to develop independent living and personal assistance for people with disabilities as part of social welfare policy, which have stressed integration into society.

Sweden provides a range of health and social services to people with disabilities including programmes for prevention, early detection and diagnosis, treatment and rehabilitation. Medical care is provided at local and County levels and is funded through social insurance. A range of support services are provided at local municipal levels including personal assistance and interpretation services which are provided free of charge. A national rehabilitation programme exists and locally based rehabilitation services are provided for all people with disabilities. There is a high rate of participation of people with disabilities in the planning and monitoring of medical, social care

and rehabilitation services. Sweden has also committed itself to the full implementation of the UN Standard Rules. The Swedish Body of Organisations of Disabled People has worked in partnership with local authorities in drawing up guidelines for the practical implementation of the UN Standard Rules.

Disability legislation

The Swedish *Disability Act* provides for support and services to people with disabilities and the *Assistance Compensation Act* covers people with physical or mental disabilities. The Disability Act is complementary legislation and may not entail any curtailment of assistance to which the individual is entitled under other law. Since this is civil rights legislation decisions can therefore be appealed in the administrative courts. The establishment of a Disability Ombudsman has also worked within a rights based approach and monitors disability legislation.

Under the Swedish *Social Services Act* of 1982, municipal social services were given greater responsibility for meeting the needs of people with disabilities and mental health difficulties, including acceptable housing and meaningful employment. A parliamentary commission in 1992 - the Committee on Psychiatric Care - concluded that social services were not being provided in a satisfactory manner. This led to further legislation, introduced in January 1995, which sought to provide for the social integration and quality of life for people with mental difficulties, on equal terms with the rest of the population.

The introduction of the *Support and Service for Persons with Certain Functional Impairments Act* on 1 January 1994 marked a new development in provisions concerning the support of adults with severe disabilities. It introduced the legal right to specified services and support for people with disabilities for families caring for disabled children. This includes rights to advice and personal support, personal assistants who can provide daily support, personal escorts, a contact person, relief service in the home, short stays away from home, short term minding for school children, foster homes and special housing for children and young people, special housing for adults and the right to daily activities. The principle is that relatives can be paid for their caring roles or have the right to a personal assistant to support them in such roles. The legislation is far-reaching and important because it provides recourse to action before the County Administrative Court. Of interest is that the Act was passed at a time when Sweden was cutting public services and in this light the legislation was seen to be critical to provide equality and basic rights for people with disabilities.

The Municipal Financial Responsibility Act requires municipalities to pay for the care of patients who have received medical treatment within the mental health in-patient system, but are still being cared for in hospital because they cannot be mainstreamed into the community into homes of their own with assisted living services. One of the aims of this responsibility is to stimulate the development of new forms of housing within the community for mentally disabled people who have been under long-term institutional care.

These laws have resulted in social investments in housing, daily occupation, work, recreation, rehabilitation, social interaction, health care and social welfare schemes. There are also specific state subsidies for the development of new services, for example, the development of support and interaction related to severely mentally ill substance abusers; family programmes with particular emphasis on family education, information and support; and the development of buddy support schemes with emphasis on user-led activities aimed at avoiding isolation and stimulating active recreation and better social networks

UK

Provision of health, social and rehabilitation services

The UK 'Beveridge' model has changed significantly since it was created in the late 1940s. The social democratic model based on universal principles has been substantially eroded and a liberal Anglo-Saxon model based on selectivity and residualism has been in evidence since the mid 1980s, based on principles of individualism, privatisation and marketisation of welfare provision. A change of government in 1997 introduced ideas of a 'third way' and new policies related to social inclusion, however, this has not resulted in any major restructuring of the neo-liberal structure that is firmly rooted in the UK. A number of reforms have been introduced to restructure local government services and employment services.

In the UK medical care is provided free of charge, funded by direct taxation and people with disabilities are treated as part of the general medical system. There exist a variety of programmes for prevention, early detection and diagnosis, treatment and rehabilitation. Local authorities provide a range of social care and support services, including personal assistance and interpretation services that are funded by local authorities and means tested payments. In recent years there has been a significant emphasis on the participation of people with disabilities in the planning and monitoring of health and social care programmes. A major programme of monitoring and evaluation of the impact of services on people with disabilities has resulted in a range of performance indicators assessing the impact on equality and quality of life. The disability movement in the UK has been successful ensuring that there has been a growth of Centres for Independent Living, direct payments for personal assistance and services provided directly by people with disabilities. There is no national rehabilitation programme for people with disabilities; community based rehabilitation exists at local levels through primary health care, community based rehabilitation and through NGOs.

Disability legislation

The 1990 *National Health Service and Community Care Act* introduced care management and assessment processes. However, the legislation has seen a number of legal proceedings relating to budget management and the extent to which local authority resources should be allocated for services that are provided for in the legislation. A number of high profile cases led to the establishment by local authorities of eligibility criteria, which led to a rationing

of resources earmarked for users who were most at risk. Other key legislation is the Disability Living Allowance and Disability Working Allowance Act 1991. The *Disability Grants Act* 1993 established the Independent Living Fund which allowed disabled people to be paid directly for services that they could then purchase, for example, for personal assistants. This legislation is likely to be extended in 2003 with a commitment by the government to make direct payments mandatory. A similar provision is currently being considered by the Scottish Executive. The 1998 *Human Rights Act* sets out rights and freedoms for the implementation of the European Convention on Human Rights and also has the possibility of extending the provision of health and social care services and rights for people living in residential institutions. In practice, there are now more firmly rooted rights to community care under existing legislation and possibilities for litigation, including claims by disabled services users to locally based community services.

The 1995 Disability Discrimination Act was introduced as part of a recognition of the social model of disability and civil rights with provision to legal recourse in the event of discrimination. It covers employment, trade organisations, goods facilities, services and premises, education and transport. The Act was recently extended to cover education and accessibility of services. The Act will impact on health and social services through the provisions related to equality of access to services, for example, the right to information in an accessible format and access to buildings and services.

In the UK a statutory duty exists under Disability Discrimination Act to ensure that there is accessibility in services provided to the public. In Northern Ireland, the statutory duty exists as a result of Section 75 of the Northern Ireland Act. This places a statutory requirement on public authorities to promote equality of opportunity, including disability. The Northern Ireland *Statutory Equality Duty* is a model of legally enforceable duties to promote equality in health by requiring public authorities to be proactive in mainstreaming services, auditing their functions regarding equality and implementing new policies and practices to promote equality. The implementation of the statutory equality duty in Northern Ireland is considered to be one viable model that can be applied to health services whereby equality of opportunity can be promoted through equality schemes and Equality Impact Assessment. Schedule 9 paragraph 9 requires the public authorities to publish the results of equality impact assessments, ensuring that data and research information, the differential impact on groups, mitigating measures, consultation processes and monitoring systems are a matter of public information and are mainstreamed.

Australia

The Home and Community Care Act is federal legislation that affirmed the rights of people with disabilities and attached money to them. This resulted in state provision of funding for personal care services for people with disability. However, in the 1990s funding was capped and has meant that services are not fully meeting the needs of people with disability.

Disability legislation

The 1992 Disability Discrimination Act is one of the most comprehensive examples of rights-based legislation in the world covering all people with disabilities. The Act led to the establishment of the Human Rights and Equal Opportunity Commission with wide ranging powers and responsibility for overseeing the Act and is headed by a Disability Discrimination Commissioner. As well as covering employment, education, accommodation and access to premises, the Act covers the provision of goods, services and facilities. An amendment to the Disability Discrimination Act in 1999 coincided with the introduction of human rights legislation. This also enabled the Attorney General to make standards under the Act. In addition, state laws have provided additional legal rights. Examples can be found in the State of Victoria where the Intellectual Disabled Persons Act (1986) covers standards of services, the admission and treatment of mentally disabled people in residential institutions, and a set of principles based on equity, integration, participation and civil rights.

The Disability Services Act (1991) defines a set of principles based on human worth and dignity and equal rights to participation and the right to receive services “in a manner which least restricts their rights and opportunities” to pursue grievances in relation to services. This legislation complements the Disability Discrimination Act. The Disability Services Act provides a legislative structure for service provision that is effective and efficient.

Canada

There are few examples of legal provisions guaranteeing rights to services in Canada. The Supreme Court ruled in 1997 that medical interpretation services should be provided for deaf patients in communicating with doctors and nurses and that failing to provide sign language in the delivery of medical services was discriminatory. (*Eldridge v British Columbia*).

Disability legislation

As the first country to include equality for disabled people in its constitution it is not surprising that the civil rights provided for people with disabilities represent good practice. The Canadian Charter of Rights and Freedoms includes the far-reaching provision of “equal protection and equal benefit” whilst allowing for affirmative action programmes. All federal and provincial legislation has to stand up to the Charter. The 1995 Canadian Human Rights Act has also been important in establishing a duty on employers and service providers to provide accessible services. In addition, people with disabilities have benefited from tax assistance in recognition of the extra costs faced by people with disabilities for medical and other expenses. The Act covers discrimination in the provision of goods, services, facilities or accommodation available to the general public (including transport). It also prohibits discrimination in employment, the provision of commercial premises or housing.

USA

The USA has built a strong tradition of civil liberties designed to empower citizens to reach their full potential. The Americans with Disabilities Act (ADA),

which came into effect in 1990, is recognised as the most comprehensive legislation in the world rooted in a philosophy that all people, including people with disabilities, have a right to equal access to public goods and services. Although US health care system is inequitable, based on a system of private insurance, the role of civil rights has been important in guaranteeing equality of access to services for people with disabilities.

The ADA covers public and private sector provision of employment, public accommodation, public transport services and telecommunications.

The preamble of the Act states that:

- ...individuals with disabilities are a discrete and insular minority who have been faced with restrictions and limitations, subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness... based on characteristics that are beyond the control of such individuals and resulting from stereotypic assumptions not truly indicative of the individual ability of such individuals to participate in, and contribute to, society.

The law also recognises that the “nation’s goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals”.

The Act prohibits discrimination in the area of employment, state and local government activities (including education, transportation, social services, etc.) public accommodations (goods and services) and telecommunication. A broad definition is given to disability and this includes protection also for those who have a relationship or an association with a disabled person. Of particular relevance is that the Act requires that a person with a disability cannot be excluded for participation or denied benefits of services, programmes or activities of a public entity or discriminated against.

The legislation has been important in giving people with disabilities rights to services, and in particular the Courts have argued that the institutionalisation of people with disabilities who are capable of living in the community may represent unlawful discrimination. In one case, *Olmstead v LC ex rel. Zimring*, the Court found that people with mental health difficulties were entitled to live in the community and receive treatment there, rather than institutional care. In this case the institutionalisation of people with disabilities who are capable of living in the community can constitute unlawful discrimination under the Act (Rosenthal and Kanter, 2000).

e) The quality of health and social care provision

There has been a growth of emphasis given to improving the quality of health and social care internationally and evidence from Europe shows the emergence of a variety of different quality systems and models. These include good practice in the development of quality through innovation and experimentation, coordination and integration initiatives, partnership approaches, the participation of users and the development of service quality initiatives (Pillinger, 2001). A useful typology, applicable to the social public services, has been developed by Rajavaara (1997), and is reproduced in the table below. It identifies the different origins, approaches and strategies being

applied to quality in the health and social services and is helpful in identifying the different approaches to quality improvement.

TABLE 32: Quality Initiatives and Approaches

Quality initiatives	Origins, context	Approaches, strategies (examples)
Political-administrative quality initiatives	Representative democracy, political control of public service production, citizen rights, equity, legal security, bureaucracy	Legislation, national quality recommendations, national/municipal service standards and quality indicators, patients' representatives
Citizen-based quality initiatives	Participative democracy, citizen society	Social movements' and action groups' concern about quality, campaigns, introduction of alternative service models
Business-oriented quality initiatives	Market mechanisms, productivity, efficiency, consumerism, consumer choice	TQM, ISO 9000, QUALITY AWARDS, BENCHMARKING
Professional quality initiatives	Professional socialisation, self-regulation, autonomy	Professional training, conditions of competence, professional ethics, professional audit, peer review, self-evaluation

Source: Rajavaara, 1997:86

Good practice in quality development includes the establishment of standards in health care for people with disabilities, good practice on which can be found in Australia, the UK, the Netherlands and New Zealand (National Disability Authority, 2001). User empowerment strategies have been growing in importance and have led to awareness-raising and information campaigns to highlight the problems faced by people with disabilities. The voice of disabled people has been growing in the last decade, as evidenced by networks of increasingly articulate disabled users' organisations nationally and across Europe.

The development of quality systems for disability services has also stressed the importance of a user-focussed and user-driven perspective of quality for example:

- *Local quality systems project in Halikko (Finland)*: This is a quality system project run by the Finnish Association on Mental Retardation and a number of municipalities to develop quality and self-evaluation tools. Services were examined firstly from a user viewpoint through quality groups and other tools, and secondly from the standpoint of quality work and activity, and from the perspective of organisations. In Halikko the objective is to integrate disabled users of services with users of regular services. Services are monitored by a variety of quality control mechanisms.

Recent European research (Pillinger, 2001) has established good practice in services for people with intellectual disability and mental health disability with a particular emphasis on user centred approaches and user empowerment and the coordination and integration of support services. Examples of this are:

- In 1998 a Ministry of Health reform package in Denmark helped to overcome some of these problems of poor coordination between services by requiring regional authorities to draw up plans for mental health services that also took account of the need to coordinate social services and primary health-care services. Further action to overcome these problems in 1995 resulted from the Status Report on the care of the mentally ill, which led to forums for dialogue in all counties to improve both coordination between social and health services and the involvement of users and their families in the development of care services and the quality of services. Additional resources and initiatives were launched under an agreement for 1997–99, whose overall impact is considered to have improved services significantly.
- In the UK progress has been made in the development of interdisciplinary Community Mental Health Teams for the provision of medically oriented services, which remain organisationally separated from social service care provision.

In some countries the problems of the institutional boundaries between health and social care pose a major difficulty to the development of fully integrated services. Nevertheless, the shift towards a social model of care can be found, which shows how good practice in coordinating services can be developed in mental health (Pillinger, 2001):

- ‘Le Méridien’ mental health service (Belgium): A non profit-making association set up in 1989 which has since become an accredited mental health service for the multicultural area of Saint-Josse in Brussels. The model is designed to strengthen the ensemble of medico-psychosocial support available to patients. It takes a multidisciplinary approach based on the notion of a network created through partnership and good collaboration with local services and organisations: medical, social, educational and community.
- *IMPACT (UK)*: Based on the Assertive Outreach model with a number of unique characteristics, with a radical approach to multidisciplinary teamworking and to providing care for those people who have been unable to engage with existing services. The team is made up of professionals from the fields of health care, social work, psychiatry, who have their own disciplines and offer a complex range of interventions and who are employed by MIND. It allows for a more integrated approach with a range of services provided in one team.

Integrating people with disabilities and mental health difficulties into mainstream employment has resulted in a shift of policy away from sheltered workshops to more active, coordinated and supported training and employment projects in most European countries. For example, developing supported work programmes for occupationally disadvantaged people in Sweden has been tied in to the need to support independence and autonomy and thereby reduce dependency. In Austria, policies to integrate disabled people into the labour market have led to new supported employment schemes and work integration measures which are facilitated by the reorganisation of Federal Social Offices that allow for more coordination between services. In 1999, new legislation in Italy established the right of disabled people to work; and the right to supervised work placement was

strengthened for adults with mental health and learning disabilities by making provinces responsible for planning and shaping employment policies. The responsibilities of employment services, local authority social and welfare services and work placement services are structured and regulated, which should help to pave the way for the provision of personalised routes for the placement of disabled persons in work. The following examples of good practice point to some interesting experiments that work within a social model of disability:

- *The PIA Group in Aarhus (Denmark)*: The 'Psychiatric Patients at Work' project began in 1989 at the initiative of the local municipality, and is now run as a private foundation. A board of management, including local public and private representatives, ensures the firm's economic viability, e.g. by securing preferential contracts from public bodies and private firms. The operations of the firm involve integrating mentally ill people with a work capacity into stable, sometimes sheltered, work. This is achieved through targeted, phased and individualised rehabilitation programmes, designed and coordinated with the municipal social and social-psychiatric services, who are responsible for the employees' situation and treatment outside work.
- *KEKKU project in Mäntsälä (Finland)*: This municipal project aims to rehabilitate mentally ill people through open employment, and to foster independence by providing a tailored employment pathway, with training, support for integration into work, information and awareness. Several different models exist, depending on the needs of the user: assisted work, protected work placements and training contract work. The work tutor provides support.

The emphasis on policies for disabled adults is evidenced by a shift away from sheltered or community workplaces towards their active integration into society, training and work, with an increasing focus on empowerment, self-determination, dignity and integration. The coordination of health, social care, housing, employment, transport, training and other relevant services is crucial to this approach.

Integrating services for people with intellectual disability

In Scotland, *Valuing People* is a new agenda for service provision for learning disabled children and adults using an integrated approach to health, social service and community provision in Lanarkshire (Lanarkshire Council, 2000) in order to plan high quality services including generic health and primary care services, which are integrated into specialist intellectual disability services. In order to develop the plan, interviews and consultations were conducted with all stakeholders: parents, carers, people with learning disabilities and workers. Issues of being treated with respect and as an individual rather than an intellectual disability, and the need for more consistent and accessible information were prominent responses to questions about health service provision.

