

Promoting Health, Supporting Inclusion



The national review of the contribution of all nurses and midwives to the care and support of people with learning disabilities

Promoting Health, Supporting Inclusion



The national review of the contribution of all nurses and midwives to the care and support of people with learning disabilities

Contents

Foreword by the Minister for Health and Community Care	2
Introduction by the Chief Nursing Officer	3
1. Background to the National Nursing Review	4
2. The policy framework for the Review	8
3. The nursing profession in Scotland	10
4. The current contribution of nurses and midwives	14
5. Meeting needs with the Tiered Model	22
6. Community, public health and strategic approaches to care	26
7. Primary care and directly accessed health services	30
8. Health services accessed via primary care	34
9. Specialist locality health services	38
10. Specialist area and regional health services	44
11. Working across all the Tiers: Education and development	48
12. Working across all the Tiers: Standards, monitoring and research	54
Summary	58
Appendices	64
Glossary	78
References	81
Acknowledgements	85

Foreword by the Minister for Health and Community Care

Delivering Social Justice is at the heart of the Government. Through Social Inclusion the Scottish Executive is committed to ensuring equality, fairness and opportunity for all. Central to this commitment is the drive to improve health, health care and social care for all. This means addressing the needs of excluded members of our society. One such group is people with learning disabilities. People with learning disabilities are valued and important members of society who must be seen as people first and foremost. This is as it should be. It is however equally important to recognise that some will need extra help so that they can access the services and care that many take for granted. The help will vary according to individual need. The key is in making sure that whether it is a child or an adult with learning disabilities or their family or carer workers, the right kind of support is there when it is needed.

The Scottish Executive has already put in place major policies designed to improve the lives of all the people of Scotland. People with learning disabilities and their families will all benefit. *The Same as You? The review of services for people with learning disabilities* recognises the importance of good health as well as a range of other fundamental issues such as good housing and education and many others. *Our National Health: A plan for action, a plan for change*, published in December 2000 is already bringing about significant change within NHSScotland. *Fair for all* recognises that everyone is entitled to fair access to health, which is one of the founding principles of the NHS. *Caring for Scotland: The Strategy for Nursing and Midwifery in Scotland* will drive the contribution that all nurses and midwives play in improving the health of the people in Scotland. These initiatives require the knowledge, skills and determination of *all* our nurses and midwives, wherever they work.

Promoting health, Supporting inclusion: The National Review of the contribution of all nurses and midwives to the care and support of people with learning disabilities is an important step forward in ensuring that people with learning disabilities receive first rate care and their families and care workers, support. The title of this National Nursing Review is important. It recognises the contributions of *all* nurses and midwives who are involved in different ways, from birth

through to old age. This is not by accident. People with learning disabilities do not always enjoy good health. We need to recognise and acknowledge this. It is however important to understand that a learning disability is not an 'illness'. People with learning disabilities have the right to fulfil their maximum health potential in order to live as full a life as possible. Their families must also have their needs recognised too and their health and wellbeing should not suffer as a result of caring. Some people with learning disabilities need extra help and support to access health services, while others require additional support at key transition points in their lives and those with the most complex needs often need specialist health services, some for life.

People with learning disabilities and their families have been at the very heart of this National Nursing Review. I recognise and appreciate their commitment. Their views, comments and experiences, good and bad, have contributed significantly and are reflected throughout. This National Nursing Review has highlighted how all our nurse and midwives, along with their colleagues, make enormous contributions towards the care and support of people with learning disabilities. Strengthening partnership working within health services and in collaboration with education, social work, voluntary organisations is the way forward. This National Nursing Review sets out significant challenges for all nurses and midwives in Scotland. Promoting good health to enable social inclusion will be the measure of the success for people with learning disabilities and their families.



A handwritten signature in black ink that reads "Malcolm Chisholm". The signature is written in a cursive, flowing style.

Malcolm Chisholm MSP

Minister for Health and Community Care

Introduction by the Chief Nursing Officer

Promoting health, Supporting inclusion: The National Review of the contribution of all nurses and midwives to the care and support of people with learning disabilities is one of the recommendations arising from *Caring for Scotland: The Strategy for Nursing and Midwifery in Scotland*. The National Nursing Review process has been a fascinating one for me. It has been comprehensive and inclusive across all areas of Scotland. Hundreds of nurses, midwives and many other interested parties have taken the time to contribute and share their views and experiences through the local area focus groups, Reference Groups, conference and other avenues. I have also been privileged to meet people with learning disabilities and their families and hear from them directly. I am particularly grateful for their commitment, enthusiasm and energy.

The National Nursing Review is set firmly within the policy context of *The Same as You?* and takes account of the evolving changes being brought about by *Joint Future*. This National Nursing Review is for *all* nurses and midwives in Scotland. The message from the review is clear; the care and support of children and adults with learning disabilities is the business of us all. There are health inequalities that exist for people with learning disabilities. Fundamentally, the National Nursing Review looks at how all nurses and midwives work in partnership with others to address them.

In the past, there has been limited focus within some nursing and midwifery education programmes on the needs of people with learning disabilities. This needs to change. Within nurse education there are significant recommendations that need to be taken forward to help develop and support the ability of all nurses and midwives to contribute effectively to promote good health and enable social inclusion. This is what people with learning disabilities and their families want and need. For nurses and midwives in practice, there is a need to develop and enhance the standards and quality of care they give. This is all work that is necessary to ensure that people with learning disabilities enjoy access to quality health and nursing care, as well as making sure they receive specialist nursing care when needed.

The recommendations arising from this National Nursing Review will help to form part of the overall recognition of the need to make sure that children and adults with learning disabilities receive the services they need, including health and nursing care. Clearly the contributions required from the many different groups of nurses and midwives would differ depending upon the area and location of their work. By utilising the knowledge and experience of nurses and midwives and by working in true partnership, models of practice and care will be developed that lead the way for others in the future.

I believe that there are exciting times ahead with many opportunities. There is much to be done, with new challenges for *all* nurses and midwives.



A handwritten signature in black ink that reads "Anne Jarvie" with a small flourish at the end.

Miss Anne Jarvie, CBE, RGN, RM, BA

Chief Nursing Officer
Directorate of Nursing
Scottish Executive Health Department

chapter 1: Background to the National Nursing Review



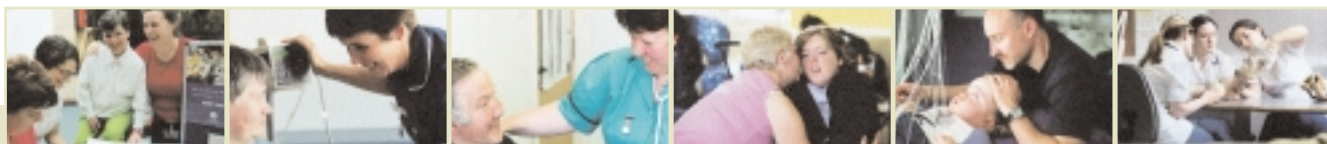
The Scottish Executive is working towards developing integrated policy that reduces inequalities in health and improves the lives of all people across Scotland. Central to this effort is a commitment to address the health needs of socially excluded and disadvantaged groups within society.

To address these issues there is need for a long-term public health vision, aimed at improving health. A public health approach must address the health needs of the population and reduce inequalities. Specific interventions must be developed and targeted at smaller, excluded groups of people who have particularly extreme or unusual health needs.