A range of locally based and client focused services have been planned, including awareness raising for health professionals, health promotion plans and health needs assessments for specialist services. Features of success

are a clear strategy/action plan; involving and listening to parents, carers and people with intellectual disability; listening to the needs of GPs, community nurses and practice staff; networking and learning from good practice; and working with enthusiastic staff (Kane, 1999).

Evidenced based service planning

An increasing emphasis is now placed on evidenced based service planning. Health or disability needs assessments can help to provide a baseline profile of health needs and an evidence base for future service planning. This is practice that has been promoted by the European Observatory on Health Care Systems, which supports and promotes evidence-based health policy-making through comprehensive and rigorous analysis of the dynamics of health care systems in Europe. New health care interventions provide new opportunities for improved health outcomes for individuals. However, this may require substantial new health funding or a reallocation of resources within healthcare budgets.

The pressures to contain the costs of health care have contributed to the growth of the evidence based practice and evidence based policy making, as a means of identifying not only what is effective, but increasingly at what cost. Collating information on the effectiveness and costs of interventions, as well as considering equity and other factors can help ensure that resources are allocated in a way that improves overall health outcomes. Of importance to the development of disability services is the extent to which non-health policies need to be considered. In the case of mental health and other disabilities this may be substantial. For this reason evidence based practice needs to look not only at disability and mental health care services, but also at the influence of environmental factors such as housing, poverty, employment and social justice on disability and mental health.

Data and information systems

The effective monitoring of services requires systematic and reliable data to be collected. An increasing number of countries have introduced management information systems for this purpose. One good example can be found in the state of Victoria in Australia where an information system has been put in place to record data for disability services. The Quarterly Data Collection (QDC) Information System was introduced in order to streamline data reporting requirements and to eliminate the duplication of data collection that was occurring across various Department of Human Services (DHS) programmes. It combines the various data collection processes into a single data information system. The Disability Services Division coordinates the Victorian collection for the National Minimum Data Set (NMDS) as an ongoing process of full year data collection. This has helped to streamline the various reporting of data to different agencies and to minimise duplication of information provided by service providers. The QDC system links four existing data sets.

The main benefit of the QDC Information System is that it provides better data to review and plan service delivery and improved outcomes for clients through more informed decisions about service planning.

Mental health service mapping

A further example of data collection concerns the Mental Health Service mapping exercise that is carried out on an annual basis in England. The objective is to monitor change and ensure greater equity of service provision in line with the government's national service framework on mental health. It consists of a national dataset covering key data and a web resource, which can be used by service providers in localities as a tool for local needs assessment, service and workforce planning. The longer-term objective is to produce a Rough Guide to mental health services that involves comments from service users on the services.

The mental health service mapping exercise seeks to improve the monitoring of the implementation of the mental health national service framework by helping to track services as they are being reformed and reconfigured, measure issues concerning equity in the provision of services, map trends in service capacity and staffing each year, make comparisons between different localities with similar levels of need. Data is inputted via an information system database and analysed and coordinated by the Centre for Mental Health at the University of Durham. The data concerns mental health service provision for working age adults in England. This is a significant attempt at data collection and the methods are developmental. The database contains information on over 16,000 services and provides a unique picture of mental health service provision. It also provides an opportunity to plot levels of service provision on an annual basis and assess trends in service provision. Data is input by service providers at local levels and an annual mental health mapping atlas is produced summarising all national data. Data sets are available for 2000 and 2001.

This provides an excellent example of the development of a computerised health mapping exercise and demonstrates how it is possible to draw together data from health and social care services in the statutory and non-statutory sectors. The database covers the following areas of service provision:

Table 33: Services Captured in Mental Health Service Mapping, England 2001

Area of Service	provision
Numbers of Community mental health teams	Community mental health teams, care staff, caseloads, fully integrated, multi agency, single agency, caseload per care staff, caseload per 100,00 population
Assertive outreach	Assertive outreach teams, care staff, caseload, caseload per care staff, caseload per 100,00 population
Crisis resolution teams	Crisis resolution teams, care staff, caseload, caseload per care staff, caseload per 100,00 population
Early intervention in psychosis	Early Intervention Teams, care staff, caseload, caseload per care staff, caseload per 100,00 population
Access to emergency assessment	Walk in clinics, crisis intervention teams, emergency duty teams, A&E liaison, no emergency health assessment
Crisis accommodation	Crisis accommodation units, bed spaces,

	spaces per 100,000 population
Clinical services	Psychiatric liaison services, day care facilities, day care attendances, weekly attendance per 100,000 population, acute in patient beds, acute in patient beds paces per 100,000 population; private provision; outpatient services, settings and attendances
Continuing care	Residential rehab bed spaces, NHS nursed bedspaces, registered home bed spaces, total residential bed spaces, rehab team case load, rehab team case load per 100,000 population
Psychiatric intensive care and secure services	PICU Services, bed spaces, beds per 100,000 population, low secure services, low secure bed spaces, low secure beds per care staff, caseload, caseload per 100,00 population
Mentally ill offender services	Liaison / diversion services, referrals, referrals per 100,000 population, Community forensic teams, prison inreach teams, community forensic services, community forensic caseload, caseload per 100,00 population, community forensic service by other teams
Acute, secure and continuing care provision in the independent sector	Private acute units, acute beds, low secure beds, medium secure beds, rehab units, rehab beds, registered home units, registered home beds
Psychological therapy services	Psychology therapies and counselling setting and caseload, specialist psychotherapy service, voluntary / private counselling,
Primary care mental health services	Community mental health team primary care liaison function, primary care mental health worker service
Day services	Attendances and provision of day centres / resource centres, drop-in centres, education and leisure opportunities, employment scheme
Support services	Advice and information services, advocacy services, befriending and volunteering scheme, self-help, service users group, staff-facilitated support group
Carers' services	Advice and information, carers support group, carers support service, self-help group for carers, short term break / respite care service
Home support	Home support services case load and caseload per 100,000 population, community mental health team home support function, hostels with home support, staffed group homes with home support, unstaffed group homes with home support, supported housing with home support, total home support from housing services.
Accommodation	Placements and accommodation, adult/family placement scheme, board and lodging scheme, hostel, local authority and registered residential care home, staffed group home, supported housing, unstaffed group home
Direct payments	Numbers supported by direct payments
Staffing in community teams	Doctors, nurses, psychologists, OTs, SWs, doctors per 100,000 population, nurses per 100,000 population, psychologists per 100,00 population, OTs per 100,00 population, SWs

	per 100,00 population
Mental health promotion	Named person responsible for mental health promotion, organisation responsible for mental health promotion, multi-agency group responsible for mental health promotion
Population	0-15 years, 16-59 years, 60 years plus, total population

Source: Glover G and D Barnes (2002) Mental Health Service Provision for Working Age Adults in England 2001, University of Durham, Centre for Public Mental Health

f) The development of a social model of disability

Good practice has been developed internationally on a social model of disability much of which has been inspired by the UN Standard Rules and human rights based approaches to disability. Examples are given of good practice in independent living, assertive outreach, direct payments and user involvement and participation.

Independent living

Much international good practice promoting the autonomy and independence of people with disabilities can be found in the development of independent living and user-led initiatives. Pioneered by the American Independent Living Movement in the 1970s and the disability rights movement in the 1980s and onwards across the world, independent living promotes the involvement of people with disabilities and their organisations in the development and running of services for people with disabilities. One of the major outcomes of this movement has been the development of Centres for Independent Living (CILs), which provide services directly to people with disabilities and their families. CILs have grown in importance in the USA, Canada and more recently in the UK. There are CILs in several health board regions in Ireland, although on a relatively small scale and with few resources. In Ireland, CILs are funded partly by health board grants and partly by FAS Community Employment funding. There are now over 400 CILs in the UK and many more in the USA and Canada.

According to Adolf Ratzka, a disabled director of the Swedish Institute for Independent Living:

- Independent living is a philosophy and a movement of people with disabilities who work for self-determination, equal opportunities and self-respect. Independent living does not mean that we want to do everything by ourselves...[it] demands the same choices and control in our everyday lives that our non-disabled brothers and sisters, neighbours and friends take for granted. We want to grow up in our families, go to the neighbourhood school, use the same bus as our neighbours, work in jobs that are in line with our education and abilities, start families of our own. Just as everybody else, we need to be in charge of our lives, think and speak for ourselves.

According to the National Centre for Independent Living, CILs provide services which help people with disabilities to live independently including information, advocacy, peer support, housing advice, personal assistance

support, and work and training advice. The demands by disabled service users to have more control over the provision of services has coincided with a political climate that has sought to contain costs. User-led initiatives have been both cost-effective and have won wide support from service users and policy makers in a number of countries (Barnes, Mercer and Morgan, 2000).

In 2002 the UK Disability Rights Commission (DRC) published a policy paper that is arguing for an enforceable right to independent living for all disabled people. The policy paper says that:

- There should be a basic enforceable right to independent living for all disabled people. Policy objectives for social care need to include guaranteed minimum outcomes, backed by a right to independence. The provision of social care must extend to beyond functional 'life and limb' support to include supports to enable participation in social and economic activities. All social care support services should be based on the principles of independent living. All organisations commissioning and providing services should be aware of the social model of disability and be fully committed to delivering services that enable choice, control, autonomy and participation (Disability Rights Commission, 2002).

Assertive Outreach

According to the Sainsbury Centre for Mental Health (2003) assertive outreach can reduce hospital admissions in frequency and duration, find and keep suitable accommodation, sustain family networks and improve social networks, improve general health, improve living and work skills, prevent relapse and ensure that help is provided at an early stage. Assertive outreach targets clients with severe and enduring mental health problems who have difficulties engaging in services, through multidisciplinary team approach, intensive frequency of client contact, work with people in their own environments and with their own support networks. Its origins can be found in the USA as an approach to helping mental health patients develop independent living through a tailored approach in a community rather than residential setting. Particular expertise has been developed in Australia through the provision of Mobile Community Treatment Teams in New South Wales and Mobile Intensive Treatment Teams in Queensland. These teams are made up of between eight and ten multidisciplinary staff with caseloads of 1:10.

Assertive outreach is a new plank of the UK's NHS Mental Health policy that works within a social model by tackling social exclusion through early intervention. It is anticipated that 50 assertive outreach teams will be established in the UK. The Sainsbury Centre for Mental Health and the Kings Fund have recently published a report of three pilot assertive outreach projects which have attempted to aid the recovery of people with long-term mental illness through social inclusion and integration of local services. The three pilot projects were set up in London in Haringey to tackle high rates of mental illness among black people; in Islington to reach people with severe long-term mental health problems and a poor history of using services; and in Lambeth to target young adults who have no links with mental health services but who are experiencing a first or second episode of mental illness. The pilots have had the effect of increasing demands for services, particularly

because the outcome of the pilots is that people who have not been service users have been tracked down and many unmet needs have been identified. However, the long term benefit of this approach that tackles exclusion and long term illness through multi-disciplinary working is that there will be cost savings in medication and hospitalisation in the longer term (Greatley and Ford, 2003). Guidance in setting up and running an assertive outreach service has been drawn up by the Sainsbury Centre for Mental Health (2003).

Direct payments and personal budgets

Direct payments or personal budgets are one element of user empowerment. On the one hand, they represent a mechanism to enhance user choice and empowerment, as pioneered through the *Independent Living Movement*, with its emphasis on personal assistance rather than care. On the other hand, they have been introduced to support family or informal care. In a European context direct payment schemes now operate in Austria, Denmark, Germany, Finland, France, Luxembourg, the Netherlands, Sweden and the UK, and pilot projects have been introduced in Belgium and Italy. A direct payment scheme has also been introduced in Australia. Direct payments are becoming increasingly popular in industrialised countries. For governments they are cost effective and take care out of the hands of the government as the main provider of services. For service users they are rated high for their quality and user-led focus.

Direct payments have been used to directly fund disabled and older people to employ their own personal assistants and to have choices through the organisation of their own care. They have the potential to radically alter the traditional relationships between service providers and service users (European Social Network, 1998). This is a reflection of significant shifts in thinking about service provision so that service users become equal partners in managing their own personal support systems or personal assistance. Direct payments enable the service user to be funded to pay for and organise their own services. This can be through cash payments or vouchers. In some cases service users have coordinated their payments and formed their own organisations and cooperatives, such as Centres for Independent Living, in order to administer the payments and provide their own care. Payments are allocated on the basis of an assessment of need and an allocation of resources to meet identified needs. The 1994 Support and Services and Support Act in Sweden was the first model of direct payments that introduced a voucher system for promoting independent living.

There are a variety of different approaches to direct payments. In Germany, Austria and Luxembourg direct payments have been relatively straightforward to introduce by virtue of the national insurance system which provide financial benefits, rather than direct provision of health and social care. In Austria, care insurance was introduced under the Long-Term Care Act. A similar system of dependency insurance was introduced in Luxembourg in 1999 and a system of care insurance also exists in Germany. Personal budgets are well established in the Netherlands and direct payments exist in the UK, Finland and Sweden. These are evidence of the greater individualisation of care, user empowerment and are related to perceptions of quality amongst users (European Social Network, 1998; Evers et al, 1994; Weekers & Pijl, 1998).

The Netherlands allows people who have been assessed as needing home care (covering older people and people with learning disabilities) to receive their own personal budget (*Persoonsgebonden budget*) to enable them to tailor their care to their own needs. In 1997 spouses and partners were also covered under the personal budget. District nurses, home care associations and private organisations are required by law to meet certain quality standards, whereas this does not apply to individuals employed to provide care. Evaluation of two experiments by the Dutch Health Care Insurance Council and a home care organization in Rotterdam found that a large proportion of the care givers were relatives or neighbours. Many of the participants did not feel that their helpers required professional qualifications; rather it was the ability to choose their helper and the trust, flexibility and shared understanding that were important. In both experiments it was the users' control and choice over their care that led to a perception of improved quality, more continuity and equality with their carer. In addition, many of the budget holders felt less of a burden, and their relationships with their carers improved.

In Luxembourg, the policy of supporting disabled people in their own homes for as long as possible is based on user-oriented care strategies and has resulted in the introduction of dependency insurance for older and disabled people. The objective is to reduce dependency on state services, provide more coordinated care and guarantee rights and choices to quality social care as a result of dependency. This enables there to be a choice about how the care will be provided, either directly by the state or by families/relatives. The legislation regulates the relationships between the state and the wide range of semi-state and private organisations providing social, family and therapeutic support, which have hitherto been largely unregulated. It also introduced systems of evaluation of services. The dependency insurance scheme promotes an integrated system of care based on a multi/interdisciplinary working methodology. By aiming to prevent dependency as a result of old age or disability, it has the potential to reduce dependence on the state, devolving funding and responsibility to family and social networks or social care organisations. This is seen to be important in empowering users and improving the quality of care.

Participation of service users in the planning, development and monitoring of services

There is a greater emphasis now given to consultation with disability organisations, including participation in the planning, development and monitoring of services. There has been a growth of local, national and international disability user movements and networks of users and their associations. Despite a growth of initiatives on user participation and empowerment there remains limited evidence of systematic research to identify user needs. The bulk of the evaluation of services, including the quality of services, takes place from a provider perspective and methods of identifying user needs and preferences are not widespread. However, the increasing focus on users' rights has had an impact on user participation and the creation of standards that include rights and participation, including more individualised and tailored packages of care and greater user choice. There

are different levels of user empowerment, participation and involvement exist and these can be identified on a continuum of: information, consultation, partnership, delegation and control. Examples of different approaches to user involvement and empowerment can be found below:

USER INVOLVEMENT

- direct user influence (to varying degrees in most EU member states, but particularly the case in Denmark, UK, the Netherlands).
- user panels/forums on municipal and regional bodies (in Germany, the Netherlands, Sweden, Denmark and the UK)
- user involvement in service provision through family associations, care associations and advisory councils (in the UK, France, Greece, Portugal, Spain, Italy), and legal powers to conclude service agreements (Germany)
- user involvement in assessment of needs (increasingly the case in all countries, particularly in Germany, the Netherlands and the UK)
- user surveys and other feedback mechanisms to evaluate services (in the Netherlands, Sweden, Denmark, Italy, France and the UK)
- involvement of users as volunteers (all EU member states)
- user involvement through local partnership strategies, in evidence through local concertation pacts in Italy

User empowerment and choice

- budgetary autonomy to employ a carer (Austria, Germany, the Netherlands, Sweden, Luxembourg and the UK, and in some circumstances in Finland and Denmark); and user choice in service options (Germany, Luxembourg, Austria, the UK and the Netherlands, and increasingly the case in Sweden and Denmark)

User rights

- user rights (particularly in the UK, Denmark, Sweden, the Netherlands, Germany and the UK)
- user advocacy schemes to defend users' rights (particularly strong in Denmark, the Netherlands and the UK)
- user information, advice centres and ombudsman services

Source: Pillinger, 2001

In the UK, *Shaping Our Lives*, is a national user-controlled development project and network. It has been established by the National User Group and funded by the Department of Health and Joseph Rowntree Foundation to develop new thinking on service provision from a user perspective. The project is designed to place service users at the heart of the government's Quality Strategy for Social Care. It covers people with physical and sensory disability as well as mental health service users and survivors. Two other user-led projects have been established. First, Our Voice in our Future supports social care service users so that they can have a voice in welfare reforms. Second, is a project to support user involvement in the General Social Care Council and other social care bodies involved in regulating standards in social care.