People with learning disabilities are one such group. They frequently have complex health, social and education needs that demand high levels of support. Failure to recognise and meet their needs often leads to their exclusion from services and facilities; it may also prevent them from gaining access to the many recreational, educational and occupational opportunities so many of us take for granted, reinforcing their social isolation. It is therefore necessary that actions required to improve health and reduce inequalities are supported by a strategic focus on planning, resourcing, knowledge and expertise.¹

Children and adults with learning disabilities are people *first*, and have needs, dreams and aspirations like everyone else. They also have health needs like everyone else. To lead full and active lives as valued members of the community, they need to receive the services and support that will keep them healthy and enable them to participate fully in society. This means that where possible, people with learning disabilities should be able to use the same local services as everyone else, with some children and adults also benefiting from the provision of specialist social, health and education services.

Providing services that work for people with learning disabilities is a complex task. In reality, there are many barriers and issues that prevent people from having their needs met effectively. Some of the barriers within health services are cultural, value-based, system-based and organisational. Others arise as a result of lack of knowledge, limited clinical experience and inadequate understanding of health needs. The barriers hide the fact that people with learning disabilities have a clear need to be considered and included in initiatives that seek to improve and promote good health.



Why the National Nursing Review was done

The National Nursing Review has been undertaken to reflect the important changes and developments that are impacting significantly upon the lives of people with learning disabilities and their families. It is set within the current context of the need to promote and enable social inclusion and address fundamental health inequalities. It takes account of:

- ⊕ Policy
- ⊕ Health inequalities
- ⊕ Changing trends
- ⊕ Utilising the nursing and midwifery resource
- ⊕ Promoting health;
- ⊕ Enabling social inclusion.

The policy context

The Scottish Executive has developed significant policies that focus on improving the lives of all people in Scotland. Some are aimed specifically at people with learning disabilities, while others focus on all the people of Scotland, including people with learning disabilities. New legislation is also being introduced that will protect the rights of people with learning disabilities.

Health inequalities and needs

Health inequalities are the differences found in aspects of health between different groups in society. People with learning disabilities have health needs like the rest of the population, yet frequently have poorer health. Their additional health needs are evident across the life course throughout childhood, adulthood and into old age.²

Assumptions have been made that health services have been meeting the full range of health needs of people with learning disability across the life course. In reality, they have never been adequately addressed. Some health needs occur as a result of the learning disabilities, with additional complex needs requiring specific interventions and support from specialist staff, including nurses. For a small but

significant number of people with very complex needs, highly specialised services will be required. Whatever the needs and responses required from services, the message is clear—the health needs of people with learning disabilities matters. After many years of neglect, their health needs are now considered a priority area.

New models of care and support are reflecting the importance of achieving improvement in health through partnership-working among health, social care and education sectors, and involving public, private, voluntary and community bodies. Bringing about health improvement among people with learning disabilities is therefore not the sole responsibility of NHSScotland; it involves a wide range of agencies and sectors.

Changing trends

Prevalence figures suggest that about 2–3 per cent of the general population – 120,000 people in Scotland – have some degree of learning disability. Around 15 per cent of these will have a severe learning disability – about four per thousand of the population.

Estimates suggest a cumulative annual increase of about 1 per cent in the prevalence of learning disabilities over the last 35 years.³ People with learning disabilities are living longer as they benefit from advances in health care, better access to health services and improved social care. Current policy is to close all remaining long-stay hospitals by 2005. It is important to recognise, however, that despite views to the contrary, very few people with learning disabilities have ever lived in long-stay hospitals; the majority have **always** lived in the community.

Health, along with other important needs, has not always been considered and addressed in the past. It is now recognised that this situation is not acceptable and that people with learning disabilities must have opportunities to develop good health to be actively included in society.

chapter 1: Background to the National Nursing Review

Promoting health and social inclusion

As the largest group of care providers in NHSScotland, nurses and midwives have a vital role in ensuring people with learning disabilities have their health needs met and gain access to services.

All nurses and midwives – not just those who have chosen to specialise in caring for people with learning disabilities – have an important contribution to make, working in partnership with people with learning disabilities and their family carers across health, social and education systems.

This important point has not been recognised in the past; as a result, aspects of the care of people with learning disabilities have been neglected. Recent research, strategies and reviews have acknowledged this and the key purpose of this National Nursing Review is to address these issues.

To contribute effectively in the future, all nurses and midwives, wherever they work, must practice according to core principles.

Core principles governing nursing and midwifery contributions to care and support of people with learning disabilities

Nurses and midwives must:

- ⊕ treat children and adults with learning disabilities with dignity and respect;
- ⊕ offer the least restrictive model of support to improve health and wellbeing;
- ⊕ prevent and seek to minimise illness and disease and maximise health;
- ⊕ work to reduce inequalities in health;
- ⊕ encourage people with learning disabilities to play an active role in improving their health and wellbeing;
- ⊕ promote access to information and advocacy services;
- ⊕ ensure, where possible, that nursing interventions are based on evidence and research findings;

- ⊕ facilitate access to general and specialised health services;
- ⊕ liaise, collaborate and contribute to joint working with social work teams and others;
- ⊕ adopt an educative and supportive role with family carers, care workers and other services;
- ⊕ take a population-wide perspective on the health needs of children and adults with complex needs; and
- ⊕ foster a culture of choice and collaborative working with children and adults with learning disabilities, their carers and other agencies and services involved in their care and support.

These core principles are compatible with the seven principles of *The Same as You?*. Nurses and midwives need a relevant level of understanding, knowledge and experience to provide and co-ordinate health care for people with learning disabilities. Those working with children and adults who have complex needs must have a range of skills that enable them to effectively assess, treat and provide therapy. Whatever their role, nurses and midwives must ensure that people with learning disabilities are supported to improve their health and be included in society.

Nurses and midwives provide twenty-four hour care, with the emphasis on meeting health and social needs within a healthcare context. They focus on promoting health and helping individuals, families and others to meet health needs. Their work involves helping people whose independence and autonomy are impaired and who have a range of disabilities and health needs.

To contribute to this public health-orientated agenda, nurses and midwives will need to work in different ways. Some of these ways are already familiar – working directly with individuals, their families, care workers and locally with communities, for instance. Nurses and midwives will need to contribute to evolving area and national agendas, requiring new thinking and practice.



The Scottish Executive is determined to ensure that nurses and midwives are prepared to meet these challenges effectively. Supporting and retaining the practitioners of today, and recruiting and training the nurses and midwives of tomorrow, are key issues for the National Nursing Review.

The National Nursing Review

The Review focused on, and was driven by, the issues at the heart of the Scottish Executive's plans for a healthy, caring Scotland – social inclusion, social justice, equal opportunities for all, anti-discriminatory practices, lifelong learning, and the involvement of service-users and the public in the design and delivery of their own services.

The central aim of the National Nursing Review is to ensure that all nurses and midwives, wherever they practice, recognise the particular needs of people with learning disabilities and work towards promoting and improving their health. It is based on an acknowledgement of the key contributions all nurses and midwives can make to supporting initiatives aimed at improving the health of the people of Scotland.

The Review was taken forward by a Project Group, supported by two Reference Groups (Appendix 2). The process was participative and inclusive, reflecting the current nature of care and support for people with learning difficulties, and focused on five key questions:

- ⊕ what are the nursing and midwifery contributions across the life course of people with learning disabilities?
- ⊕ what are the areas of best practice across Scotland, where nurses and midwives make a difference?
- ⊕ what will the contribution of nurses and midwives need to be in the future?
- ⊕ what are the education needs of nurses and midwives?
- ⊕ what are the continuing practice development and research issues for nurses and midwives?

The contributions of nurses and midwives were considered from a number of perspectives:

- ⊕ a 'top-down' look at legislation, policy and standards affecting children and adults with learning disabilities
- ⊕ a 'bottom-up', Scotland-wide look at current nursing and midwifery practice in relation to the care and support of children and adults with learning disabilities
- ⊕ a review of the evidence in relation to the health needs of children and adults with learning disabilities.

Key aspects of the Review process are described in Appendix 3.

chapter 2: The policy framework for the Review



A number of key policy documents on health have been published in recent years, initially by The Scottish Office then, post-devolution, by the Scottish Executive. Brief summaries of these policies are given in Appendix 4. Policies that have particular relevance to the Review are discussed below.

The Same as You?

The Scottish Executive published *The Same As You? A review of services for people with learning disabilities* in May 2000.⁴ The review is the first in-depth analysis of services and support for people with learning disabilities in Scotland for over two decades, and acts as a blueprint for services over the next 10 years. People with learning disabilities were central to the review process. The emphasis is on individuals and their families being able to access the services and support they need in order to live full lives in their community.

The Same as You?, defined people with learning disabilities as having:

'...a significant, lifelong condition that started before adulthood, that affected their development and which means they need help to: understand information; learn skills; and cope independently.'

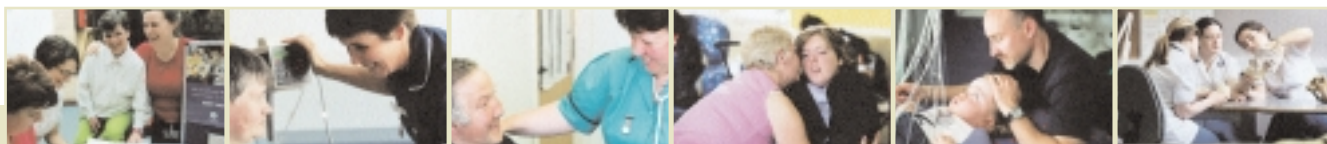
The Same as You? clearly reflects Scottish Executive policy on social inclusion, equity and fairness and the provision of

opportunities for all people to develop themselves through lifelong learning. Key principles on helping people with learning disabilities to lead full and active lives were identified. These principles are endorsed in this National Nursing Review, and underpin the service models proposed. *Valuing People*, published in 2001 is the English equivalent.⁵

Fair for all (2001) supports and recognises that everyone is entitled to fair access to health and addresses issues relating to access and use of the NHS.⁶

Caring for Scotland

Caring for Scotland: The Strategy for Nursing and Midwifery in Scotland, published in March 2001, recognises the impact that changes in health technology and increasing public demand for greater involvement in decision-making make on nurses and midwives.⁷ It aims to equip nurses and midwives to meet the challenges of modern health care and emphasises the value of caring in enhancing patient care.



The key focus-points for the Strategy are:

- ⊕ the promotion and delivery of quality, evidence-based clinical nursing and midwifery care;
- ⊕ empowerment of people and promotion of their ability to self-care;
- ⊕ promotion of people's access to appropriate health care;
- ⊕ co-ordination of care throughout the patient's journey;
- ⊕ the change in NHS culture from one of illness and treatment to one of health promotion and illness prevention;
- ⊕ effective team-working across different professional groups and agencies; and
- ⊕ ongoing development and improvement of nursing and midwifery practice.

The key factors that influence health and health care for people in Scotland underpin the Strategy. These factors include:

- ⊕ tackling health inequalities;
- ⊕ promoting social justice;
- ⊕ promoting social inclusion;
- ⊕ ensuring equity and allocation of health care resources among rural, urban and remote communities;
- ⊕ helping services and communities work together to improve health;
- ⊕ working in partnership across professional and agency lines; and
- ⊕ encouraging individuals to take responsibility for improving their own health.

The Welsh Assembly published *Inclusion, partnership and innovation* in May 2002, as part of the strategic framework for Nursing, Midwifery and Health Visiting in Wales, confirming the continuing development of learning disability nurses.⁸

Joint resourcing and joint management of community care services

The need for joint resourcing and management of community care services, including those for people with learning disabilities, is spelled out as a key commitment in *Our National Health: a plan for action, a plan for change* (2000).⁹ NHSScotland and local authorities now have a statutory duty to co-operate at a strategic and individual level.

Joint management refers to the elements needed to bring about a co-ordinated approach to planning, commissioning and operational management. *Joint resourcing* refers to all aspects of resources – staff, money, equipment and property – brought together in a single focus for planning, commissioning and delivering services.

The Scottish Executive has set out a framework – *Joint Future*¹⁰ – that will put in place joint resourcing and joint management arrangements within primary care and community care services. The aim of joint management and resourcing of services is to:

- ⊕ support people to remain in their own homes;
- ⊕ develop new and better ways of working;
- ⊕ provide a better quality of life for people with learning disabilities and others;
- ⊕ promote early assessment and intervention;
- ⊕ remove barriers within the care journey;
- ⊕ promote integrated services locally;
- ⊕ create a single point of access to community care services;
- ⊕ strengthen locality working;
- ⊕ develop 'whole person' approaches to care;
- ⊕ break down professional barriers; and
- ⊕ support the development of new skills.

Single Shared Assessment

Nurses and midwives are highly visible within primary care and community care services. They bring vast knowledge and experience that is crucial in taking forward plans to introduce Single Shared Assessment, which will:

- ⊕ create a single point of entry to for assessment of need and community care services for users;
- ⊕ ensure that agencies adopt a holistic approach to assessing and meeting people's needs;
- ⊕ reduce bureaucracy and duplication in assessment and planning care.

The developments outlined in the *Joint Future* report recognise that nurses have a significant contribution to make and their experience of caring for those with the most complex needs will be invaluable, whatever their area of practice. It is recognised that some nurses may be well placed to assume the role of care manager, particularly for those with the most complex needs, within the *Joint Future* context.

chapter 3: The nursing profession in Scotland



Nurses and midwives are perhaps the most visible and recognised symbol of NHSScotland. The nursing and midwifery profession is a large complex academic discipline. To provide competent, effective care, nurses and midwives use their technical, cognitive and interpersonal skills. They have the skills to assess and treat health problems and promote good health in individuals, families and communities. They also possess the expertise to design, co-ordinate and deliver health care.

The nursing and midwifery contributions to care outlined in *Caring for Scotland* and the changing care agenda arising from *The Same as You?* set the framework for establishing their responses to the care and support of children and adults with learning disabilities throughout their lives.

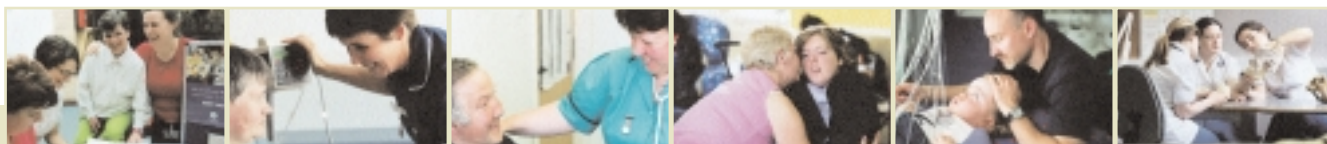
Background

There are approximately 52,000 in the nursing workforce in NHSScotland. Thirty-three thousand work full-time, and 80% are women.

The regulation of the nursing profession in the United Kingdom is a reserved matter for the United Kingdom parliament in Westminster. Significant changes have occurred with the establishment of the Nursing and Midwifery Council

(NMC) on 1 April 2002 as the successor body to the United Kingdom Central Council for Nursing, Midwifery and Health Visiting (UKCC) and the four National Boards.