3.6 Conclusions

This review of international good practice provides information about international, European and national legal and policy initiatives that can point to new learning and practices in Ireland. Much good practice is being established through international instruments and policies found in the UN, the WHO, the Council of Europe and the European Union. These have in common a greater emphasis on human rights approaches to disability health services and the social model of disability.

Several conclusions can be made from this survey of good practice that can be useful to inform future service developments and the commissioning of services in Ireland. Health services should promote and support the principles of equality, independence and social inclusion of disabled people through non-discriminatory service provision and health improvement programmes. In Ireland guaranteeing rights to certain services could be considered in this context.

Whilst people with disabilities may need mainstream, specialist or targeted medical services, it may be that the medical model is incompatible with the provision of a range of services to support the community integration and equal participation of disabled people in society. It might therefore be reasonable to question why it is that health funding in Ireland is used for the provision of specialist housing, rehabilitative training and sheltered work, advocacy and other support services, such as sign language for deaf people.

Equality and anti-discrimination approaches

The role of civil rights and enforceable anti-discrimination laws and policies is part of good practice in evidence in many countries today. This is part of a commitment to the promotion of equality and the prevention of discrimination in employment, goods and services. In some cases the legislation may guarantee rights to specific services although in others general principles may underpin equal participation through user-led approaches and a social model of disability. Although legislation varies from country to country this is part of good practice in the development of equality and access to services. The UK Disability Discrimination Act and the American Disabilities Act are considered as good examples, both of which will shortly be amended to provide for a more enhanced rights-based approach.

At the national level there is a growing recognition of the importance of anti-discrimination legislation as part of the civil rights model. However, this approach sits alongside more traditional approaches to disability policy at the national level which tend to operate within a medical model and sit alongside long-established social security schemes, segregated education and housing programs, and employment quotas, many of which exist within a social welfare model. This tension suggests the need to consider disability policy with a new framework of a social model and requires fundamental re-thinking of the existing organisation, funding and provision of health and social care services.

A further key issue is the extent to which services are provided equitably. According to the World Health Organisation (WHO) “..societies should

organise their resources for health equitably, so as to make them accessible to everyone” (WHO, 1999a:5). Those countries that have good quality health and social care systems are also ones that are equitable. This is particularly the case in Canada and the Nordic countries where access to good quality health and social care are coupled with disability rights and anti-discrimination policies.

Social model of disability

Good practice in disability health and social care related supports may also mean that the health and social care sector plays a relatively limited role in providing disability services. It follows that community-based services, which are also led (and sometimes provided by disabled people) within a social model would represent the good practice whereby the emphasis is placed on the disabling environment rather than on the disability. Here the growth of the independent living movement in the USA, Canada and the UK means that direct payments and Centres for Independent Living have enabled independence rather than dependence on disability supports. This works within the framework of the more holistic approach to disability support by securing equal access and participation to community based housing, transport, medical, employment and other services and facilities as recommended by the World Health Organisation (WHO, 2001) and promoted by the UN Standard Rules.

International best practice shows that services should be provided within a framework of the social model of disability. Whilst medical services may be necessary for people with disabilities, support, assistance and care should not be organised around a medical model. The increasing focus on rights-based approaches and the emphasis on legal protections are an important part of this broader framework. This also means that services should be provided within a context of enablement and empowerment. Social care services can help to support the integration and participation of disabled people by providing support that promotes independence, social inclusion, choice and control for all disabled people.

Good practice services identified in this report include a social model of disability that is designed to remove barriers to participation, independent living, personal assistance, direct payments and personal budgets, civil rights for people with severe disabilities, and community integration. Services should be user-led and provided, planned and monitored with the full participation of people with disabilities and their families. The emphasis on service provision in the future should be community-based, with a greater role to be given to health promotion and primary health care as models of service delivery.

Good quality services

Promoting equitable access to quality health care and social supports is critically related to the structure of the health care system and whether rights to services have been established. For example, in Sweden the high quality, accessible health and social care system exists in the wider context of a universal welfare state that promotes the dual objectives of free and universal health care with equality of access for all. This has led to a wide range of

social supports, including some of the most progressive systems of independent living and personal assistance. In contrast the model has not been so positive in relation to access into employment for people with disabilities. In Canada, similarly health supports for people with disabilities result from a high quality, public health care system that provides free and equal access to services.

A key aspect of quality is the enhanced role given to users, through user involvement and participation in the planning and monitoring of services and the development of empowerment and independence as guiding principles in service delivery. Whilst accessible and high quality health and social care services are an essential component of good practice, it is important that they operate within a social model of disability and place the user at the centre of the service. A key role for the future of health and social care services is to ensure that there is integration and coordination with the full range of services that are essential for participation in society (health, social care, education, training, transport etc). This also means that services should be provided in a multidisciplinary framework.

An important issue is the development of more effective evaluation and information systems so that service needs can be identified and translated into service planning and workforce planning. This is essential to the provision of quality services that map services as they develop and measures issues such as equity of service provision, local needs assessment, service and workforce planning.

Finally, improving the quality of services for people with disabilities needs to consider how barriers to participation can be overcome, how user-led, advocacy and participatory approaches can promote choice and autonomy, how unmet needs can be identified and met, and how quality criteria can be applied to local settings and meaningfully implemented so that the service users experience improved quality and access to services.

Chapter 4: Conclusions and key findings

The emphasis now placed on anti-discrimination has provided an important backdrop to the development of more inclusive services for disabled people. The claims by disabled people, their advocates and families for better quality and more accessible and appropriate services has challenged service providers to consider how services can be mainstreamed and how the integration and inclusion of disabled people in all areas of society can be promoted and supported. This is also a reflection of a greater understanding of disabled people's experiences of discrimination in accessing services as well as the impact of disabling barriers on independence and autonomy. As a result service providers have had to address the consultation and participation of disabled people in planning and service delivery.

However, although these claims to services are increasingly part of the policy agenda, as seen in the Commission on the Status of People with Disabilities, the Health Strategy Quality and Fairness and the report of the Disability Legislation Consultation Group amongst others, there is yet to be a real impact on the end user. The challenge, therefore, is how to translate the

objectives and aspirations of the social model of disability and improved health and other supports into real service improvements that impact on the end user. Key issues concern the need to shift organisational cultures and overcome negative and disabling barriers. The opportunities evident in the reform programme in health services provide an excellent opportunity to mainstream disability in health and social care.

Key findings from the health mapping research:

Data issues

- Health service mapping is not undertaken by health boards on a routine basis.
- Problems exist in identifying an accurate picture of service provision, including gaps in services because of data inadequacies.

Funding

- Funding for mental health and disability services has grown in recent years, but still remains below the optimum level of service required. The increase in funding for general health services has not resulted in a major improvement in funding for disability services. In particular mental health services are now receiving a declining share of overall health expenditure.

Services

- There is a general shortage of therapeutic services for people with disabilities, and shortfalls in the numbers of day, residential and respite places.
- Services continue to be provided within a medical model. Despite an increasing emphasis given to the social model of disability and the development of community-based services, services remain medically oriented.
- Much greater attention needs to be given to the social model of disability, independent living and personal assistance. This means addressing disabling barriers that exist, for example, because of a lack of sign language interpretation, appropriate housing or personal assistance, inaccessible buildings and information, and communications barriers.
- There are variations across the health boards in the provision of services. There is poor coordination of disability services with other services such as local authority housing services and employment services.
- There continues to be problems in accurately identifying what services are provided by the non-statutory sector, including the quality of services. There is a need to introduce an inspection service for all non-statutory day and residential services and a more effective system of reporting against agreed standards.
- Despite this, health boards are making good attempts to provide specialist services for specific groups, for example, homeless people with mental health difficulties, psychiatry in later life services, suicide prevention services. This also includes the development of some innovative services and advocacy schemes.

- Health boards are increasingly involved in longer term planning of disability and mental health services, through the development of strategic plans and service planning.
- Attention is being given by the health boards to concluding service agreements and implementing service quality initiatives, including standards set by the NDA.
- The mapping questionnaire developed for this mapping exercise has been effectively piloted in the ERHA and in the Midland Health Board and could be used for further mapping exercise. This is valuable resource outcome from the mapping research project.

Data collection and management of data

A key finding from the health mapping research is that health mapping is not undertaken by the health boards other than where data is required for existing reporting requirements to the DOHC and/or to the development of board strategies, reviews or needs assessments that have been undertaken on disability services. For this reason this report drew on what existing data and information sources that are available in order to provide the most comprehensive map of the range and quantum of health services.

The research carried out for this health mapping exercise has identified the need for systematic and standardised data collection. This is also highlighted in Butler and Boyle's (2001) study of service planning which concludes that the role of service planning will in the future require more systematic needs assessment and analysis, monitoring and evaluation, including standardised data definitions and compatible data collection. Similarly, they recommend the need for operational and business planning, greater collaboration between health boards and agencies to share good practice and the development of comparable care groups in order to ensure that a more strategic approach to service planning is put in place. Whilst this study shows that there is now much greater evidence of a more strategic approach to service planning by the health boards and to longer term strategic planning in disability and mental health services, this approach has highlighted gaps in services and the need for new and enhanced services and additional resources to put these in place.

The data issues highlighted in this report are crucial to future health mapping exercises and to more systematic and comparable information collection and performance monitoring. The poor reporting on the DOHC's disability performance indicators in 2002 is a reflection of the low priority placed on data collection. It is anticipated that the publication of the health information strategy and a number of pilot projects in health boards will lead to more effective management information systems in the future and more systematic and comparable data collection. This particularly applies to the data collection and reporting that should be increasingly required of the non-statutory bodies providing services for people with disabilities and the associated accountability and transparency that is required in service provision. □

Access to and provision of services

This report has identified a range of gaps in the provision of services ranging from day, residential and therapeutic services through to advocacy and other

support services that can support independence. In a large number of cases it is volunteers, disability organisations representing disabled service users, and advocacy groups that provide important information, help, care, support and home based support services. It is only when substantial care needs exist, or where there is an absence of family or informal care support, that services are provided. Services are rated often favourable by disabled people, families or carers that are in the 'care chain' and are known to the health board. However, there remain many people who are outside of the 'care chain' for whom no services are provided.

Disability Services

Despite progress in moving from institutional to community based care services and a greater emphasis on person-centred services, a number of key problems remain for disability services and some very clear gaps in services that need to be urgently addressed:

- Shortfall in key services including residential, day and respite services and shortages of staff particularly providing therapeutic supports.
- Poor coordination of services.
- Inadequate planning of services for young disabled people particularly in their transition into adulthood.
- Insufficient support for carers who are caring for disabled people with complex needs.
- Limited choices and control available to people with intellectual disabilities.
- Unmet health needs for people with intellectual disabilities.
- Restricted possibilities for independent living and housing choice.
- Inadequate or inappropriate day services that do not meet the needs or abilities of people with intellectual disabilities.
- Poor access to general health services, for example, for deaf or blind people.
- Absence of deaf professionals to deliver services to deaf people in their first language, for example, doctors, nurses, psychologists, social workers.
- Limited employment opportunities for people with disabilities.

Mental health services

In mental health services the gaps include key problems related to:

- The promotion and protection of child mental health with appropriate supports and services to support children's psychological well-being. There is currently a lack of mental health services for children and young people, but there is commitment to their development through the implementation of recommendations in the First Report of the Review Group on Child and Adolescent Psychiatric Services and *Get Connected*.
- Early intervention and children's services with new models of practice.
- Prevention and an educational model for prevention working with children and families whose parent or sibling has mental health support needs. There is currently a particular vacuum for 16-18 years olds in mental health and support services.

- Lack of a comprehensive and modern service; hospital psychiatric services are still provided in an outmoded physical infrastructure and in old buildings, whilst community care and housing services remain inadequate.
- An absence of services for homeless people with mental illness and minority ethnic people with mental illness. In particular, there is an absence of services and supports to address the mental health difficulties faced by refugees and asylum seekers.
- Poor throughput of people through acute beds and particularly intensive psychiatric care beds.
- Inadequate services and gaps in coordination and moving people between hospital and community care.
- The need for funding for the development of assertive outreach and out of hours services

Funding

Although there has been an increase in funding for disability services in recent years, the history of chronic under-funding of services means that under-funding has not yet been resolved. In addition, the shift towards more community based provision and new needs, particularly for services for specific groups of people with disabilities and a changing age profile of services users, has led to increased demands for services. There has been an additional €550 million funding for disability services resulting in 1,700 additional residential places, with increased numbers of people availing of day, respite and residential care. However, as a proportion of total health expenditure disability services have not grown significantly (from 9.6% of total health expenditure in 1999 to 12.5% in 2003). In contrast, expenditure for mental health services has declined (from 10.6% of total health expenditure in 1999 to 6.8% in 2003). Although there are plans to speed up the shift from institutional care to the provision of community based services and psychiatric units in general hospitals, the pace of these developments has been slow because of low levels of funding.

Towards a social model of disability

The importance of the social model of disability is reflected in consultations with disability organisations carried out in the context of this mapping exercise and evidence from written submissions by disability organisations to consultation exercises carried out for the Health Strategy, the NAPS Working Group on Health, City and County Development Strategies and Action Plans and the Disability Legislation Consultation Group. Similarly, health boards themselves are giving greater attention to consulting with disabled service users in order to develop strategies and plans for disability services within a social model. The increasing emphasis being placed on patient-centred, client and consumer oriented services has been an important new development in disability services and this is reflected in health board service plans and strategies that place an emphasis on user involvement in planning services. Common themes run through all of these consultative fora relate to the need for the establishment of rights and entitlements to services and the need for more effective care planning and independent needs assessment. In particular, they stress the need for the development of new services that

support independence including independent living, advocacy, home and community based supports, and improved access to employment and training.

The Commission on the Status of People with Disabilities highlighted a number of problems including the inaccessibility of health services, the centralisation of key services in Dublin, the unpredictability and under funding of community services such as home helps and respite care, as well as widespread lack of disability awareness and of a clearly defined complaints procedure (NDA, 2001). The poor quality of services or lack of services for people with disabilities has been strongly criticised in submissions to the NAPS and Health Working Group and the Health Strategy. These comments reiterate the position taken by the Commission on the Status of People with Disabilities in 1996, which also criticised the medical model within which disability services are provided:

- Up to now, the needs of people with disabilities have almost always been met on a medical basis; thus many services which are not medical in nature e.g. training and employment, have inappropriately been provided under the aegis of the Department of Health.

However, education, training, income support and housing services for people with disabilities continue to originate from the Department of Health and Children, which further marginalises people with disabilities and prevents their full inclusion in society. A major problem is the inadequate financial support for Independent Living, which could enable people with disabilities to exercise choices and independence. This raises some important questions about how a social model of disability can improve the levels of awareness of service providers and improve the representation and participation of people with disabilities in policy formation and service delivery. Many disability organisations argue that disabled user participation has to become more deeply embedded into citizen's rights and in service users' involvement in the planning and delivery of care and other services.

Feedback from service users about the future development of disability health services

Key issues raised in consultations with disabled service users as a part of the health mapping research concern a range of attitudinal, communications, physical, coordination, and service barriers:

- Attitudinal barriers: patronising staff and a lack of awareness about disabled people by front-line staff, doctors and other professionals.
- Communications barriers: the general experiences of deaf people are dominated by difficulties in getting access to services because of prejudices and a medical model of deafness; rather deaf people regard deafness in positive ways on the basis that they can lead purposeful and fulfilling lives.
- Physical barriers: access to health service buildings is poor.
- Coordination barriers: poor coordination of services and of information.
- Information barriers: lack of accessible information; written information should be provided in a variety of written formats, large print, Braille, audio and video format.
- Service barriers: disabled people are treated unfairly and disability

services are seen as Cinderella services. Services are decided by the providers, not the users. This means that disabled people are sometimes forced into pre-selected categories in order to meet criteria set for accessing services. Disabled people want to access mainstream services, rather than be seen as dependent on specific low quality disability services. Further barriers are faced by people with multiple disabilities. There should be deaf professionals providing services. One deaf woman has trained as a social worker (in the USA) but has never been able to practice in Ireland.

- Participation barriers: there is limited involvement in the planning and monitoring of services, in most cases disabled people are not asked. Inadequate complaints systems and no mechanism for complaints to be fed back into service planning. High level service users have difficulty in complaining because there are no alternatives. The assumption is that if you don't pay (i.e. purchase private health care) then you should not expect a high quality service.

The Forum of People with Disabilities is critical of the lack of resources for independent advocacy particularly for people who live in residential environments and because disabled people's needs and rights are not met on an equal basis. Similarly, disability groups argue that a lack of accessible community based services means that many disabled people have to rely on costly health services at a later stage. The lack of effective advocacy for people with mental health support needs and a continuing focus on a medical rather than a social model of care creates an unnecessary dependence on institutional care. This in turn means that: "Disabled people have and currently experience levels of discrimination, which impacts on every aspect of their participation within Irish life...(this)...requires fundamental change on the part of all institutions of the state: Public and Private" (Forum of People with Disabilities, 2001).