The NMC has now assumed responsibility for the regulation of nurses, midwives and health visitors across the United Kingdom. Its responsibilities also include investigating allegations of professional misconduct as a means to ensure public safety and accountability, quality assurance of pre-registration education programmes, and the provision of advice and guidance on midwifery supervision. All registered nurses remain professionally accountable for their practice under the Nursing and Midwifery Council Code of Professional Conduct wherever they may practice.



Pre-registration preparation of nurses

In the United Kingdom, pre-registration nurse education programmes lead to registration on the Professional Nursing Register and are divided into two parts – a one-year Common Foundation Programme and a two-year Branch Programme.

Pre-registration preparation of nurses (3-year Diploma course)	
The Common Foundation Programme (CFP)	The Branch Programmes
Duration: 12 months	Duration: 24 months
The CFP provides the base from which nursing practice evolves. It includes theory in practice of nursing, communication processes, social, behavioural and life sciences, and defines the framework for the provision of health care.	The second part, the Branch Programme, is designed to build on the CFP to prepare nurses to practice in hospitals or the community. There are four Branch Programmes, and a separate one for the preparation of midwives: <ul style="list-style-type: none"> ➤ Adult Nursing ➤ Mental Health Nursing ➤ Learning Disability Nursing ➤ Children's Nursing.

Ninety per cent of students who train as nurses in Scottish Higher Education Institutions, graduate with a Diploma in Higher Education and increasingly an ordinary degree in nursing with registration on the appropriate part of the Professional Register following a three-year programme. *Caring for Scotland* states that education providers will aim for the programme to produce 80% graduates at the point of registration by 2005. The Scottish Executive centrally funds these courses. Ten per cent are funded by the Scottish Higher Education Funding Council (SHEFC). These programmes offer students the opportunity to study to honours degree level and, upon successful completion, they are eligible for the academic award and Registration on the appropriate part of the Nursing Register.

In addition to these three-year courses, there are shortened conversion courses to other parts of the Nursing Register for those who are already Registered Nurses. There is a separate programme for registration as a midwife.

chapter 3: The nursing profession in Scotland

Institution	Three Year Programmes	Branch
Robert Gordon University, Aberdeen	Diploma in Higher Education in Nursing/BA in Nursing	Adult Mental Health Child
	Diploma in Higher Education in Midwifery/Bachelor in Midwifery	
Napier University, Edinburgh	Diploma in Higher Education in Nursing /Bachelor in Nursing	Adult Mental Health Child Learning Disabilities
	Diploma in Higher Education in Midwifery/Bachelor in Midwifery	
Bell College, Lanarkshire	Diploma in Higher Education in Nursing/BSc in Nursing	Adult Mental Health
	Diploma in Higher Education in Midwifery/BSc in Midwifery	
University of Stirling	Diploma in Higher Education in Nursing/Bachelor of Nursing	Adult Mental Health Learning Disabilities
	Diploma in Higher Education in Midwifery/Bachelor of Midwifery	
University of Paisley	Diploma in Higher Education in Nursing/Bachelor of Nursing	Adult Mental Health
	Diploma in Higher Education in Midwifery/Bachelor of Midwifery	
Glasgow Caledonian University	Diploma in Higher Education in Nursing/Bachelor of Nursing	Adult Mental Health Child Learning Disabilities
	Diploma in Higher Education in Midwifery/BSc in Midwifery	
University of Dundee	Diploma in Higher Education in Nursing/Bachelor of Nursing	Adult Mental Health Child Learning Disabilities
	Diploma in Higher Education in Midwifery/Bachelor of Midwifery	



Institution	Four Year Programmes	Branch
University of Edinburgh	BSc(Honours) in Nursing	Adult Mental Health
Queen Margaret University College, Edinburgh	BSc(Honours) in Nursing	Adult
University of Abertay, Dundee	BSc(Honours) in Nursing	Adult
University of Glasgow	BSc(Honours) in Nursing	Adult

chapter 4: The current contribution of nurses and midwives



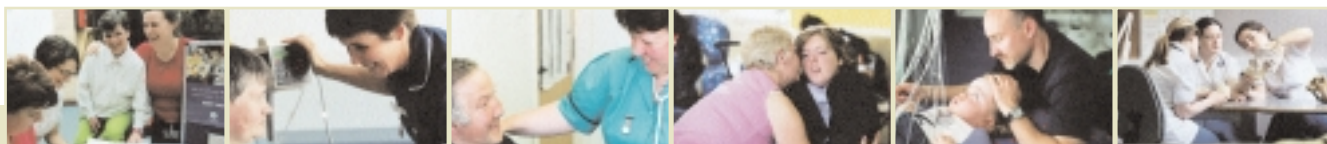
One of the aims of the National Nursing Review is to identify the current contributions made by nurses and midwives to the care and support of children and adults with learning disabilities. A series of local area focus groups with practitioners was set up throughout Scotland to obtain a picture of how services are being delivered, defining what is working well and identifying deficiencies. The local area focus group areas are set out in Appendix 6.

Local Area Focus Groups

A number of key themes emerged from the focus groups, including:

- ⊕ the need to recognise the health needs of people with learning disabilities;
- ⊕ the impact of changing policy on the contribution of nurses;
- ⊕ how partnership working is producing changes and developments in practice;
- ⊕ the need for improved collaborative working between learning disability nurses and others groups of nurses;
- ⊕ the importance and relevance of contributions from nurses and midwives across the life course;
- ⊕ gaining access to and support from specialists in learning disabilities, including nurses;
- ⊕ issues around the education of nurses, generalist and specialist – the past, present and future;
- ⊕ the need to identify research and development priorities;
- ⊕ recognising the public health needs of people with learning disabilities and the contribution of nurses and midwives to meeting those needs;
- ⊕ the need for strategic-level health needs assessment;
- ⊕ the need for leadership and vision within nursing.

The main recurring theme, however, was recognition that different groups of nurses and midwives make significant contributions, in many ways, across the lives of children and adults with learning disabilities. To help focus group participants identify and define some of the contributions, a 'life course' approach which spanned from pre-conception to old age was adopted (Figure 1).



Nursing and Midwifery contributions - generalist and specialist, across the life course of children and adults with learning disabilities

Genetics Nurses

Midwives

Public Health Nurses -
Community & Schools

Practice Nurses
District Nurses

Nurses and Midwives contributions across the life course

Paediatric
Nurses

Learning Disability
Nurses - Community
& Residential

Mental
Health
Nurses

Acute
Care
Nurses

Palliative
Care Nurses

Residential
care home
Nurses

Participants saw wellbeing and good health as central to the social inclusion agenda. Without recognition of the specific health needs of people with learning disabilities and adequate planning and services to meet them effectively, they will continue to be marginalised. The need to enjoy good health was seen as fundamental, with many local health initiatives being instigated, led and developed by nurses, particularly those with specific learning disabilities nurse training.

The need to develop and enhance their role was viewed by many as a priority as it was recognised that there would be an increasing and changing need for their skills, not a diminishing one. Many practice developments carried out in partnership with nursing colleagues from specialist learning disability teams, primary care and acute care are already taking place. Innovative and groundbreaking work is undoubtedly being undertaken across Scotland. Much of the work, however, has been developed locally on an ad hoc basis

and is not co-ordinated in a way that encourages sharing and wider implementation. In addition, participants at the focus groups were also able to identify significant deficiencies in current knowledge, practice and service provision.