The Disability Federation of Ireland (2001), in their submission to the NAPS Health Working Group, have spelt out what helps people get the health and social services that they need:

- Local access and availability of services
- Knowing someone in similar circumstance who has some knowledge and/or involvement with the services
- Personal skills, confidence, advocacy
- Access to information sources, formal and informal
- Transport and/or personal support to get to services
- Physical access to services

These are crucial areas related to improving access to services and enhancing independence and autonomy that could also help to improve access to services. This also relates to the increasing recognition now being given to issues of autonomy and advocacy and the crucial links that they have to health gain and well-being.

Equality and disability proofing

Expertise and knowledge about equality, disability, gender and poverty proofing is leading to the development of an integrated approach to equality proofing. The Partnership 2000 *Equality Proofing Working Group* has recommended an integrated proofing process based on the experience of gender mainstreaming, poverty proofing under the National Anti-Poverty Programme and equality proofing across the nine grounds. In addition, there is also learning to be utilised from other proofing and impact assessment mechanisms. This includes Health Impact Assessment, which assesses the impact of health policies, programmes and projects. For example, Northern Ireland is currently developing an integrated screening tool for all impact assessments used by government departments and agencies and the move to the integration and rationalisation of sectoral impact assessment is mirrored at the European level through work currently being undertaken by the European Commission. Technical guidelines are due to be published in 2003, and along with guidelines already developed on gender mainstreaming, will help to inform the development of the methodology in Ireland. An integrated approach to proofing will have the benefit of achieving coherence and of progressing learning of the links between poverty and inequality and a better understanding of how such inequalities may lead to poverty.

A recent report for the Equality Authority on *Equality and Health* (Burke and Pillinger, 2004, forthcoming) highlights a number of equality challenges for health services for people with disabilities and mental health users that are rooted in independence and autonomy. This recommends the development of the following services and models of provision:

- Independent and appropriate advocacy services for people with mental health support needs, people with learning disability and people with physical and sensory disabilities in each health board so that they can understand their rights, participate in and monitor their treatments and be involved in decisions in relation to care plans, service planning and implementation.
- The development of models to support Independent Living so that people with disabilities can live in communities rather than being segregated in costly residential environments. This means promoting the rights to funding for people with disabilities to independent living and personal assistance, as well as coordination of care in the community.
- Development of mental health services so that there is a continuum of services, a focus on prevention and early intervention, an improved profile of mental health services and fewer stigmas associated with mental health and illness.
- Mainstreaming of participatory models of mental health user consultation and involvement for the planning of psychiatric, hospital and community based services.
- Voluntary organisations, users, providers and statutory bodies should establish ways of working together as partners to improve the quality of services in ways that are responsive and accessible to people with disabilities.
- Research and monitoring of the link between youth suicide and sexual

orientation and more attention to be given to and consultation in the mental health strategy.

- Development and implementation of disability proofing to the planning of primary, community and hospital based services within a framework of equality proofing.

In particular the research highlights a number of proactive equality challenges that can be implemented in the health boards, including the development of Equal Status Reviews. The Equality Authority has begun to establish a framework for carrying out Equal Status Reviews in the area of health and this work is a priority established in its current strategic plan. The reviews will assess equality in service provision and highlight potential areas of discrimination in service delivery and for compliance with the Equal Status Act. This will also address good practice and actions that can be built upon and developed to enhance equality outcomes. A pilot project with the NWHB for the development of a template and pilot of an Equal Status Review will be complete in March 2004. Equal Status Reviews have the potential to establish how disability intersects with women, minority ethnic groups, Travellers, lesbian, gay and bisexual people, and older people.

Chapter 5: Recommendations

This final section contains recommendations for the continuous improvement of disability health services in the light of international best practice and evidence from the mapping exercise in the following areas:

- Data
- Health service mapping
- Disability policy development and the reform programme in health
- Service provision
- Coordination and integration of services
- Rights and a social model of disability
- Quality developments and standards
- Awareness raising, training and guidance
- Information accessibility
- User involvement and participation
- Equality, equal status reviews and disability proofing

Disabled service users and organisations representing disabled people should be consulted in all of the areas of policy and service developments that are outlined below.

Many of these recommendations should be embedded into and should inform the reform programme in health.

5.1 Data

This report has highlighted some of the difficulties in mapping services and significant data gaps that exist that impede effective monitoring of health services. Health service mapping should be able to capture key developments and gaps in services, for example, waiting lists. In some services no waiting lists are held, in others waiting lists only operate once needs assessments or

referral has taken place. There are key issues that also need addressing in the future development of the Physical and Sensory Disabilities Database and the Intellectual Disability Database that can help with future health mapping. In particular, improved and more targeted data is important for the development of evidence based service planning.

Department of Health and Children and Health Boards

- There needs to be more systematic and coordinated data collection and reporting. A management information strategy with systems to collate information electronically needs to be put in place to coordinate data and reporting requirements. This has cost and other implications for the provision of computerised information systems at the level of disability services. Funding for this needs to be built into the new information strategy.
- The DOHC should hold waiting lists for disability services in the same way that it does by hospital and speciality. This practice should be extended to disability services and this would help to identify the numbers of people waiting for assessments and for services and the average waiting time for services.
- Regarding the intellectual and physical and sensory disabilities databases it is important to ensure the validity and accuracy of the data provided by health boards, particularly to ensure that there is no double counting and that the data is comprehensive. The appointment of disability database coordinators in the health boards will be important to this, as will the guidance and training given to them in their roles. Health boards should also be able to verify the numbers receiving the service with their own data.
- Where the data reveals gaps and deficits in services, mechanisms should be put in place to addressing these in service planning. The evidence from the databases and new service demands needs to be properly tied into service planning and resource allocation. For example, the Intellectual Disability Database shows that the high incidence rate of intellectual disability in the 1960s and longer life expectancies has service implications for an increasing population of people with intellectual disability aged over 35 years. This has resulted in demands for new residential services, fewer free places, demands for therapeutic support services for people living with their own families, and increasing demands for more intensive services and services designed specifically to meet the needs of older people with intellectual disability.
- It will be important to ensure that databases do not inadvertently suppress important future needs. For this reason it will be important that sufficient information is given to people about the services they can avail of in the future, even if the services do not currently exist in a particular health board, so that accurate service needs can be identified.
- Serious consideration should also be given to the introduction of a database or other mechanism to assist mental health service planning, although issues of disclosure and confidentiality would need to be tightly checked.
- Attention needs to be given to data issues concerning staffing including

the need for agreed statutory staff-client ratios and the integration of workforce planning into the strategic development of services and service planning.

- There should be disaggregation of health board staffing data so that it reflects whole time equivalent staffing in mental health and disability services. This should be included in the DOHC Personnel Census and health board reporting requirements.
- It is important that the NDA be represented at the National Monitoring Committee, which was established in 2000 by Minister Cowen to track new service developments in disability services.

5.2 Health service mapping

A key conclusion from this research is the need for greater coordination of data and more effective data collection in order to contribute to evidenced based service planning and more effective workforce planning.

Department of Health and Children

- The DOHC should convene a working group of health boards, the NDA, the DOHC, service providers and disability organisations to agree a framework and protocol for health mapping. This should be built into the forthcoming health information strategy and the reform programme in health by reaching agreement about a common framework of health reporting.
- The framework should agree common definitions of services and highlight information and data gaps and requirements. Coordinating data so that there is more systematic and transparent data on services is increasingly crucial for the health boards and service providers in this respect and could help to avoid repetition of and inconsistencies in data collection. A major development to assist this process is the need for effective and computerised management information systems to be put in place in all health boards.
- The UK model of health service mapping in mental health services should be explored for its applicability in Ireland.

National Disability Authority

- The NDA should support further disability health service mapping pilots in partnership with health boards using the framework developed for health mapping. This should also involve groups and organisations representing disabled people.
- There should also be a database / information system for presenting health and other disability mapping information. In order to maintain health mapping as a dynamic mechanism identifying health gaps the NDA could work in partnership with voluntary organisations and health boards in the development of a database / information system for collating health mapping data that could be updated on a regular basis.

5.3 Disability policy development and the reform programme in health

Department of Health and Children

- The momentum behind implementing the commitments on disability services made under *Quality and Fairness* needs to be sustained and progressed. These issues should be built into the reform programme on health.
- Funding needs to be more equitably allocated for all service users. The chronic under-funding of mental health services should be urgently addressed. Spending on disability health services needs to increase overall as a proportion of GDP in line with best practice in other countries.
- There needs to be a progressive, strategic and planned funding increase over the next five to ten years. Whilst the problems facing health service funding need to be resolved at a political level, there is scope for building in more sustained and progressive funding increases year on year. This will be particularly important to realising many of the priorities set out in *Quality and Fairness* and other key policies.

Department of Health and Children, Local Authorities and the National Disability Authority

- Policy developments should also be guided by international and European best practice and policy development. This should include reference to the principles underpinning the Madrid Declaration: legal measures that include anti-discrimination legislation, changing attitudes, services for independent living, support to families, special attention to disabled women, mainstreaming of disability and consultation and involvement of disabled people.

Department of Health and Children, Health Boards and Department of Social and Family Affairs

- Explore, by reference to international best practice and through pilot projects, the development of direct payments and personal budgets to enable disabled people to employ their own personal assistants and other care services.

5.4 Service provision

Despite some positive service developments in recent years in orienting services towards a social model of disability and the development of community based services, there remains a continued under-funding of core services and in many cases poor quality services. In this respect many of the policy developments in recent years have yet to be realised in practice. This is particularly the case in mental health services where the absence of a modern service and inadequate community based provision has resulted in inappropriate and inadequate services.

Mental Health Services

Department of Health and Children and statutory and non-statutory service providers

- In mental health there is an urgent need to develop more out-patient services, day and day hospital services, community-based care and housing services to meet the demands for services in the community as part of the general shift away from institutionalised care. Services need to be developed within a social model through the provision of advocacy, independent living and mainstreaming.
- The continued inappropriate placements of people with intellectual disability in mental hospitals needs to be addressed through accelerated provision of appropriate community, day and residential accommodation.
- New service developments should focus on the need for more specialist mental health services including the expertise and provision of mental health services for homeless people, the prison population and ex-offenders, young people and older people. This also includes the need for assertive outreach programmes, out of hours services, preventative programmes, positive mental health and early intervention. There should be pilot projects to test new models of practice and these should be rolled out across the health boards.
- Mechanisms for the more effective participation of mental health service users, their families and carers are essential, including training and capacity building for service users so that they can be more effective participants in the planning, development and monitoring of services.
- In the ERHA in particular the continued problem of acute bed capacity needs to be addressed urgently with better provision of community-based and appropriate residential accommodation.
- The establishment of the Mental Health Review Expert Group, as signalled in *Quality and Fairness*, is a welcome development. The Review Group should be as participative and far reaching as possible and should emphasise new service developments in the areas of advocacy, needs assessment, coordinated care planning, multi-disciplinary services, services for specific groups, counselling services, community-based psychiatric services, community-based provision and the coordination of health, social care, housing and employment services. Clinical services should be properly balanced against supporting autonomy, independence and user participation.

Local authorities and Health Boards

- The provision of community-based housing and alternative housing solutions needs to be planned in strategic ways and in partnership with local authorities and health boards. This should be further progressed through local coordination mechanisms such as the City and County Development Boards.

Irish College of General Practitioners

- In partnership with the health boards, mental health organisations and the

NDA, the Irish College of General Practitioners should identify the training and other needs of GPs in providing community-based mental health services. This training should be embedded into GP practice.

National Disability Authority, Mental Health Commission and mental health advocacy organisations

- Working with relevant professional organisations the NDA and the Mental Health Commission should produce guidelines on working with people with mental health difficulties in community settings. The objective will be to raise awareness about people with mental health support needs, and how professionals, local communities and services can respond.

People with an intellectual disability

Department of Health and Children, Health Boards, statutory and non-statutory providers

- Additional services need to be developed for people with an intellectual disability in order to address shortfalls and gaps in services. This includes the need for additional community-based residential accommodation, high support respite, home support services, counselling services, respite and personal support services.
- Additional and new services need to be developed for the dependent population of older people with intellectual disability, services for people with challenging behaviour, and people with acquired brain injury.
- The programme to transfer people with intellectual disability from large residential centres and psychiatric hospitals into the community needs to be accelerated with additional funding and capacity to provide community-based services. Targets for transfer need to be revisited with a view to completing transfers within a year.
- Evidence from the Intellectual Disability Database of service needs over the coming five years needs to be built into service planning and resource allocation.

People with a physical and sensory disability

Department of Health and Children, Health Boards, statutory and non-statutory providers

- Additional services need to be developed to address the shortfall and gaps in services for people with physical and sensory disabilities. This includes personal assistants for people with physical and sensory disabilities, services for older people, speech and language therapy services for pre-school children and young people, and speech and language therapy services for infants and disabled people with swallowing problems, respite services, and high, medium and low support community-based housing.
- These service developments need to take place in line with the actions outlined in *Towards an Independent Future* (1996) and *Quality and Fairness* (DOHC, 2001a).

- Services need to be reoriented towards a social model of disability, with new services that include independent needs assessment, advocacy, independent living and personal assistance.
- The NDA can progress its strategic priority of influencing attitudes in Irish society by supporting research into attitudes towards people with disabilities, identifying examples of best practice in this area and supporting the development of standards in disability equality awareness training.
- The forthcoming review of rehabilitation services, as signalled in *Quality and Fairness (DOHC, 2001a)*, should emphasise the development of new service developments in the areas of advocacy, needs assessment, coordinated care planning, multi-disciplinary services, services for specific groups, community-based provision and the coordination of health, social care, housing and employment services. Services should support autonomy, independence and user participation.

5.5 Coordination and integration of services

Improving the coordination and integration of disability health services is vital as service provision becomes more community based and organised within a social model of disability. There are a number of national, regional and local coordination mechanisms that need to be made effective in practice.

Government Departments

- There should be more coordination of policy under the Strategic Management Initiative (Department of the Taoiseach) and the Office of Social Inclusion (Department of Social and Family Affairs) on services for disabled people. These should draw together the Department of Health and Children, Department of Enterprise, Trade and Employment, Department of Social and Family Affairs and the Department of the Environment and Local Government into the strategic planning of services.
- The Department of Health and Children should initiate a service coordination group as part of the reform programme in health in order to address the policy and resource implications of coordination and integration of services.

Local authorities, Health Boards and City and County Development Boards

- City and County Development Board Strategies and Action Plans should be initiating and developing more effective mechanisms for coordinating local services. These should prioritise the coordination of services for people with disabilities. Local authorities, health boards and other service providers have an important role to play in coordinating their activities and services. Service coordination of health, social care, housing and employment services should be carried out strategically.

5.6 Rights and the social model of disability

Disability policy has tended to be framed in a medical model with limited coordination of resources for independent living and the mainstreaming of disability. New legislation on disability is signalled to provide some limited rights to services and there is now a greater awareness of a social model of disability.

Department of Justice, Equality and Law Reform

- The forthcoming Disability Bill should provide for a range of actions that contribute to mainstreaming and a social model of disability as outlined in the report of the Disability Legislation Consultation Group (2003). This includes rights to needs assessment, leading to the coordinated provision of services, advocacy and redress.

Department of Health and Children, statutory and non-statutory providers

- The future development of policy, by the DOHC and by providers in the statutory and non-statutory sector, should be informed by the social model of disability and with reference to the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (1993), the Madrid Declaration, and in line with international best practice in this area.

National Disability Authority

- The NDA is in a unique position to be able to raise awareness and understanding about the social model of disability and its impact on health. This can be through support and development of good practice regarding awareness raising and disability awareness training as well as the dissemination of good practice guidelines on how to develop services that are focussed on a social model of disability.

Comhairle and Advocacy Organisations

- Explore and disseminate different models of advocacy and ensure so that health providers plan for the development of advocacy programmes. This includes a dual approach of training of professionals in advocacy, for example, based on the nurses advocacy training programme in the SWAHB, as well as independent and user led forms of advocacy.
- Produce training and good practice guidelines on the development of advocacy and disseminate these throughout the health boards.
- Fund and support the development of independent advocacy.

5.7 Quality development and standards

The growth of activity around the development of quality and standards is likely to be of great important to the development of more outward and responsive health services. However, it is vital that these developments focus on service improvements that have a positive impact on service provision and service users experiences and take up of services.

Department of Health and Children

- Future activities on standards and quality need to be effectively coordinated between the DOHC, ISQSH, HeBE, and the NDA. This will be particularly important in the context of the health service reform programme and it will be essential to ensure that standards concerning person centred care, equality, dignity, independence and participation are given priority.

Department of Health and Children and the National Disability Authority

- Appropriate standards should be developed for all health services, and should cover all statutory and non-statutory service provision. This is particularly important for those sectors that are not covered by inspection or other regulatory mechanisms for the control of quality. The evaluation of the NDA/DOHC standards pilot should be used as a basis for the further development and widening scope of the standards.
- Effective and confidential complaints procedures should be put in place. All health services, including those in the non-statutory sector should be covered under the Ombudsman's remit.

5.8 Awareness raising, training and guidance

In the disability sector there is a need to build organisational capacities to deliver the range of services now required to enable people to live independently. Many health providers have made significant progress in moving in this direction, however, progress is often hampered by organisational regimes that prevent change. There is a key role to be played in raising awareness, and in providing disability awareness training and guidance.

National Disability Authority and the Equality Authority

- Provide guidance and information about disability awareness training, including a list of disabled trainers who can provide awareness training for health providers.