Some nurses spoke about a 'fear' of people with learning disabilities and expressed concerns about their lack of skills in communication. Others were unclear of the difference between mental ill health and learning disabilities. Many were unaware that specialist learning disability teams, which included Community Learning Disability Nurses, were available to offer advice and support. There were examples of some people with learning disabilities not having their health needs competently assessed and of others not receiving investigations and treatment. Concerns over obtaining informed consent were often cited, and recognition of the implications for all nurses, midwives of the Adults with Incapacity (Scotland) Act (2000) was lacking.

chapter 4: The current contribution of nurses and midwives

A consistent concern expressed by many nurses and midwives was their lack of significant knowledge and clinical experience in the health and nursing needs of children, adults and parents with learning disabilities. Defining, recognising and understanding important issues such as complex needs was difficult for some.

The need for collaborative working with parents who have a learning disability and complex needs such as mental health problems, drug and alcohol dependency, challenging behaviour, poor parenting skills and problems in developing and adapting skills, was cited. Some identified people with severe challenging behaviour, autistic spectrum disorder and mental health problems as posing the greatest challenge. Child protection and abuse identification was also seen as an important area, and excellent examples of joint working with the full range of health, social, education and police services were given.

'Generic' and 'Specialist' nurses

In considering the range of contributions of nurses and midwives to the care and support of children and adults with learning disabilities, the focus groups felt that looking at the separate roles of 'generic' nurses and 'specialist' nurses would offer a useful way forward.

Generic nurses

For the purpose of the Review, *Generic* is adopted as a wide-ranging term to describe all those nurses who have not opted to care specifically for people with learning disabilities. *Generic nurses* are defined as those who have taken one (or a combination of more than one) of the non-learning disabilities Branch Programmes – adult, children's or mental health – and are likely to be found working in general areas, such as an acute medical and surgical admission and receiving units in a general hospital, as a practice nurse in a GP surgery or in children's or mental health services. They are unlikely to have received significant, if any, education and practical experience in caring for people with learning disabilities, and it is very unlikely that they will have developed the range of competencies required for professional practice in this area.

These 'generic' nurses may be providing care for people with learning disabilities and are doing so as one dimension of a wider role. Their main focus in relation to the care and support of children and adults with learning disabilities is in meeting everyday health needs as part of other nursing roles.

Specialist nurses

Specialist nurses for the purpose of this Review are those whose main or key role is caring and supporting children and adults with learning disabilities. This could, for example, include a children's nurse who is working as part of a child development service or a paediatric outreach team, or a learning disability nurse working in a multidisciplinary community team or specialist team for people with challenging behaviours. The main focus of these roles is to educate, support and enable children and adults with learning disabilities to access everyday health services, and requires advanced skills in working with those who have complex health needs.

The range of 'generic' nursing and midwifery contributions

Nurses make contributions to the care and support of people with learning disabilities even before conception. Nurses working within well-women and family planning services contribute to the health of people with learning disabilities by providing sexual health, health promotion, counselling, family planning and contraception advice. Some nurses work as part of highly specialised teams in genetic departments where the focus is on detection and counselling in relation to genetic issues. This is an important contribution, as some learning disability conditions have a genetic cause and early identification and detection is vital in helping to ensure effective assessment and management of associated health needs.

Midwives make a significant contribution to promoting and maintaining health during pregnancy. The key focus of their role is to support parents and facilitate a 'normal' pregnancy. Midwives in the Local Area Focus Groups identified particular needs when people with learning disabilities present to maternity services. Parentcraft and education can pose a problem; the midwives spoke of difficulties in



educating parents and of the need to adapt the terms and language used, suggesting their need to obtain help and support to develop material into community language.

The midwives described how an increasing number of people with learning disabilities were becoming parents, and made clear their need to have improved access to and joint working with specialist learning disability nurses. They particularly valued links with community nurses in specialist learning disability teams, although some were unaware of their existence in their area.

Public Health Nurses – Health Visitors and School Nurses – make considerable contributions to the care and support of children and young people with learning disabilities, their parents and care workers. Their contributions are most evident in the early developmental years, with support continuing from School Nurses up to leaving school. Child health surveillance programmes are well established, bringing together the skills to assess and monitor children's health. The Health Visiting role creates the potential to work with all groups across their entire life course, including people with learning disabilities. In practice, most Health Visitors work up to and just beyond the time when children begin school.

Public Health Nurses are often seen as a point of contact and referral to other services, and are expected to have detailed knowledge of their practice population and locality. When asked, few had received any significant special education or training to equip them to work with people with learning disabilities. The Public Health Nurses nevertheless made significant contributions in monitoring developmental progress, assisting with the initial diagnosis of learning disability and providing parental support and advice.

Many have developed areas of particular interest and some work with children with learning disabilities who have continence needs and sleep disturbances. Others have a particular interest in working with parents with learning disabilities and helping them to develop positive parenting skills.

Child protection is a central responsibility for all Public Health Nurses. Examples of joint collaborative working and positive relations with social work teams and colleagues in specialist learning disability teams were given. Community Learning Disability Nurses were viewed as having an important role to play in preventing child abuse by working directly with parents and children with learning disabilities to help address issues such as challenging behaviour and sleep disturbance. Links with the specialist learning disability nurses were seen as particularly important at the time of transition between services, most noticeably between children's and adult services.

Practice Nurses and Treatment Room Nurses based in primary care teams are increasingly the first points of contact with health services. They run nurse-led clinics and take on key roles in the management of chronic diseases such as diabetes and asthma. They make an important contribution to promoting good health, with health screening and illness prevention work being a significant part of their repertoire.

As with other nurses and midwives who participated in the focus groups, few of the practice nurses, who were all adult general nurses by training, had any previous knowledge or clinical experience of the health and nursing needs of people with learning disabilities.

Examples of joint working between practice nurses and community learning disability nurses in the area of health screening were given. The community learning disability nurses instigated these developments, and the practice nurses were clear that their contribution and ongoing support was crucial for their success. The joint work has brought about many positive developments for people with learning disabilities.

District Nurses are usually attached to a specific GP practice and work as part of a primary care team. District Nurses provide a range of nursing care and often work with people with learning disabilities by providing direct care in areas such as bowel management, wound dressings and enteral feeding.

chapter 4: The current contribution of nurses and midwives

Children's Nurses work with all children, including those with a learning disability, and their families. Children's nurses have particular skills in working with children who have complex physical needs and their professional training equips them to care for children and promote their development. They also have a role in the identification of child abuse and play a part in child protection.

Children with learning disabilities can pose particular challenges when admitted to paediatric units. Often, effective care can only be provided with the help and support of parents. Children with challenging behaviour are often seen as disruptive, demanding high levels of skill and attention from nurses.

An issue that arose at almost every focus group was the disparity between child and adult health services. Children were seen to be under the care of health professionals who had knowledge and skills to meet their physical health needs, and Community Child Health Services take a lead role in co-ordinating and monitoring health. There is no comparable service for adults. In children's services, the areas of mental health, challenging behaviour and autistic spectrum disorder were less well addressed. In comparison, adults with learning disabilities can access specialist health services for mental health and challenging behaviour needs.

Community Child Health Services, working with local and specialist paediatric units, were described as providing most ongoing health assessment and care for those with complex health needs, with General Practitioners (GPs) sometimes playing a minimal role. Following transition to adult services, young adults were effectively 'returned' to the care of GPs and primary care teams, who tended to have little knowledge or experience of their health needs. Children's nurses and others questioned what was being done strategically and individually by NHS Boards to plan for the health needs of young people when they move to adult services.

Concerns were expressed about the complexity of the needs of some of the children currently being cared for by child health services. 'Health'-based respite care was often available for children, but not within adult health services. A variety of creative support packages have been developed in adult services to address complex health needs issues, but many would not be viewed as acceptable in child health services. This is an area of concern for parents of young adults with complex health needs, and was considered by some to amount to an overall 'dilution' of care.

Acute Care Nurses work in all areas of general and specialist hospital care. People with learning disabilities use general hospitals to meet their everyday health needs. Some also need hospital health services as a result of specific health needs; children and adults with learning disabilities have higher incidences of epilepsy and neurological, gastrointestinal, endocrine and orthopaedic problems, for example.

A frequently raised issue in the focus groups was the difficulty some acute care nurses have in recognising that a person has a learning disability. Where the learning disability is associated with characteristic facial or physical signs, such as in Down syndrome, the problem does not arise. Other people whose learning disability is not so apparent could, however, face the possibility of their learning disability being unrecognised by the nurses caring for them in acute settings.

All the acute care nurses who attended the focus groups spoke of the changing demands and changing patterns of care in general hospitals. These included the introduction of same day investigation and surgical units, acute admission units and early discharge procedures. In community/hospital interface areas such as Accident and Emergency and Out-patients Departments, acute care nurses seldom knew in advance which of their patients had a learning disability, making planning problematic.



Although all had experience in their current role of caring for people with learning disabilities, some of the nurses had a negative view of them. This most commonly arose as a result of fear, based on little or no knowledge or clinical experience of their health and nursing needs.

In general, they perceived that the patients they routinely cared for now are older, more acutely ill and present with complex social and health care needs. While people with learning disabilities were seen as a challenging and important group, the nurses emphasised that they are also required to work with other groups of patients who present with complex nursing needs.

Mental Health Nurses work with people who have mental health needs. It is recognised that there is a higher incidence of mental illness within the learning disability population than in the general population. People with a mild learning disability are increasingly being admitted to mental health acute admission units, which often act as first point of contact for emergency assessment.

Mental Health Nurses spoke of their concerns about the quality of care received by some people with learning disabilities when accessing mental health services. They cited the often inappropriate and vulnerable position of people with learning disabilities compared to the rising number of other patients with complex mental health needs. Often, they claimed, people with learning disabilities were 'lost' in the service as a result.

They were concerned about the increase in the number of people with learning disabilities in mental health services. Mental Health Nurses stated that they did not have the specific knowledge or clinical practice experience to allow them to practice competently with people with learning disabilities. It was recognised that assessment skills, recognition of the differing presentation of mental ill-health in people with learning disabilities and the complexities of differential diagnosis require particular skills and underpinning knowledge.

Attempts to educate the mental health workforce in the necessary skills were dismissed as inadequate. The idea that specialist learning disability nurses could provide 'half-day workshops' that would fully 'skill-up' other groups of nurses was seen as unacceptable, and would be viewed as indefensible in other areas of nursing. Some student mental health nurses had been allocated clinical placements in learning disabilities settings during their training, but even these did not equip them with the skills necessary to contribute effectively to their care and support.

They questioned why it was considered appropriate for mental health nurses to care for people with learning disabilities without the requisite education, while the same situation would be unlikely to occur with other groups of patients or clients. An excellent opportunity exists for shared learning.

The need to separate 'learning disabilities' from 'mental health' was frequently raised. To some, learning disability was seen as a 'sub-speciality' of mental health nursing and psychiatry. While the higher incidence of mental ill-health in this group was recognised, the point was made that learning disability includes a wide spectrum of needs, of which mental ill-health is only one. The emphasis must be on the need to recognise the individual and his or her needs.

The range of 'specialist' nursing contributions

Learning Disability Nurses differ from nurses emerging from the other Branch Programmes in that they have specifically chosen to work with children and adults with learning disabilities; the others come into contact with them as a small part of their wider nursing role.

Work within some of the focus groups helped to identify some of the main attributes of Learning Disability Nurses.

chapter 4: The current contribution of nurses and midwives

Distinct Attributes of Learning Disability Nurses

Learning Disability Nurses:

- ⊕ have the same core nursing skills as other branches of nursing, obtained during the Common Foundation Programmes;
- ⊕ opt to work and specialise in the area;
- ⊕ focus on the health and care needs of children and adults with learning disabilities;
- ⊕ acquire specific knowledge and theory on the needs of children and adults across the whole learning disability spectrum;
- ⊕ have the knowledge and experience to assess and identify needs and plan care for those with the most complex health needs;
- ⊕ have knowledge of the special health needs of people with learning disabilities;
- ⊕ have the knowledge and skills to work individually or with groups across the learning disability spectrum to improve health and wellbeing;
- ⊕ actively engage people with learning disabilities, their families and care workers in promoting health and planning and delivering health care;
- ⊕ co-ordinate care pathways for people with learning disabilities through the health and social care systems;
- ⊕ advise, educate and support others about the health and nursing needs of children and adults with learning disabilities;
- ⊕ act as advocates for people with learning disabilities, and encourage their own self-advocacy;
- ⊕ meet the requirements for *Fitness for Practice* and are professionally accountable and responsible for their nursing practice;
- ⊕ have flexible, transferable and portable skills that can be used in a range of settings.

Historically, Learning Disability Nurses have their origins in long-stay hospitals, where the main focus of their role was caring. Today, they have developed their practice and make a wide range of contributions in varied settings to promote and improve health. Research published by the English National Board for Nursing, Midwifery and Health Visiting in 2001 supports this.¹¹

They practice within a health and nursing model, as opposed to a medical model, with the focus on promoting and improving health in its' widest sense. They are health promoters and health enablers, drawing on their knowledge and skills of the needs of children and adults with learning disabilities to promote wellbeing and enable and support social inclusion.

They are playing an increasing role in the education and support of primary and secondary care colleagues and care workers in meeting the everyday health needs of people with learning disabilities, however some children and adults have health needs beyond those which can be met by generalist services. Learning Disability Nurses are supporting, co-ordinating and providing specialist health services for those with the most complex needs, most commonly within the context of Community Learning Disability Teams (CLDTs).

Community Learning Disability Teams

CLDTs are multi-professional, and usually consist of community learning disability nurses, social workers, clinical psychologists, psychiatrists and therapists. They have been developed in many areas of Scotland. The teams are focused at present on providing specialist services. They are most commonly part of primary care trusts, but different structural models are used throughout Scotland.

Learning Disability Nurses in community settings tend to work within the CLDT structure, but alternative models of care delivery are developing. The future focus will be on determining the most appropriate models that meet the defined needs of local populations and make the most effective use of resources and skills.



As children's nurses in the focus groups identified, young people at the transition between child and adult services require additional support, and Learning Disability Nurses meet these needs. A range of different models have been used, with Learning Disability Nurses practising in Assessment and Treatment Units, Additional Community Support Teams, Challenging Behaviour Teams, Out-reach and In-reach Teams and Secure Units. They are also seconded into jointly managed projects for people with complex needs.

Learning Disability Nurses view themselves as important key partners in relation to joint working and recognise their contribution within the *Joint Future* context. They have considerable skills and experience across the learning disability spectrum, particular with people who have the most complex needs. They have a breadth of understanding of the issues around health needs of people with learning disabilities, the theory and knowledge base on which to base assessment and interventions, and the clinical skills and interest to make a difference to their lives.

Moving forward...

It is essential to have the contributions of knowledgeable, experienced and skilled specialist staff – including nurses – who are trained in the care and support of children and adults with learning disabilities across the life course. They have a key role in interfacing with generic nurses and other professionals working in mental health, acute care, child health and public health settings. The challenge is to harness the range of contrasting skills, talents and abilities of these groups and bring them together to improve the health of people with learning disabilities.