Department of Health and Children

- Service planners, statutory and non-statutory service providers, front-line staff, medical professionals and personnel should be required to undergo disability awareness training as part of their contracts. This should be carried out in conjunction with both professional training and as part of ongoing staff development and customer service training.

National Disability Authority and the Department of the Taoiseach

- In partnership with the Quality Customer Service Working Group on Equality/Diversity a good practice checklist should be drawn up to help managers and front line service providers improve customer service to disabled service users. This should also include guidelines on integrating disability awareness into customer service and staff development training

for front-line.

5.9 Information accessibility

Information about disability health services is often not accessible to people with disabilities. Many disabled people refer to lack of information or inaccessible information as being a major barrier to health service utilisation and satisfaction with services.

- There should be an exploration of different formats (including large print, alternative print formats, Braille, video and audio, accessibility for web sites etc) that can be used for health service information. This should result in a set of accessibility guidelines for health boards, statutory and non-statutory service providers. Consultations with and feedback from people with disabilities should be sought in drawing up the guidelines. This should also be carried out in partnership with the DOHC, representative from health boards and service providers.
- The development of tools, guidelines and codes of practice to support disability awareness and equality should be developed and disseminated through information in different formats.

5.10 User involvement and participation

User participation and consultation is a key area for development in the health boards. User involvement has been established in consultations for the development of disability strategies and service plans in several health boards and in the NWHB the piloting of consumer panels in several service areas. Despite these notable developments in user participation and consultation, disabled service users are poorly represented and consultations have tended to be at the level of Disability Coordinating Committees.

Department of Health and Children, National Disability Authority and Health Boards

- It will be important in the future that consumer panels and other forms of consultation involve disabled service users, their advocates and families. This will require more effective models developed for user participation, including the most marginalised service users. This means exploring different forms of supported and advocacy based forms of participation and empowerment evaluation.
- Guidelines for user consultation need to be established and agreed with the health boards on communicating effectively with disabled service users.
- The health boards should consider establishing consumer panels for specific groups of disabled people, for example, people with mental health difficulties, people with physical disabilities, deaf people, blind people, and people with intellectual disabilities. Specific panels should also be established for carers. The panels should give feedback on issues concerning the quality of services, planning of services and monitoring of services.

5.11 Equality, equal status reviews and disability proofing

A greater emphasis is now being given to equality proofing and disability proofing. In addition, the development of Equal Status Reviews will help to assess equality in service provision and highlight potential areas of discrimination in service delivery and for compliance with the Equal Status Act. Equal status reviews have the potential to establish how disability intersects with women, minority ethnic groups, Travellers, lesbian, gay and bisexual people, and older people.

Equality Authority, National Disability Authority and Health Boards

- The NDA should work in partnership with the Equality Authority and health boards in rolling out equal status reviews across the health boards. The specific issues facing disabled service users should be identified.
- The learning from the pilot Equal Status review in the North Western Health Board should be rolled out across all health boards.
- Pilot projects for equal status reviews should be carried out in mental health and disability services. These should be supported by the NDA and the Equality Authority.
- In addition, guidelines on health impact assessment, disability impact assessment and disability proofing of health services should be developed. In particular, the NDA could help to widen the breath of health impact assessment so that it includes a focus on equality issues and outcomes.

Bibliography

- Albrecht, G. (1992) *The Disability Business: Rehabilitation in America*, London, Sage Library of Social Research
- Amnesty International (2003) *Mental Illness: The Neglected Quarter*. Summary Report. Amnesty International: Dublin
- Bacon, Peter & Associates (2001) *Current and Future Demand Conditions in the Labour Market for Certain Professional Therapists*, Dublin
- Barnes, C. G. Mercer, and H. Morgan (2000) *Creating Independent Futures*, Disability Press: Leeds
- Barnes, Colin and G. Mercer (1996) *Exploring the Divide: Illness and Disability*, The Disability Press: Leeds
- Beresford, Peter and Jane Campbell, (1994), *Disabled People, Service Users, User Involvement And Representation*, *Disability And Society*, Vol 9, No 3, pp 315-325.
- Beresford, P. (1994), *Changing The Culture, Involving service users in social work education*, Paper 32.2, London, Central Council for Education and Training in Social Work. Barnes, C. and (1995) 'Disability: Emancipation, Community Participation and Disabled People' in Mayo, M. Craig, G (eds.) *Community Empowerment: A Reader in Participation and Development*, London, Zed Books
- Beresford, P. (1996) "Poverty and disabled people: challenging dominant debates and policies" in *Disability and Society*, 11 (4): 553-67
- Bickenbach, J. E. (1993) *Physical Disability and Social Policy*, Toronto, University of Toronto Press.

- Bosco Conama, John and Carmel Grehan (undated) Poverty in the Deaf Community. Report on the interviews of randomly selected members of the Deaf Community in Dublin to determine the extent of poverty within the community, Dublin:Irish Deaf Society
- Boyle, R. & P.C. Humphreys (2001) A New Change Agenda for the Irish Public Service, CMPR Discussion Paper 17. Dublin: IPA
- Boyle, Michelle & Richard Boyle (2001) Service Planning in the Health Sector, CMPR Discussion Paper 13, Institute of Public Administration
- Brown, et. al. (2001) Quality Assurance in Health Care in Developing Countries. The Quality Assurance Project, Centre for Human Services, Bethesda, MD
- Burke, S. (2002) Giving People a Say on Poverty and Health, Learning from the National Anti-Poverty Strategy and Health Consultation Process. Dublin: Institute of Public Health in Ireland
- Butler & Boyle (2001) Chief Executive Officers of the Health Boards. Suicide in Ireland: A National Study, 2001. Navan: North Eastern Health Board
- Comhairle (2002) Developing Advocacy Services: A Report on the Deliberations of Regional Consultation Fora, Comhairle: Dublin
- Comhairle (2002) Entitlements for People with Disabilities, Comhairle: Dublin
- Commission on the Status of People with Disabilities (1996) A Strategy for Equality, Dublin: Stationery Office
- 1066 Consultancy and Health Care Consultancy Limited (2002) St Mary's Drumcar Residential Services: Report on the Staffing and Skill Mix Review, November
- Council of Europe (2000) Recommendation (2001)12 of the Committee of Ministers to member states on the adaptation of health care services to the demand for health care and health care services of people in marginal situations, Strasbourg: Council of Europe
- Council of Europe (2002) The Adaptation of health care services to the demand for health care and health care services of people in marginal situations. Strasbourg: Council of Europe
- Council of Europe, Committee of Ministers (2001) Recommendation Rec(2001)12 of the Committee of Ministers to member states on the adaptation of health care services to the demand for health care and health care services of people in marginal situations. Adopted by the Committee of Ministers on 10 October 2001 at the 768th meeting of the Ministers' Deputies.
- Croft S. and Peter Beresford, (1993), Getting Involved: A practical manual, Open Services Project, London.
- Daly, A. and D. Walsh (2002) Activities of Irish Psychiatric Services, 2002, Dublin: Health Research Board
- Daly, A. and D. Walsh (2002) Irish Psychiatric Hospitals and Unit Census, 2001, Dublin: Health Research Board
- Daly, A. and D. Walsh (2002) Psychiatric Reporting System Bulletin, Midland Health Board, Issue 1, Dublin: Health Research Board
- Daly, A. and D. Walsh (2002) Psychiatric Reporting System Bulletin, Midland Health Board, Issue 1, Dublin: Health Research Board

- Daly, A. and D. Walsh (2002) Irish Psychiatric Hospitals and Units Census, 2001, Health Research Board: Dublin
- Daw, R. (2000) The Impact of the Human Rights Act on Disabled People, Disability Rights Commission and the Royal National Institute for Deaf People
- Degener, T. and G. Quinn (2000) "A Survey of International, Comparative And Regional Disability Law Reform", From Principles to Practice: An International Disability Law and Policy Symposium, October
- Department of Health (2003) Health Statistics 2002
- Department of Health and Children (2000) Report of the Inspector of Mental Hospitals: For the year ending 31st December, 1999
- Department of Health and Children (2001) Report of the Inspector of Mental Hospitals: For the year ending 31st December, 2000
- Department of Health and Children (2001a) Quality and Fairness, A Health System for You. Dublin: Stationery Office
- Department of Health and Children (2001b) Primary Care: A New Direction. Dublin: Stationery Office
- Department of Health and Children (2001c) The Health of Our Children, Annual Report of the Chief Medical Officer, 2000. Dublin: Department of Health and Children
- Department of Health and Children (2001d) Your Views about Health. Report on Consultation. Dublin: Department of Health and Children
- Department of Health and Children (2001e) Making Knowledge Work for Health, A Strategy for Health Research. Dublin: Department of Health and Children
- Department of Health and Children (2002) Report of the Inspector of Mental Hospitals: For the year ending 31st December, 2001, Dublin: Stationery Office
- Department of Health and Children (2002) Towards Workforce Planning. The Nursing and Midwifery Resource: Final Report of the Steering Group, Dublin: Stationery Office
- Despouy, L (1993) Human Rights and Disabled Persons, Centre for Human Rights, UN: New York/Geneva
- Disability Legislation Consultation Group (2003) Equal Citizens NDA: Dublin
- Disability Rights Commission (2002) DRC Policy Statement on Social care and Independent Living, August
- Eastern Regional Health Authority (2002) Service Plan 2002
- Eastern Regional Health Authority (2003) Service Plan 2003
- Elliott, I (2000) Unique Insight: a report on the consultation with users of the St Loman's Mental Health Service. Dublin: South Western Area Health Board.
- Equality Authority (2001) An Equality Position on the National Action Plan for Social Inclusion. Dublin: Equality Authority
- Equality Authority (2001) An Equality Proofing Template for the City and County Development Boards, Dublin
- Equality Authority (2001) Equality, Poverty and Social Inclusion. The National Action Plan on Social Inclusion. An Equality Authority Position.

Equality Authority: Dublin

- Equality Commission Equality Impact Assessment: Practical Guidance, Equality Commission: Belfast
- Equality Commission Guide to Statutory Duties: A guide to the implementation of the statutory duties on public authorities arising from Section 75 of the Northern Ireland Act 1998, Equality Commission: Belfast
- Esping-Anderson G (1990) The Three Worlds of Welfare Capitalism, Polity Press: London
- European Commission (2000a) Council Decision of 27 November 2000 establishing a Community action programme to combat discrimination (2001-2006), OJ of 2.12.2000, L 303/24).
- European Commission (2000b) Social Policy Agenda, European Commission: Brussels
- European Commission (2000c) Building an Inclusive Europe, Communication from the Commission, COM(2000) 79 final, European Commission: Brussels
- Finkelstein, Vic (1980) Attitudes and Disabled People, London,
- Finkelstein, V. (2001) Rethinking care in a society providing equal opportunities for all, WHO
- Forum of People with Disabilities (2001) Advocacy: A Rights Issue, FPWD: Dublin
- Glover, G. and D. Barnes (2002) Mental Health Service Provision for Working Age Adults in England 2001, University of Durham, Centre for Public Mental Health
- Greatley, A. and R. Ford (2003) Out of the Maze, Sainsbury Centre for Mental Health / Kings Fund
- Health Research Board (1997) National Intellectual Disability Database, Annual Report of the National Intellectual Disability Database Committee. Dublin: HRB
- Health Research Board (2001) Report of the National Physical and Sensory Disability Database Development Committee. December. Dublin: HRB
- Humphreys, Peter, Fleming, Sile and Orla D'Donnell (1999) Improving Public Services in Ireland, CPMR Discussion Paper 11, Institute of Public Administration
- Kalisch, D., Aman, T. and L. Buchel (1999) Social and health policies in OECD countries: A survey of current programmes and recent developments, Labour Market and Social Policy, Occasional Papers No 33
- Kathleen, Kane (1999) Lanarkshire Joint Learning Disability Strategy: We Want a Life, Report of Survey Work
- Keogh, F., Roche, A. & D. Walsh (1996) "We have no more Beds..." An enquiry into the availability and use of Acute Psychiatric Beds in the Eastern Health Board Region, Dublin: Health Research Board
- Lanarkshire Council (2000) We Want a Life Learning Disabilities in Lanarkshire, Strategic Framework
- Michailakis, D. (1997) Government Action on Disability Policy: A Global

Survey, Liber Publishing House: Stockholm

- Midland Health Board (2002) A Five Year Strategy for Physical and Sensory Disabilities, 2002 - 2007
- Comhairle (2002) Entitlements for People With Disabilities, Dublin: Comhairle
- Midland Health Board (2002) Annual Report 2001
- Midland Health Board (2002) Service Plan 2002
- Midland Health Board (2002) Statistical Addendum to the Annual Report 2001
- Midland Health Board (2003) Service Plan 2003
- Morris, J. (1993) Independent Lives: Community Care and Disabled People, Basingstoke, Macmillan
- Mullally, S. and O. Smith (2000) Partnership 2000 Working Group Report on Equality Proofing, January, Department of Justice, Equality and Law Reform/University College Cork: Dublin
- National Association of Mental Handicap Ireland (2000) Forever Waiting? Report of the NAMHI Waiting List Task Group, April
- National Association of Mental Handicap Ireland (undated) Standards of Care
- National Disability Authority Act (1999) Ireland
- NDA (2001) A Matter of Rights, Strategic Plan 2001-2003. Dublin: NDA
- NDA (2002) Ask Me: Guidelines for Consultation with People with Disabilities NDA: Dublin
- NDA (2002a) Disability Research in Ireland, 1996 – 2001. Dublin: NDA
- NDA (2002b) Submission to the Equality Unit, Department of Justice, Equality and Law Reform on the development of indicators for equality proofing in relation to people with disabilities
- NDA (2002c) Building for Everyone: Inclusion, Access and Use NDA: Dublin
- NEHB (2001) Model for a New Community Mental Health Service: The Cavan / Monaghan Project
- North Eastern Health Board (2002) Annual Report 2001
- North Eastern Health Board (2002) Service Plan 2002
- North Eastern Health Board (2003) Service Plan 2003
- North Western Health Board (2002) Annual Report 2001
- North Western Health Board (2002) Service Plan 2002
- North Western Health Board (2003) Service Plan 2003
- Oliver, M. (2001) "Where will older people be? Independent Living Versus Residential Care", paper presented to Care and Management of Older People with Complex needs, UK, 21 June 2001
- Pathways Research Team (2002), Experiences of Mental Health Services from a user-led perspective, Pathways: Galway
- Priestley, M. (2003) Disability and the life course: Global Perspectives, Cambridge University Press: Cambridge
- Priestley, M. (2001) Disability: A Life Course Approach, Polity Press: London
- Pillinger, J. (2001) Quality in social public services. Dublin: European Foundation for the Improvement of Living and Working Conditions

- Pillinger, J. (1998) Social Public Services in Europe: The Quality of Working Life and the Quality of Service. An Overview of Developments in Ireland, Luxembourg, the Netherlands, Portugal and Sweden, European Foundation: Dublin
- Pillinger, J. (2001) The Quality of Social Public Services: European Synthesis Report, European Foundation: Dublin
- Pillinger, J. (2002) Equality/Diversity and Quality Customer Service, Research Report for the Equality Authority/Department of the Taoiseach: Dublin
- Pillinger, J. (2002a) Disability and the Quality of Services: Irish and European perspectives, Policy Institute Working Paper (PIWP04), Dublin: Trinity College Dublin
- Priestly, M. (ed) (2001) Disability and the Life Course: Global Perspectives, Cambridge: Cambridge University Press
- Quinn G (1995) "The International covenant on civil and political rights and disability: a conceptual framework" in T Degener and Y Koster-Dreese (eds) Human Rights and Disabled Persons: International Studies in Human Rights, Volume 40.
- Rajavaara, M., 'Professionals and quality initiatives in health and social services', in Evers et al, Developing Quality in Personal Social Services: Concepts, Cases and Comments, European Centre: Vienna, Aldershot, Ashgate, 1997.
- Rosenthal, E. and A. Kanter (2000) The Right to Community Integration for People with Disabilities under United States and International Law, Paper presented to Disability and Law Symposium: From Principles to Practice, October
- Sainsbury Centre for Mental Health (2003) Assertive Outreach, Sainsbury Centre:
- Shakespeare, T. (2000) "The Social Relations of Care" in Lewis G, Gewirtz S and Clarke J Rethinking Social Policy, Sage: London
- Socialstyrelsen (1996) Welfare and freedom of choice? Final report from the evaluation of the 1995 psychiatric care reform, Socialstyrelsen: Stockholm
- South Eastern Health Board (2002) Service Plan 2002
- South Eastern Health Board (2003) Service Plan 2003
- Southern Health Board (2002) Annual Report 2001
- Southern Health Board (2002) Focussing Minds...Developing Mental Health Services in Cork and Kerry
- Southern Health Board (2002) Service Plan 2002 Southern Health Board (2003) Service Plan 2003
- The Irish National Health Promoting Hospital Network (2002) Mental Health Project Report, The Irish National Health Promoting Hospital Network: Dublin
- UNDP (2000) Human Development Report 2000, United Nations: Geneva
- UNDP (2001) Human Development Indicators, United Nations: Geneva
- UNDP (2002) Human Development Report 2002, United Nations: Geneva
- United Nations (1971) Declaration on the Rights of Mentally Retarded Persons, Proclaimed by General Assembly resolution 2856 (XXVI) of 20 December