Nursing has a specific contribution in taking forward this agenda and in meeting the needs of people at all stages of the life course. Expectations of what can be delivered by 'generic' nurses must be realistic, however. They have received no significant education and tend to have little clinical experience in assessing, identifying and meeting the health needs of people with learning disabilities. It is nevertheless reasonable to expect that all nurses should have knowledge of where to access specialist nursing support, and that all nurses are able to demonstrate appropriate attitudes when caring for people with learning disabilities.

In order to take forward the implementation of the recommendations contained in *The Same as You?* and *Caring for Scotland*, it is vital that the knowledge and skills of the existing specialist nurses working with children and adults is directed, developed and enhanced to ensure that the appropriate level of support is available. Education programmes for all nursing students must reflect a positive value base, and the group of students who elect to specialise in caring and supporting people with learning disabilities must be seen as a valuable resource who are appropriately prepared for the challenges ahead.

chapter 5: Meeting needs with the Tiered Model



People with learning disabilities need to access a variety of health services, ranging from everyday services such as primary care to those that are more specialised.

The National Nursing Review considered the health needs of all children and adults with learning disabilities in the context of the Tiered Model of care, with a focus on:

- ⊕ strategic and public health needs
- ⊕ everyday health needs
- ⊕ health needs resulting from the learning disability
- ⊕ complex health needs.

The Tiered Model

The **Tiered Model** provides a framework to help describe what can often be complicated needs across multiple areas of health care, and offers a way of conceptualising and mapping the health needs of people with learning disabilities.

The model describes an elaborate structure of health provision around which services need to be responsive and flexible. It supports and emphasises the importance of advocacy, co-ordination and enabling across all the tiers, to ensure equitable access and the right to health care appropriate to the individual. It has been used in other areas of health care, such as psychological therapies, child and adolescent mental health and eating disorders.

Five 'Tiers' (0-4) are set out in the model:

Tier 0 – Community, public health and strategic approaches to care

Tier 1 – Primary care and directly accessed health services

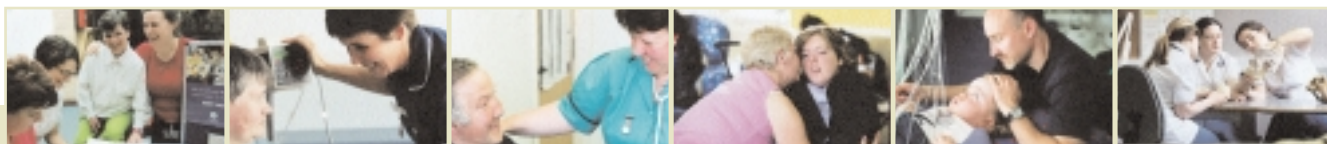
Tier 2 – Health services accessed via primary care

Tier 3 – Specialist locality health services

Tier 4 – Specialist area health services.

All people with learning disabilities have everyday health needs, just like anyone else (Tier 0,1 and 2). Some have additional health needs that will also require assessment, support and treatment across several or all of the Tiers simultaneously (Tier 0,1,2,3 and 4). A number will require very specialised services (Tiers 3 and 4).

The Same as You? recognises that for any of these needs the level of support required by people with learning disabilities will vary. Some may need occasional, short term support or during periods of change or crisis, others, long term support or constant and highly intensive support. The concept of person centred planning is central across all the Tiers.



A sound understanding of health needs in people with learning disabilities and the core principles outlined earlier is necessary to work with the model, as is knowledge of the organisations, structures and systems in which health care is provided. Specific assessment and therapeutic skills may be required to identify and meet the needs of some people with learning disabilities and to assess capacity. Skills in promoting and developing collaborative working and clinical networking are central.

The Tiered Model is set out in Figure 1. Figure 2 sets out the range of nursing contributions across the Tiers. Detailed description of the services provided at the different Tiers is included in Appendix 9.

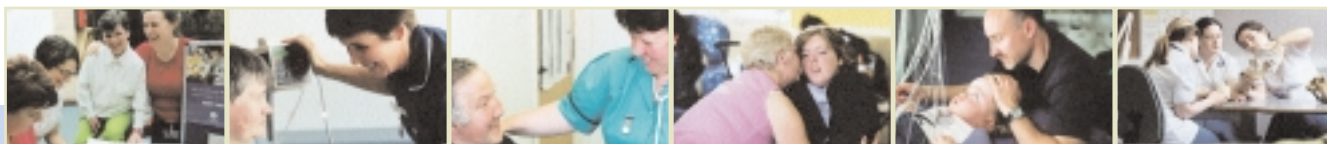
Figure 1. The Tiered Model

Tier 0	<p>Community, public health and strategic approaches to care</p> <p>The promotion of the general health and wellbeing of all people with learning disabilities in all settings in the community. This includes public health and specialist nurses working with communities and local services to promote involvement, social inclusion and raise awareness of health issues.</p>
Tier 1	<p>Primary care and directly accessed health services</p> <p>Access for all people with learning disabilities to primary care services and directly accessed health services such as community pharmacy, dental and optician services.</p>
Tier 2	<p>Health services accessed via primary care</p> <p>These services work in support of primary care services in meeting general and additional health needs by providing appropriate assessment, treatment and specialist advice if required. Such services include outpatient, domiciliary and in-patient services delivered from general hospital services, and includes palliative care.</p>
Tier 3	<p>Specialist locality health services</p> <p>Focuses on specialist learning disability/mental health/child health services that are provided on a locality basis. These services work to support primary care services and others by providing advice, assessment, interventions and treatments for complex specialist learning disability health needs. Specialists provide advice and practical support to people with learning disabilities, their families, and to local authority or voluntary sector providers such as schools, day services and short breaks services.</p>
Tier 4	<p>Specialist area health services</p> <p>These consist of highly specialist area and regional services. They might be special assessment and treatment in-patient units, or area-wide specialist Additional Support Teams for people with complex challenging needs, or forensic services for people with learning disabilities. May be in-patient as well as in-reach models.</p>

chapter 5: Meeting needs with the Tiered Model

Figure 2: The range of nursing contributions across the tiers

<i>The Needs</i>	<i>The Responses</i>
To promote the health and general wellbeing of all people with learning disabilities in all settings	<ul style="list-style-type: none"> ⊕ Increased involvement of people with learning disabilities ⊕ Disability awareness ⊕ Access to information and support ⊕ Local signposts to services ⊕ Development of community networks, supports systems and inclusion opportunities
For all people with learning disabilities to access Primary Care Services and Directly Accessed Health Services	<ul style="list-style-type: none"> ⊕ Information for planning ⊕ Support for primary care to enable access and meet every day health needs ⊕ Screening for complex health needs ⊕ Information on services and support ⊕ Long-term support needs
For people with learning disabilities to access specialists via Primary Care Services	<ul style="list-style-type: none"> ⊕ Access to specialist knowledge and skills as available for the whole population ⊕ Support for general specialists so the service is accessible ⊕ Co-ordination and continuity of health care ⊕ Effective assessment, treatment plans, monitoring of care ⊕ Planning for life transitions ⊕ Evaluation of outcomes
For people with learning disabilities to access Specialist Locality Health Services	<ul style="list-style-type: none"> ⊕ Access to specialist multi-professional teams with specialist skills and knowledge of health needs of people with learning disabilities ⊕ Assessment, treatment and evaluation ⊕ Planning for life transitions ⊕ Robust referral pathways
For people with learning disabilities to access Area-wide and Regional Health Services	<ul style="list-style-type: none"> ⊕ Area-wide specialist assessment and treatment in-patient and in-reach services for complex needs ⊕ Access to specialists in child development, mental health, challenging behaviour, forensic care, autism, dementia, palliative care.