1971)

- United Nations (1975) Declaration on the Rights of Disabled Persons, Proclaimed by General Assembly resolution 3447 of 9 December 1975
- United Nations (1991) Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care, Adopted by General Assembly resolution A/46/119 of 17 December 1991
- United Nations (1993) The Standard Rules on the Equalization of Opportunities for Persons with Disabilities, Adopted by General Assembly resolution A/48/96, annex of 20 December 1993
- United Nations (2000) Substantive Issues arising in the implementation of the International Covenant on Economic, Social and Cultural Rights, Committee on Economic, Social and Cultural Rights, Twenty-second session, General Comment No. (2000) The right to the highest attainable standard of health, 11/08/2000. E/C.12/2000/4, CESCR, 22nd Session. Geneva: United Nations
- United Nations Economic and Social Council (2002) Concluding Observations of the Committee on Economic, Social and Cultural Rights: Ireland. 05/06/2002. Concluding Observations and Comments. United Nations: Geneva
- Waddington, Lisa and Matthew Diller (2001) Tensions and Coherence in Disability Policy: The Uneasy Relationship Between Social Welfare and Civil Rights Models of Disability in American, European and International Employment Law
- Ward, Linda (ed) (1998) Innovations in Advocacy and Empowerment for People with Intellectual Disabilities, Lisieux Hall Publications
- Western Health Board (2001) Annual Report 2000
- Western Health Board (2002) Service Plan 2002
- Western Health Board (2003) Service Plan 2003
- WHO (1998) Ottawa Charter for Health Promotion. Geneva: WHO
- WHO (1999) Health 21 – the health for all policy framework for the WHO European Region. Europe Health for All Series, No 6. Copenhagen: WHO Regional Office for Europe. Copenhagen: WHO
- WHO (1999) Health21 – the health for all policy framework for the WHO European Region. Europe Health for All Series, No 6. Copenhagen: WHO Regional Office for Europe. Copenhagen: WHO
- WHO (1999) Reducing Inequalities in Health – proposals for health promotion policy and action, Consensus Statement, European Committee for Health Promotion Development, WHO Regional Office for Europe. Copenhagen: WHO
- WHO (2001) Rethinking Care From the Perspective of Disabled People, Conference and Report and Recommendations, WHO Disability and Rehabilitation Team
- WHO (2001) Rethinking Care From the Perspective of Disabled People, Conference and Report and Recommendations, WHO Disability and Rehabilitation Team, WHO: Geneva
- WHO (2001a) Mental Health: New Understanding, New Hope, WHO: Geneva

- WHO (2001b) Government responses to the implementation of the UN Standard Rules on medical care, rehabilitation, support services and personnel training: Main Report, WHO: Geneva
- WHO (2001c) Rethinking Care from the PErerspective of Disabled People, COnference and Report and Recommendations, WHO Disability and Rehabilitation Team, WHO: Geneva

Appendix 1: List of relevant legislation and policy documents relevant to disability and health

1. Key legislation

- Mental Health Act 2001
- Disability Education Act 2001
- Equal Status Act 2000
- National Disability Authority Act 1999
- Employment Equality Act 1998
- Public Service Management Act, 1997
- Health (Eastern Regional Health Authority) Act, 1999
- Health Act, 1970

2. National health policy statements/documents

- Audit of the Irish health system for Value for money,
- Acute Hospital Bed Capacity, A National Review. Department of Health and Children, 2002
- *Quality and Fairness – A System for You*, Department of Health and Children, 2001
- *Primary Care: A New Direction*, Department of Health and Children, 2001
- Acute Hospital Bed Capacity. A National Review, Department of Health and Children, 2002
- *Reports of the Chief Medical Officer*, 1999, 2000, 2001, Department of Health and Children
- *National Health Promotion Strategy 2000-2005*, Department of Health and Children, 2000
- Making knowledge work for Health: A Strategy for Health. Department of Health and Children, 2000
- *The National Health and Lifestyle Surveys (SLAN and HBSC)*, Department of Health and Children, 1999
- Management Development Strategy, For Health and Personal Social Services, Department of Health and Children, 1996
- *Charter of Rights for Hospital Patients*, Department of Health and Children, 1994
- *Shaping a Healthier Future*, Department of Health and Children, Strategy for Healthcare, 1994

3. National policy documents on disability

- *Strategy for Equality*, Report of Commission on Status of People With Disabilities, 1996
- *Towards Equal Citizenship*, Progress Report on the Commission on the Status of People with Disabilities, 1999

Mental Health

- Report of the Review Group on Child and Adolescent Psychiatric Services, Department of Health and Children, 2001
- Activities of Irish psychiatric services, Department of Health – Health Research Board, 1997, 1998
- Guidelines on Good Practice & Quality Assurance in Mental Health Services, Department of Health and Children, 1998
- *Planning for the Future*, Department of Health (Psychiatric Services), 1984
- Report of the National Task Force on Suicide Department of Health and Children, 1998
- *Suicide in Ireland: A National Study*. North Eastern Health Board / Departments of Public Health on Behalf of the Chief Executive Officers of the Health Boards, 2001
- Annual Reports of the Inspector of Mental Hospitals, 1999, 2000, 2001
- First Report of the Working Group on Child and Adolescent Psychiatry, Department of Health and Children, 2001

Physical Disability

- Towards an Independent Future, Report of the Review Group on Health and Personal Social Services on People with Physical and Sensory Disabilities 1996,
- *Personal Assistant Service for people with physical disabilities*, Report of Advisory Group, Department of Health and Children, 1995
- Report on the National Physical and Sensory Disability Database Development Committee, 2001
- National Physical and Sensory Disability Database – Information, Department of Health and Children, 2001

Intellectual Disability

- *National Intellectual Disability Database*, Annual Report of the National Intellectual Disability Database Committee. Health Research Board
- *Assessment of Need for Services to Persons with a Mental Handicap 1999-2003*, based on information from the National Intellectual Disability Database, 1998
- *Assessment of Need for Services to Persons with a Mental Handicap 1997-2001*, based on information from the National Intellectual Disability Database, 1997
- The Services to Persons with a Mental Handicap/Intellectual Disability - An Assessment of Needs and Abilities, (1997-2001), Department of Health

and Children

- Enhancing the Partnership: Working group on Implementation of Health Strategy for Mental Handicap, Department of Health and Children, 1996
- *Widening the Partnership*, Department of Health and Children, 1997
- *Services and People with Autism*, Department of Health and Children, 1994
- *Needs and Abilities*, Review Group on Mental Handicap Services, 1990
- *A policy for the Intellectually Disabled*, Report of the Review Group on mental handicap services, 1990
- Medical Aspects of Mental Handicap Services, Comhairle na nOspideal, 1998

4. Disability and other groups

Children

- Developing a Partnership with Families. Best Health for Children, 1999
- *Adolescent Health Strategy*, Best Health for Children, 2001
- Investing in Parenthood to Achieve Best health for Children. The supporting parents strategy. Best Health for Children, 2002
- Putting Children First: Promoting and Protecting the Rights of the Children, 2002
- *Best Health for Children*, Chief Executive Officers of the Health Boards, 1997
- Children First: National Guidelines for the Protection of Children, Department of Health and Children, 1999
- The National Children's Strategy: Our Children – Their Lives, Department of Health and Children, 2000
- *Our Duty to Care*, guidelines to the voluntary and community sector in providing safe environments for children they are dealing with, Department of Health and Children, 2002
- The Health of Our Children, Annual Report of the Chief Medical Officer, 2000. Department of Health and Children
- *Strengthening Families for Life*. Department of Social, Community and Family Affairs, 1998

Older people

- The Years Ahead: A Policy for the Elderly, 1984
- Report of the Working Party on Services for the Elderly, 1988

Women

- *A Plan for Women*, Department of Justice, Equality and Law Reform, 2001
- *A Plan for Women's Health 1997-1999*, Department of Health and Children, 1997

5. *Disability, Health and Poverty*

- Setting health targets for the National Anti-Poverty Strategy, a background research paper. Institute of Public Health in Ireland, 2000
- Report of the Working Group on NAPS and Health, Institute of Public Health, 2001
- Giving People a Say on Poverty and Health, Learning from the National Anti-Poverty Strategy and Health Consultation Process. Institute of Public Health in Ireland
- National Action Plan Against Poverty and Social Exclusion 2001-2003. Department of Social, Community and Family Affairs, 2001
- Building an Inclusive Society, Review of the National Anti-Poverty Strategy under the Programme for Prosperity and Fairness. Department of Social, Community and Family Affairs, 2002
- Your Views about Health: Report on Consultation for Quality and Fairness, Department of Health and Children, 2001
- *National Anti-Poverty Strategy*, Department of Social, Community and Family Affairs, 1997

6. *Strategy Statements/Service Plans*

- Working for Health and Well Being, Strategy Statement 1998 – 2001, Department of Health and Children, 1998
- *Progress Report on Strategy Statement*, Department of Health and Children
- *Business Plan 2001*, Department of Health and Childre
- *Business Plan 2002*, Department of Health and Children
- *Service Plans 2001, 2002 and 2003*: Southern Health Board, Mid-Western Health Board, North-Eastern Health Board, Midland Health Board, South Eastern Health Board, North Western Health Board, Western Health Board, Eastern Regional Health Authority
- *Customer Action Plan 1998-2001*, Department of Health and Children

7. *Other relevant national, European and International provisions*

- Programme for Prosperity and Fairness, 2000
- National Development Plan, 2000-2006
- Entitlements for People with Disabilities, published annually, Comhairle

International legal provisions that may impact on disability and health services

- The Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Healthcare
- [Proposal] for a UN Convention to Promote and Protect the Rights and Dignity of Persons with Disabilities.
- United Nations International Covenant on Economic, Social and Cultural Rights (ICESCR) including the right to “the enjoyment of the highest attainable standard of physical and mental health”

- The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities, 1993.
- UN International Covenant on Civil and Political Rights (ICCPR)
- UN Convention Eliminating Discrimination Against Women
- UN Convention on the Rights of the Child, Articles 23 and 24
- UN Convention Against Torture
- Council of Europe, Social Charter, Article 15.
- EU Resolution on Equality of Opportunity for Persons with Disabilities
- EU provisions on anti-discrimination (Treaty of Amsterdam) and Directive on equal treatment in employment and occupation for people with disabilities. 2000/78/EC (the Framework Directive).
- EU Charter of Fundamental Rights, Article 24
- EU Public Health Action Programme, 2002-2006
- WHO Health for All

Appendix 2: Department of Health and Children Performance Indicators for Disability Services Intellectual

Disability Services – Performance Indicators

Effectiveness

Performance Indicator ID1

The percentage of people with an Intellectual Disability in residential care for whom a written person centred plan* is in place.

***Person centred plan:** “A person centred plan is more than a care plan. It is a statement of the person’s vision for the future and the services designed to assist the person to move towards that future. The Plan is a tool used to document specific information about individualised supports for each person. It also communicates priorities to all support personnel and provides a point of reference for reviewing progress and change.

Plans are based on information from the person, the person’s primary support network and other service personnel who know and interact with the person. It reflects discussions and decisions about services and supports during planning sessions. The plan provides a road map for the achievement of personal outcomes”.

Rationale

Person Centred Planning is an important component of the provision of services for clients with intellectual disability. The presence of a person centred plan will ensure the needs of users will be identified and implemented

Source of Information

National Intellectual Disability Database

Frequency of Reporting

Annually: At the end of the 2nd Quarter i.e. 25th July (for the 12 month period from April of the previous year to April of the current year)

Specific Questions to be asked:

(a1) Number of people with an Intellectual Disability in residential care in the health board region during the reporting period?

(a2) Number of people with an Intellectual Disability in residential care in the health board region during the reporting period for whom a written person centred plan is in place?

Commentary required:

Where a person centred plan is not in place, please describe what is in place and the measures being made to introduce person centred plans, if any.

Health Improvement

Performance Indicator ID2

1. The percentage of people with an Intellectual Disability (by organisation) in residential care including group homes who have been vaccinated* against Hepatitis B.
2. The percentage of people with an Intellectual Disability (by organisation) who declined the vaccination
3. The percentage of staff (by organisation) in residential services for people with an Intellectual Disability who have been vaccinated* against Hepatitis B.
4. The percentage of staff (by organisation) who declined the vaccination

* Vaccinated: A person is considered vaccinated when they have been tested for immunity post vaccination.

Rationale

Hepatitis B is an important cause of serious liver disease. The Immunisation Guidelines for Ireland (1999) recommend immunisation for the above mentioned at risk groups.

Source of Information

Organisational Records

Frequency of reporting

Annually: At the end of the 3rd Quarter, i.e. 25th October (For the 12 month period from 1st October of the previous year to 30th September of the current year).

Specific Questions to be asked:

- (a1) Number of people in Intellectual Disability residential care/group homes in the health board region at the end of the reporting period?
- (a2) Number of people in Intellectual Disability residential care/group homes in the health board region who are currently vaccinated against Hepatitis B as at the beginning of the reporting year.
- (a3) Number of people in Intellectual Disability residential care/group homes in the health board region at the end of the reporting period who have been offered vaccination against Hepatitis B?
- (a4) Number of people in Intellectual Disability residential care/group homes in the health board region at the end of the reporting period who have been offered vaccination against Hepatitis B and accepted same?

(b1) Number of people in Intellectual Disability residential care/group homes in the health board region at the end of the reporting period who have been offered vaccination against Hepatitis B and declined same?

(c1) Number of staff in Intellectual Disability residential care/group homes in the health board region at the end of the reporting period?

(c2) Number of staff in intellectual disability residential care/group homes in the health board region who are currently vaccinated against Hepatitis B as at the beginning of the reporting year.

(c3) Number of staff in Intellectual Disability residential care/group homes in the health board region at the end of the reporting period who have been offered vaccination against Hepatitis B?

(c4) Number of staff in Intellectual Disability residential care/group homes in the health board region at the end of the reporting period who have been offered vaccination against Hepatitis B and accepted same?

(d1) Number of staff in Intellectual Disability residential care/group homes in the health board region at the end of the reporting period who have been offered vaccination against Hepatitis B and declined same?

Appendix 3: Mental Health Services Mapping Framework

1. Day, residential and respite care

a) Service profile

	Day centres	Residential care	Mental health hospital/ psychiatric hospital	Community residences/ group homes	Respite care
Service provided Y = Yes N = No					
Name & location of service provider					
Budget					
Funding source					
Staffing (wte)					
Source of referrals					
Waiting list referral system					
Numbers of the waiting list					

Average waiting list time					

b) Numbers receiving the service and places in 2002

	Day centres	Residential care	Mental health hospital/ psychiatric hospital	Community residences/ group homes	Respite care
Numbers receiving the service (wte): -Under 18 years -18-64 years -65 years + -Total					
Number of places or sessions (wte): -Under 18 years -65 years + -Total					

c) Gaps in service, emerging issues and plans for 2003

	Day centres	Residential care	Mental health hospital/ psychiatric hospital	Community residences/ group homes	care
Gaps in service					
Emerging issues					
Plans for 2003					

2. Home and community based supports

a) Service profile

	Psychiatrist	Community mental health nursing	Occupational therapy	Social work	Community alcohol and drugs service	Opiate treatment and addiction counsellors	Counselling for adult survivors of institutional abuse	Support services
Service provided Y = Yes N = No								
Name & location of service provider								
Budget								
Funding source								
Staffing (wte)								
Source of referrals								
Waiting list referral system								
Numbers on waiting list								
Average waiting list time								

b) Numbers receiving the service and places in 2002

	Psychiatrist	Community mental health nursing	Occupational therapy	Social work	Community alcohol and drugs service	Opiate treatment and addiction counsellors	Counselling for adult survivors of institutional abuse	Suicide prevention services	Me he pr
Numbers receiving the service (wte): -Under 18 years -18-64 years -65 years + -Total									
Number of places or sessions (wte): -Under 18 years -18-64 years -65 years + -Total									

c) Gaps in service, emerging issues and plans for 2003

	Psychiatrist	Community mental health nursing	Occupational therapy	Social work	Community alcohol and drugs service	treatment and addiction counsellors	Counselling for adult survivors of institutional abuse	S p s
Gaps in service								
Emerging issues								
Plans for 2003								

3. Mental health services for specific groups

a) Service profile

	Mental health services for people with intellectual disability	Mental health services for older people	Child and adolescent mental health services	Other services for specific groups
Service provided Y = Yes N = No				
Name & location of service provider				
Budget				
Funding source				
Staffing (wte)				
Source of referrals				
Waiting list referral system				
Numbers of the waiting list				
Average waiting list time				

b) Numbers receiving the service and no of places in 2002

	Mental health services for people with intellectual disability	Mental health services for older people	adolescent mental health services	Other services for specific groups
Numbers receiving the service (wte):				

-Under 18 years -18-64 years -65 years + -Total				
Number of places or sessions (wte): -Under 18 years -18-64 years -65 years + -Total				

c) Gaps, emerging issues and plans for 2003

	Mental health services for people with intellectual disability	Mental health services for older people	Child and adolescent mental health services	services for specific groups
Gaps in service				
Emerging issues				
Plans for 2003				

Other services

a) Service profile

	Needs assessment	Advocacy Service	Rehabilitative training	Sheltered workshops	Vocational training	Housing support	Transport services (including taxis)	Other
Service provided Y = Yes N = No								
Name & location of service provider								
Budget								
Funding source								
Staffing (wte)								
Source of referrals								
Waiting list referral system								
Numbers of the waiting list								
Average waiting list time								

b) Numbers receiving the service and places in 2002

	Needs assessment	Advocacy Service	Rehabi- litative training	Sheltered workshops	Vocational training	Housing support	Transport services (including taxi)	Other
Numbers receiving the service (wte): -Under 18 years -18-64 years -65 years + -Total								
Number of places or sessions (wte): -Under 18 years -18-64 years -65 years + -Total								

c) Gaps in service, emerging issues and plans for 2003

	Needs assessment	Advocacy Service	Rehabi- litative training	Sheltered workshops	Vocational training	Housing support	Transport services (including taxi)	Other
Gaps in service								
Emerging issues								
Plans for 2003								

Appendix 4: Services for People with Physical and Sensory Disabilities Mapping Framework

1. Therapeutic, rehabilitative and medical supports

a) Service profile

	Occupational therapy	Physiotherapy	Speech and language therapy	Social work	Psychology	Counselling	Public health nurse	Hospital (in-patient and out-patient)
Service provided Y = Yes N = No								
Name & location of service provider								
Budget								
Funding source								
Staffing (wte)								
Source of referrals								
Waiting list referral system								
Numbers of the waiting list								
Average waiting list time								

b) Numbers receiving the service and places in 2002

	Occu- pationa l therapy	Physio- therapy	Speech and language therapy	Social work	Psychology	Counselling	Public health nurse	Hospital (in- patient and out- patient)
Numbers receiving the service (wte): -Under 18 years -18-64 years -65 years + -Total								
Number of places or sessions (wte): -Under 18 years -18-64 years -65 years + -Total								

c) Gaps in service, emerging issues and plans for 2003

	Occu- pationa l therapy	Physio- therapy	Speech and language therapy	Social work	Psychology	Counselling	Public health nurse	Hospital (in- patient and out- patient)
Gaps in service								
Emerging issues								
Plans for 2003								

1. Day, residential and respite care

a) Service profile

	Day services	Residential services	Planned respite	Emergency respite	Planned home-based respite	Emergency home support	Summer camps (day/residential)	Holiday respite placement
Service provided Y = Yes N = No								
Name & location of service provider								
Budget								
Funding source								
Staffing (wte)								
Source of referrals								
Waiting list referral system								
Numbers of the waiting list								
Average waiting list time								

Numbers receiving the service and places in 2002

	Day services	Residential services	Planned respite	Emergency respite	Planned home-based respite	Emergency home support	Summer camps (day/residential)	Holiday respite placement
Numbers receiving the service (wte): -Under 18 years -18-64 years -65 years + -Total								
Number of places or sessions (wte): -Under 18 years -18-64 years -65 years + -Total								

Gaps in service, emerging issues and plans for 2003

	Day services	Residential services	Planned respite	Emergency respite	Planned home-based respite	Emergency home support	Summer camps (day/residential)	Holiday respite placement
Gaps in service								
Emerging issues								
Plans for 2003								

3. Home and community based supports

Service profile

	Personal assistant	Home help	Peer support	Sign language inter- pretation	Sign language training	Library support (Braille, large print, tape etc)	Sighted guide	Other services
Service provided Y = Yes N = No								
Name & location of service provider								
Budget								
Funding source								
Staffing (wte)								
Source of referrals								
Waiting list referral system								
Numbers on waiting list								
Average waiting list time								

Numbers receiving the service and places in 2002

	Personal assistant	Home help	Peer support	Sign language interpretation	Sign language training	Library support (Braille, large print, tape etc)	Sighted guide	Other services
Numbers receiving the service (wte): -Under 18 years -18-64 years -65 years + -Total								
Number of places or sessions (wte): -Under 18 years -18-64 years -65 years + -Total								

Gaps in service, emerging issues and plans for 2003

	Personal assistant	Home help	Peer support	Sign language interpretation	Sign language training	Library support (Braille, large print, tape etc)	Sighted guide	Other services
Gaps in service								
Emerging issues								
Plans for 2003								

4. Other services

Service profile

	Needs assessment	Advocacy Service	Rehabilitative training	Sheltered workshops	Vocational training	Housing support	Transport services (including taxis)	Other
Service provided Y = Yes N = No								
Name & location of service provider								
Budget								
Funding source								
Staffing (wte)								
Source of referrals								
Waiting list referral system								
Numbers of the waiting list								
Average waiting list time								

Numbers receiving the service and places in 2002

	Needs assessment	Advocacy Service	Rehabilitative training	Sheltered workshops	Vocational training	Housing support	Transport services (including taxis)	Other
Numbers receiving the service (wte): -Under 18 years								

-18-64 years -65 years + -Total								
Number of places or sessions (wte): -Under 18 years -18-64 years -65 years + -Total								

Gaps in service, emerging issues and plans for 2003

	Needs assessment	Advocacy Service	Rehabi- litative training	Sheltered workshops	Vocational training	Housing support	Transport services (including taxi)	Other
Gaps in service								
Emerging issues								
Plans for 2003								

Appendix 5: Services for People with Intellectual Disability Mapping Framework

1. Day, residential and respite care

Service profile

	Day centres/ day services	Residential care	Psychiatric hospital	Community residences/ group homes	Respite care	Holiday and residential placements	Crisis and relief care with a family	Other
Service provided Y = Yes N = No								
Name/location of service provider								
Budget								
Funding source								
Staffing (wte)								
Source of referrals								
Waiting list referral system								
Numbers of the waiting list								
Average waiting list time								

Numbers receiving the service and places in 2002

	Day centres/ day services	Residential care	Psychiatric hospital	Community residences/ group homes	Respite care	Holiday and residential placements	Crisis and relief care with a family	Other
Numbers receiving the service (wte): -Under 18 yrs -18-64 years -65 years + -Total								
Number of places or sessions (wte): -Under 18 yrs -18-64 years -65 years + -Total								

Gaps in service, emerging issues and plans for 2003

	Day centres/ day services	Residential care	Psychiatric hospital	Community residences/ group homes	Respite care	Holiday and residential placements	Crisis and relief care with a family	Other
Gaps in service								
Emerging issues								
Plans for 2003								

2. Therapeutic, medical and other supports

Service profile

	Occu- pationa l therapy	Physio- therapy	Speech and language therapy	Social work	Psycho- logist	Counsellor	Therapy	Public health nursing	Nutri- tionis t	Other services
Service provided Y = Yes N = No										
Name & location of service provider										
Budget										
Funding source										
Staffing (wte)										
Source of referrals										
Waiting list referral system										
Numbers on waiting list										
Average waiting list time										

Numbers receiving the service and places in 2002

	Occu- pationa l therapy	Physio- therapy	Speech and language therapy	Social work	Psych- ologist	Counsellor	Therapy	Public health nursing	Nutri- tionis t	Other services
Numbers receiving the service (wte): -Under 18 years -18-64 years -65										

years + -Total										
Number of places or sessions (wte): -Under 18 years -18-64 years -65 years + -Total										

Gaps in service, emerging issues and plans for 2003

	Occupational therapy	Physiotherapy	Speech and language therapy	work	ologist	Counsellor	Therapy	health nursing	Nutritionist	Other services
Gaps in service										
Emerging issues										
Plans for 2003										

3. Services to specific groups

a) Service profile

	Autism services /supports	Services for people with dementia	Other services for specific groups
Service provided Y = Yes N = No			
Name & location of service provider			
Budget			
Funding source			
Staffing (wte)			
Source of referrals			

Waiting list referral system			
Numbers of the waiting list			
Average waiting list time			

Numbers receiving the service and places in 2002

	Autism services /supports	Services for people with dementia	Other services for specific groups
Numbers receiving the service (wte): -Under 18 years -18-64 years -65 years + -Total			
Number of places or sessions (wte): -Under 18 years -18-64 years -Total			

Gaps in service, emerging issues and plans for 2003

	Autism services /supports	Services for people with dementia	specific groups
Gaps in service			
Emerging issues			
Plans for 2003			

4. Other services: needs assessment, advocacy, training, transport and housing

Service profile

	Needs assessment	Advocacy Service	Rehabilitative training	Sheltered workshops	Vocational training	Housing support	Transport services (including taxis)	Other
Service provided Y = Yes N = No								
Name & location of								

service provider								
Budget								
Funding source								
Staffing (wte)								
Source of referrals								
Waiting list referral system								
Numbers of the waiting list								
Average waiting list time								

Numbers receiving the service and places in 2002

	Needs assessment	Advocacy Service	Rehabilitative training	Sheltered workshops	Vocational training	Housing support	Transport services (including taxis)	Other
Numbers receiving the service (wte): -Under 18 years -18-64 years -65 years + -Total								
Number of places or sessions (wte): -Under 18 years -18-64 years -65 years +								

Gaps in service, emerging issues and plans for 2003

	Needs assessment	Advocacy Service	Rehabilitative training	Sheltered workshops	Vocational training	Housing support	Transport services (including taxis)	Other
Gaps in service								
Emerging issues								
Plans for 2003								

Appendix 6: Descriptions and Definitions of Services

Adult Dental Treatment Service Scheme

Free dental service for medical card holders over 16 years of age

Adult Sight Testing Scheme

Free sight testing scheme for medical card holders

Aids and Appliances

The supply and maintenance of medical and surgical appliances for people with medical cards and/or prescribed long term illnesses.

Blind Welfare Allowance

Additional payment to qualified persons who require additional resources to meet their Basic needs. The applicant must be registered with the National Council for the Blind. Paid as a supplement to a blind person receiving Blind Pension or Old Age Pension.

Counselling Nurse for People with Disabilities (MWHB)

This is a service provided by the public health nurse for children and adults with physical and sensory or learning disability and provides ongoing and early intervention support to families.

Community Residential Units

These are provided for people with long-term mental illness who require medical and other community supports to enable them to live in the community. The Inspector of Mental Hospitals refers to these units as group homes. Some units provide short-term respite care. They include low, medium and high support residencies. High support residencies are residential homes in the community for people who do not need hospital care but who require 24-hour nursing care and support. Medium support residencies are residential homes for people who are able to live independently but who require some support in daily living tasks. Staffing is provided during the day by nursing and trained care staff. Low support residencies are unstaffed residential homes for people who are independent, but who may need support from time to time from a community psychiatric nurse or other supports.

Day Hospital

Day hospitals provide assessment, treatment or nursing care equivalent to that provided to hospital in-patients. They provide an alternative for someone who requires hospital admission, but who can be cared for in their own homes. Clinics are also held and a range of psychiatric treatments are provided.

Day Centre

Day centres are provided in community settings and staffed by psychiatric nurses and other therapists where required, for example, occupational therapists. Activities are tailored to suit individual needs

and mainly focussed on social care, rehabilitation and activation services, occupational therapy, social skills training etc.

Day Care Services

These are community based services provided for people with physical and sensory disabilities and people with intellectual disability living at home or in residential care. Transport is sometimes provided by the centres. Services provided include training in social skills, recreation and activation, therapy (physiotherapy, occupational therapy, personal care).

Domiciliary Care Allowance

A monthly payment in respect of the care of children. Children must normally reside in the community and require continuous care or supervision substantially greater than that, which would normally be required by a child of the same age. Applicants undergo a medical assessment.

Drugs Payment Scheme

Available to non medical card holders which assists individuals to meet a portion of the cost of prescribed drugs and medicines. Applicants are required to pay a maximum of €53.33 per month per family in 2003.

General Medical Services Scheme

Entitles medical card holders and their families to free GP services, prescribed drugs, medicines and surgical appliances and free out-patient and in-patient public hospital services.

Home Help / Home Support

Services provided to enable a person to remain within their own homes through assistance in daily living tasks. Normally access to home help services is through the public health nurse, GPs or home help organisers.

In-patient Care

Provided in a psychiatric unit in a hospital or psychiatric hospital and include medical and nursing care. Health board policy is to replace large psychiatric institutions with smaller psychiatric units attached to general hospitals. This includes acute admission wards, continuing care wards, rehabilitation wards, special care units and secure wards, care of the elderly units, and occupational therapy.

Infectious Disease Maintenance Allowance

A weekly cash allowance paid to persons suffering from certain diseases. Applicants must undergo a means and medical assessment.

Long Term Illness and Disabilities Scheme

People with a prescribed long-term illness receive free prescribed drugs, medicines and medical/surgical appliances for the treatment of that specific illness or disability

Learning Disability Early Intervention Programme (MWHB)

Structured and coordinated early intervention programme with initial referral and diagnosis for a range of services. Has input from the Health Board and Voluntary Organisations.

Medical and Surgical Appliances

Provided to eligible persons in order to maintain that person at home and to improve their quality of life. Applications are usually made by a health professional e.g. Public Health Nurse, Physiotherapist, Occupational Therapist following assessment. Applicants must be either medical cardholders or eligible for the Long Term Illness and Disabilities Scheme and may have to pay a minimal contribution towards the cost of such equipment.

Mental Health Centre

The mental health centre combines both day hospital and day care facilities as well as the centre of the psychiatric services for a sector. It is also where the sector team's headquarters is based. It can also provide 24-hour care beds for assessment and crisis prevention. The centres are generally viewed to be a more positive method for organising community-orientated psychiatric services.

Mobility Allowance

A monthly allowance payable by the Health Board, subject to a means test, to individuals who have been medically assessed with a severe disability. Applicants must be in a condition to benefit from occasional trips away from home and be over 16 and under 66.

Motorised Transport Grant

Available in certain circumstances for the purchase of cars to persons with severe physical disabilities subject to a means test.

Occupational Therapy

This is provided for people with physical, sensory or intellectual disabilities on a temporary or permanent basis. The objective is to maximise functionality in activities of daily living (dressing, personal care, feeding, kitchen skills etc). Assessments can also include recommendations regarding a person's home, school, place of work and transport and include recommendations for alternations to the structured environment and aids / appliances.

Outpatient Care

Out-patient clinics, day hospitals, day centres, home visits, also provide referrals to other services such as clinical psychological services, addiction counselling, social work or occupational therapy.

Outpatient Clinic

Provided in the community where people attend for assessment, follow-up and the continuing management of their illness. Clinics are held in community health centres and services are provided by a mental health team headed up by a consultant psychiatrist and includes community psychiatric nurses. The team provides this service whether it be in hospital or community based care.

Public Health Nursing

A range of personal, health and social services, including health promotion, education, treatment and care. They are also responsible for monitoring child development, monitoring children with disability.

Physical and Sensory Disability early intervention programme (MWHB)

Planning stage.

Physiotherapy

To provide for the optimum quality of life through a client's physical needs and where possible to provide rehabilitation and independence as well as limit and prevent disability.

Psychology

Clinical psychology services are provided to a variety of clients, including children with emotional, behavioural, cognitive and abuse problems in their families.

Rehabilitation Training Services

Since June 2000 responsibility for training, work and employment services for people with disabilities has been divided between the Health Boards and FAS. The health boards have responsibility for Rehabilitative/Foundation Training (for the development of life skills, social and basic work skills), Sheltered Work and Supported Work, while FAS has responsibility for vocational training and employment services

Residential care services

Residential care is where a person lives in a staffed residential home, usually where a person cannot be cared for in their own home. It includes:

Semi-independent living with supervision and support for people who require assistance with daily living but not necessarily nursing care. This would normally be combined with daily attendance at a day centre or a vocational training workshop.

Care facilities that require constant supervision and high levels of paramedical and nursing care.

Respite care services

This is temporary residential care, based either in a centre or community based, that is intended to support the maintenance of people with disabilities in their own homes. It can cover a crisis period, on a periodic basis to enable a carer to have a break, or can provide the person with disability with medical, therapeutic or support services.

Section 65 Grants

Payable to bodies who provide services similar or ancillary to a service provided by the Health Board.

Speech and language therapy

For the management of communications and swallowing disorders associated with a physical, sensory or learning disability.

Sheltered workshop

Sheltered workshops provide work in areas suited to the skills and support needs of people with mental disabilities with support and guidance from staff.

Appendix 7: Summary Tables of Health Board Provided and Funded Services

MENTAL HEALTH: HEALTH BOARD FUNDED SERVICES

Day, residential and respite care

	Day centres	Residential care	Psychiatric hospital	Psychiatric unit in general hospital	Forensic service	Community residences	Respite care
ERHA	√	√	√	√	√	√	√
SHB	√	√	√	√	√	√	√
SEHB	√	√	√	√		√	√
MHB	√	√	√	√		√	√
MWHB	√	√	√	√		√	√
NWHB	√	√	√	√		√	√
NEHB	√	√	√	√		√	
WHB	√	√	√	√		√	

Home and community based supports

	Psychiatrist	Community mental health nursing	Occupational therapy	Social work	Community alcohol and drugs service	Opiate treatment and addiction	Counselling for adult survivors of institutional	Suicide prevention services
--	--------------	---------------------------------	----------------------	-------------	-------------------------------------	--------------------------------	--	-----------------------------

						counsellors	abuse		
ERHA	√	√	√	√	√	√	√	√	
SHB	√	√	√	√	√	√	√	√	
SEHB	√	√	√	√	√	√	√	√	
MHB	√	√	√	√	√	√	√	√	
MWHB	√	√	√	√	√	√	√	√	
NWHB	√	√	√	√	√	√	√	√	
NEHB	√	√	√	√	√	√	√	√	
WHB	√	√	√	√	√	√	√	√	

Services for specific groups

	Mental health services for people with intellectual disability	Mental health services for older people	Child and adolescent mental health services
ERHA	√	√	√
SHB	√	√	√
SEHB	√	√	√
MHB	√	√	√
MWHB	√	√	√
NWHB	√	√	√
NEHB	√	√	√
WHB	√	√	√

Other services

	Needs assessment	Advocacy Service	Rehabilitative training	Sheltered workshops	Vocational training	Transport services (including taxis)
ERHA	√	√	√	√	√	√
SHB	√	√	√	√	√	√
SEHB	√	√	√	√	√	√
MHB	√	√	√	√	√	√
MWHB	√	√	√	√	√	√
NWHB	√	√	√	√	√	√
NEHB	√	√	√	√	√	√
WHB	√	√	√	√	√	√

PEOPLE WITH INTELLECTUAL DISABILITY: HEALTH BOARD FUNDED SERVICES

1. Day, residential and respite care

	Day centres/ day services	Residential care	Psychiatric hospital	Community residences/ group homes	Respite care	Holiday and residential placements	Crisis and relief care with a family
	√	√	√	√	√	√	√
SHB	√	√	√	√	√	√	√
SEHB	√	√	√	√	√	√	√
MHB	√	√	√	√	√	√	
MWHB	√	√	√	√	√	√	√
NWHB	√	√	√	√	√	√	√
NEHB	√	√	√	√	√	√	√
WHB	√	√	√	√	√	√	√

2. Therapeutic, medical and other supports

	Occupational therapy	Physio-therapy	Speech and language therapy	Social work	Psychologist	Counsellor	Therapy	Public health nursing	Nutritionist
ERHA	√	√	√	√	√	√	√	√	√
SHB	√	√	√	√	√	√	√	√	√
SEHB	√	√	√	√	√	√	√	√	√
MHB	√	√	√	√	√	√	√	√	√
MWHB	√	√	√	√	√	√	√	√	√
NWHB	√	√	√	√	√	√	√	√	√
NEHB	√	√	√	√	√	√	√	√	√
WHB	√	√	√	√	√	√	√	√	√

3. Services to specific groups

	Autism services /supports	Services for people with dementia	Other services for specific groups
ERHA	√	√	√
SHB	√	√	√
SEHB	√	√	√
MHB	√	√	√
MWHB	√	√	√
NWHB	√	√	√
NEHB	√	√	√
WHB	√	√	√

4. Other services: needs assessment, advocacy, training, transport and housing

	Needs assessment	Advocacy Service	Rehabilitative training	Sheltered workshops	Vocational training	Housing support	Transport services (including taxis)
ERHA		√	√	√	√	√	√
SHB		√	√	√	√	√	√
SEHB			√	√	√	√	√
MHB			√	√	√	√	√
MWHB			√	√	√	√	√
NWHB			√	√	√	√	√
NEHB			√	√	√	√	√
WHB			√	√	√	√	√

PEOPLE WITH PHYSICAL AND SENSORY DISABILITIES: HEALTH BOARD FUNDED SERVICES

1. Therapeutic, rehabilitative and medical supports

	Occupational therapy	Physiotherapy	Speech and language therapy	Social work	Psychology	Counselling	Public health nurse	Hospital (in-patient and out-patient)
ERHA	√	√	√	√	√	√	√	√
SHB	√	√	√	√	√	√	√	√
SEHB	√	√	√	√	√	√	√	√
MHB	√	√	√	√	√	√	√	√
MWHB	√	√	√	√	√	√	√	√
NWHB	√	√	√	√	√	√	√	√
NEHB	√	√	√	√	√	√	√	√
WHB	√	√	√	√	√	√	√	√

2. Day, residential and respite care

	Day services	Residential services	Planned respite	Emergency respite	Planned home-based respite	Emergency home support	Summer camps (day/residential)	Holiday respite placement
ERHA	√	√	√	√	√	√	√	√
SHB	√	√	√	√	√	√	√	√
SEHB	√	√	√	√	√	√	√	√
MHB	√	√	√				√	√
MWHB	√	√	√	√	√	√	√	√
NWHB	√	√	√	√	√	√	√	√
NEHB	√	√	√	√	√	√	√	
WHB	√	√	√	√	√	√	√	

3. Home and community based supports

	Personal assistant	Home help	Peer support	Sign language interpretation	Sign language training	Library support (Braille, large print, tape etc)	Sighted guide	Other services
ERHA	√	√	√	√	√	√	√	√
SHB	√	√	√	√	√	√	√	√
SEHB	√	√	√	√	√	√	√	√
MHB	√	√	√	√	√	√	√	√
MWHB	√	√	√	√	√	√	√	√
NWHB	√	√	√	√	√	√	√	√
NEHB	√	√	√	√	√	√	√	√
WHB	√	√	√	√	√	√	√	√

4. Other services

	Indepen dent needs assessm ent	Advocac y Service	Rehabilita tive training	Sheltered workshop s	Vocationa l training	Housing support	Transport services (including taxi)
ERH A		√	√	√	√	√	√
SHB		√	√	√	√	√	√
SEH B			√	√	√	√	√
MHB			√	√	√	√	√
MWH B			√	√	√	√	√
NWH B		√	√	√	√	√	√
NEH B			√	√	√	√	√
WHB			√	√	√	√	√

Appendix 8: UN Standard Rules

Standard Rules on the Equalisation of Opportunities for Persons with Disabilities

I. Preconditions for Equal Participation

- Rule 1. Awareness-raising
- Rule 2. Medical care
- Rule 3. Rehabilitation
- Rule 4. Support services

II. Target Areas for Equal Participation

- Rule 5. Accessibility
- Rule 6. Education
- Rule 7. Employment
- Rule 8. Income maintenance and social security
- Rule 9. Family life and personal integrity
- Rule 10. Culture
- Rule 11. Recreation and sports
- Rule 12. Religion

III. Implementation Measures

- Rule 13. Information and research
- Rule 14. Policy-making and planning
- Rule 15. Legislation
- Rule 16. Economic policies
- Rule 17. Coordination of work
- Rule 18. Organizations of persons with disabilities
- Rule 19. Personnel training
- Rule 20. National monitoring and evaluation of disability programmes in the implementation of the Rules
- Rule 21. Technical and economic cooperation
- Rule 22. International cooperation

IV. Monitoring Mechanism

I. Preconditions for Equal Participation

Rule 1: Awareness-raising

- States should take action to raise awareness in society about persons with disabilities, their rights, their needs, their potential and their contribution.
- States should ensure that responsible authorities distribute up-to-date

information on available programmes and services to persons with disabilities, their families, professionals in the field and the general public. Information to persons with disabilities should be presented in accessible form.

- States should initiate and support information campaigns concerning persons with disabilities and disability policies, conveying the message that persons with disabilities are citizens with the same rights and obligations as others, thus justifying measures to remove all obstacles to full participation.
- States should encourage the portrayal of persons with disabilities by the mass media in a positive way; organizations of persons with disabilities should be consulted on this matter.
- States should ensure that public education programmes reflect in all their aspects the principle of full participation and equality.
- States should invite persons with disabilities and their families and organizations to participate in public education programmes concerning disability matters.
- States should encourage enterprises in the private sector to include disability issues in all aspects of their activity.
- States should initiate and promote programmes aimed at raising the level of awareness of persons with disabilities concerning their rights and potential. Increased self-reliance and empowerment will assist persons with disabilities to take advantage of the opportunities available to them.
- Awareness-raising should be an important part of the education of children with disabilities and in rehabilitation programmes. Persons with disabilities could also assist one another in awareness-raising through the activities of their own organizations.
- Awareness-raising should be part of the education of all children and should be a component of teacher-training courses and training of all professionals.

Rule 2: Medical care

- States should ensure the provision of effective medical care to persons with disabilities.
- States should work towards the provision of programmes run by multidisciplinary teams of professionals for early detection, assessment and treatment of impairment. This could prevent, reduce or eliminate disabling effects. Such programmes should ensure the full participation of persons with disabilities and their families at the individual level, and of organizations of persons with disabilities at the planning and evaluation level.
- Local community workers should be trained to participate in areas such as early detection of impairments, the provision of primary assistance and referral to appropriate services.
- States should ensure that persons with disabilities, particularly infants and children, are provided with the same level of medical care within the same system as other members of society.

- States should ensure that all medical and paramedical personnel are adequately trained and equipped to give medical care to persons with disabilities and that they have access to relevant treatment methods and technology.
- States should ensure that medical, paramedical and related personnel are adequately trained so that they do not give inappropriate advice to parents, thus restricting options for their children. This training should be an ongoing process and should be based on the latest information available.
- States should ensure that persons with disabilities are provided with any regular treatment and medicines they may need to preserve or improve their level of functioning.

Rule 3: Rehabilitation

- States should ensure the provision of rehabilitation services to persons with disabilities in order for them to reach and sustain their optimum level of independence and functioning.
- States should develop national rehabilitation programmes for all groups of persons with disabilities. Such programmes should be based on the actual individual needs of persons with disabilities and on the principles of full participation and equality.
- Such programmes should include a wide range of activities, such as basic skills training to improve or compensate for an affected function, counselling of persons with disabilities and their families, developing self-reliance, and occasional services such as assessment and guidance.
- All persons with disabilities, including persons with severe and/or multiple disabilities, who require rehabilitation should have access to it.
- Persons with disabilities and their families should be able to participate in the design and organization of rehabilitation services concerning themselves.
- All rehabilitation services should be available in the local community where the person with disabilities lives. However, in some instances, in order to attain a certain training objective, special time-limited rehabilitation courses may be organized, where appropriate, in residential form.
- Persons with disabilities and their families should be encouraged to involve themselves in rehabilitation, for instance as trained teachers, instructors or counsellors.
- States should draw upon the expertise of organizations of persons with disabilities when formulating or evaluating rehabilitation programmes.

Rule 4: Support services

- States should ensure the development and supply of support services, including assistive devices for persons with disabilities, to assist them to increase their level of independence in their daily living and to exercise their rights.
- States should ensure the provision of assistive devices and equipment, personal assistance and interpreter services, according to the needs of

persons with disabilities, as important measures to achieve the equalization of opportunities.

- States should support the development, production, distribution and servicing of assistive devices and equipment and the dissemination of knowledge about them.
- To achieve this, generally available technical know-how should be utilized. In States where high-technology industry is available, it should be fully utilized to improve the standard and effectiveness of assistive devices and equipment. It is important to stimulate the development and production of simple and inexpensive devices, using local material and local production facilities when possible. Persons with disabilities themselves could be involved in the production of those devices.
- States should recognize that all persons with disabilities who need assistive devices should have access to them as appropriate, including financial accessibility. This may mean that assistive devices and equipment should be provided free of charge or at such a low price that persons with disabilities or their families can afford to buy them.
- In rehabilitation programmes for the provision of assistive devices and equipment, States should consider the special requirements of girls and boys with disabilities concerning the design, durability and age-appropriateness of assistive devices and equipment.
- States should support the development and provision of personal assistance programmes and interpretation services, especially for persons with severe and/or multiple disabilities. Such programmes would increase the level of participation of persons with disabilities in everyday life at home, at work, in school and during leisure-time activities.
- Personal assistance programmes should be designed in such a way that the persons with disabilities using the programmes have a decisive influence on the way in which the programmes are delivered.

Appendix 9: Non Statutory Service Providers in the Disability Sector

A. Organisations Representing Non-Statutory Service Providers

- Not-for-Profit Business Association
- Alliance for Mental Health
- Disability Federation Ireland
- Federation of Voluntary Bodies

B. Non-Statutory Service Providers Receiving Health Board Funding

Intellectual Disability

- Ard Aoibhinn Centre, Wexford
- Association of Parents and Friends, Co Monaghan
- BEAM Services
- BRAINWAVE
- Brothers of Charity, Clare.
- Brothers of Charity, Cork.
- Brothers of Charity, Galway.
- Brothers of Charity, Limerick.
- Brothers of Charity, Roscommon.
- Brothers of Charity, South Eastern Region, Waterford.
- Carers Support Group
- Camphill Communities of Ireland.
- Centres for Independent Living
- Charleville & District Association, Charleville, Co. Cork.
- Cheeverstown House Ltd, Dublin 6
- Cheeverstown House Ltd., Templeogue, Dublin 6W.
- Children's Sunshine Home, Foxrock, Dublin 18.
- Co-Action West Cork.
- COPE Foundation, Cork.
- County Tipperary Association for Mentally Handicapped Children & Adults.
- County Wexford Community Workshop, Enniscorthy.
- County Wexford Community Workshop, New Ross.
- County Wicklow Association for the Mentally Handicapped
- County Wicklow Association, Wicklow
- DARA Residential Services Ltd, Celbridge, Co Kildare.
- Daughters of Charity, Dublin & Limerick.
- Delta Services, Carlow.
- Drumlin House, Cootehill, Co Cavan
- Down Syndrome Ireland
- Drumlin House, Cootehill, Co. Cavan.
- Festina Lente Foundation
- Festina Lente, Bray Co Wicklow
- Galway County Association for Mentally Handicapped Children
- Galway County Association, Galway.
- Hospitaller Order of St. John of God (Leinster, Louth, Monaghan, Cavan & Kerry).
- Irish Sisters of Charity, St. Mary's, Merrion Rd., Dublin 4.

- Irish Society for Autism
- KARE , Co Kildare
- KARE, Newbridge, Co. Kildare.
- Kerry Parents and Friends.
- L'Arche Ireland (Kilkenny, Cork & Dublin).
- Little Angels Association
- Meath Association
- Meath Sheltered Workshop Ltd., Navan, Co. Meath.
- National Federation of Arch Clubs
- North West Parents and Friends Association, Co.s Sligo & Leitrim.
- Order of Malta
- Order of Malta Regional Services
- Peacehaven
- Peamount Hospital, Newcastle, Co. Dublin.
- Prosper Fingal, Ltd, North County Dublin
- RehabCare
- Rosminian Services, Upton, Cork.
- Sisters of Charity of Jesus and Mary Services, Kildare.
- Sisters of Charity, St. Patrick's Kilkenny.
- Sisters of La Sagesse, Sligo.
- Sisters of the Bon Sauveur, Dungarvan, Co. Waterford.
- SOS Kilkenny Ltd.
- St. Aidan's Day Care Centre, Gorey, Co. Wexford.
- St. Anne's, Sean Ross Abbey, Rocrea, Co. Tipperary.
- St. Christopher's Services, Longford.
- St. Cronan's Workshop Association, Roscrea, Co. Tipperary.
- St. Hilda's Services, Athlone, Co. Westmeath.
- St. Mary of the Angels, Killarney, Co. Kerry.
- St. Mary's Hospital and Residential School, Baldoyle, Dublin.
- St. Michael's House, Dublin.
- St. Vincent's Centre
- Stewarts Hospital, Palmerstown, Dublin 20.
- Sunbeam House Services, Bray, Co. Wicklow.
- The Jack and Jill Children's Foundation
- Waterford Association for the Mentally Handicapped, Waterford City.
- West Limerick Community Workshop
- Western Care Association
- Western Care Association, Castlebar, Co. Mayo.
- Windmill Therapeutic Training Unit, Wexford

Physical and sensory disability

- Anne Sullivan Foundation for Deafblind
- Central Remedial Clinic
- Cheshire Homes Foundation Ireland
- Co Roscommon Support Group for People with Disabilities
- Disabled Drivers Association
- Disabled People of Clare
- Doorway to Life Ltd
- Dyslexia Association of Ireland
- Enable Ireland
- Gandon Enterprises Ltd
- Headway Ireland (Acquired Brain Injury)
- Independent Living Community Services
- Irish Deaf Society
- Irish Guide Dogs for the Blind
- Irish Haemophilia Society
- Irish Motor Neurone Disease Association
- Irish Wheelchair Association
- Leitrim Association of People with Disabilities
- Multiple Sclerosis Society of Ireland
- Muscular Dystrophy Ireland
- National Association for Deaf People
- National Council for the Blind of Ireland
- National Training and Development Institute
- North West M.S. Therapy Centre
- Polio Fellowship of Ireland
- Post Polio Support Group
- Reach Ireland
- Riding for Disabled Association Ireland
- Royal Hospital Donnybrook
- Shannon Community Workshops Ltd
- Spinal Injuries Action Association
- St Gabriel's School and Centre
- St Mary's Hospital and Residential School
- The Rehab Group / RehabCare

Mental health

- Alzheimer's Association of Ireland
- Aware
- Schizophrenia Ireland

- GROW
- OANDA (Out and About Association)
- Headway Ireland
- The Samaritans
- Bodywhys
- Recovery Inc

All disabilities

- AHEAD (Association for Higher Education Access and Disability)
- A.P.T. (Rehabilitative Training Services)
- C.A.S.A. (Caring and Sharing Association)
- Focus Ireland (Homelessness)
- VANTASTIC (Transport)

Housing Associations

- B.I.H. Housing Association (IRL) Ltd
- The Coach House, Slane, Co. Meath
- HAIL-Housing Association for Integrated Living, Dublin
- Vergemount Housing Fellowship (Mental Health)
- Sophia Housing Association Ltd