Level of Need	All Levels	The Range of Nursing Contributions
Level 0 – People in the community	<ul style="list-style-type: none"> ⊕ Audit ⊕ Research ⊕ Practice Development ⊕ Education & Training ⊕ Clinical Governance ⊕ Evidence Based Practice 	<ul style="list-style-type: none"> ⊕ Robust referral pathways ⊕ Partnership working with users, families, care workers and organisations ⊕ Act as a knowledgeable resource ⊕ Advocate for the Rights of people with learning disabilities ⊕ Identify needs in the local community ⊕ Provide disability awareness education ⊕ Enable health improvement
Level 1 – Primary Care and Directly Accessed Health Services	<ul style="list-style-type: none"> ⊕ Evaluation of outcomes and interventions ⊕ Service planning information and data collection ⊕ Evidence based Commissioning 	<ul style="list-style-type: none"> ⊕ Enable and promote social inclusion ⊕ Promote the use of ordinary services ⊕ Promote collaborative working ⊕ Promote effective data collection ⊕ Promote evidence based practice ⊕ Participate in community development ⊕ Promote health and safety
Level 2 – Specialists working in support of Primary Care	<ul style="list-style-type: none"> ⊕ Policies for abuse and neglect ⊕ Clear and explicit referral pathways at all levels ⊕ Partnership working to promote inclusion ⊕ Quality and Standards 	<ul style="list-style-type: none"> ⊕ Undertake direct case work ⊕ Undertake nursing and health assessments ⊕ Participate in the identification of an individual's need ⊕ Undertake the development of plans of care ⊕ Provide direct clinical therapy ⊕ Provide direct clinical care ⊕ Participate in crisis interventions ⊕ Undertake the evaluation of plans of care ⊕ Enable access to services and care
Level 3 – Locality based specialist health professionals	<ul style="list-style-type: none"> ⊕ Inspection and Monitoring ⊕ Robust communication pathways 	<ul style="list-style-type: none"> ⊕ Work directly with service users, families and care workers ⊕ Maintain an over view of health needs ⊕ Participate in multi-professional team working ⊕ Participate in Care Management ⊕ Contribute to person-centred-planning ⊕ Contribute to Single Shared Assessments ⊕ Contribute to Personal Life Plans
Level 4 – Area and Regional Health Services		<ul style="list-style-type: none"> ⊕ Provide health promotion and Health education ⊕ Provide health facilitation and co-ordination ⊕ Act as an expert resource ⊕ Participate in service planning and developments ⊕ Act as service managers ⊕ Act as researchers ⊕ Act as educators



Tier 0

Community, public health and strategic approaches aim to promote the general health and wellbeing of all people to care with learning disabilities in all settings in the community. This includes public health and specialist nurses working with communities and local services to promote involvement, social inclusion and raise awareness. A strategic approach is required to identify health needs to inform evidence-based care.

Scotland is a diverse country with a varied geographical landscape, ranging from large urban settings to remote and rural areas. There are major differences in the way in which health services are and can be provided due to these geographical and sociological variations.

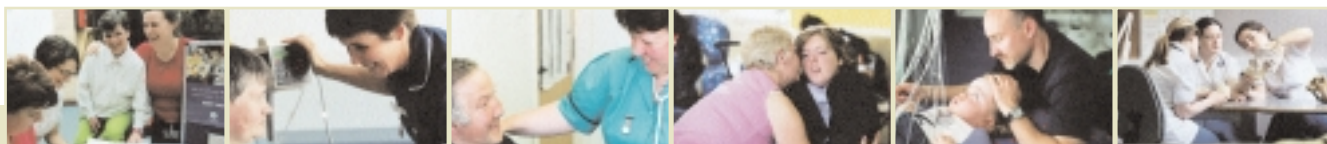
Improving the public's health is a complex and long-term objective of the Scottish Executive. Multiple issues impact on the public's health, including cultural, economic, environmental, social and physical factors. No single professional group has responsibility for the improvements and changes required; collaboration amongst all agencies, including health professionals, is essential.

Demography

Population projections indicate that by 2021, Scotland's population will fall from 5.12 million to 5.06 million, with a 15% reduction in children aged under 15 and a 30% rise in the number of people aged over 75. The predicted increase in the population of older people, both in absolute terms and as a percentage of the total population, is set to continue for the coming decades. The over 75s will form the fastest growing population in the UK.

Morbidity and mortality

Mortality rates in Scotland remain high in relation to the rest of the UK. There are clear associations between deprivation and most cancers, coronary heart disease and some common mental health problems.



Morbidity from chronic diseases and conditions associated with ageing is increasing, and there are also general increases in cancer, obesity, diabetes, tuberculosis, sexually transmitted diseases and mental ill-health across all ages.

People with learning disabilities commonly live within socio-economically deprived communities; they are also living longer and are therefore prone to the chronic diseases that affect the rest of the population, in addition to a range of special health needs resulting from their learning disability. Their use of and need to access a range of health services will therefore be significant.

While strategies to deal with chronic disease may tackle some of the health and social care problems facing the general population, they are insufficient on their own to respond to the needs of people with learning disabilities. More sophisticated assessment skills may be required to identify needs and develop meaningful plans to promote and improve health.

The changing profile of the general and learning disability population will have an impact on all services, including health. Innovative approaches and models of service delivery that take account of their health needs have been lacking in the past. The emphasis must be placed on improving access to health services and co-ordinating the care journey. These approaches will challenge traditional boundaries and ways of working; all involved in providing care, including nurses, will need to develop and adopt new ways of practising.

Social inclusion

The impact of poverty and social exclusion at individual, family and community levels is particularly relevant to children and adults with learning disabilities. Many live in socio-economically disadvantaged circumstances, and have poorer general health and greater health needs than the general population. The need to develop a positive health culture that promotes wellbeing and inclusion is therefore vital for children and adults with learning disabilities.

Good practice – ethnic and cultural awareness

A nurse is leading the way in ensuring that issues of ethnicity and culture are to the forefront for people with learning disabilities in the Greater Glasgow Health Board Area. The role involves educating and training a wide variety of community-based and professional groups on ethnic and cultural issues, direct case work with learning disabled clients from ethnic minority groups, joint working with colleagues in social care, health and voluntary agencies, and advising on ethnic and cultural issues to a variety of policy makers who are focusing on service provision and access.

Recognising and addressing health needs

The boundaries between health and social care for people with learning disabilities are continually being redrawn, with a greater emphasis on the role of primary care and the need for support from and access to specialist health services. This is particularly the case for those people with learning disabilities who have the most complex needs.

All too often, however, the health needs of people with learning disabilities go unrecognised and untreated. The term 'diagnostic overshadowing' is now used when symptoms and illness are dismissed as being a result of learning disability, means that potential illness and conditions go unrecognised and therefore untreated. 'Differential diagnosis' is extremely important and is the term used to describe the conditions and illness a person may have and possible diagnosis options. This requires considerable knowledge, skill and experience, as the presentation of ill-health can differ within children and adults with learning disabilities. Skilled specialist professionals with the knowledge of the 'right' health questions to ask and then plan appropriate treatment and care are necessary.

Health promotion and health screening services such as hearing and sight tests, which are accessible to most of the population, are under-used by people with learning disabilities. The changing needs of those with the most complex health problems may not be recognised.

chapter 6: Community, public health and strategic approaches to care

Two-thirds of people with learning disabilities need **more** health support than primary care alone can provide, with some requiring referral to specialist services. Services must recognise this and work in partnership to ensure that the assessment of needs is planned, co-ordinated and managed through the person's life course, in collaboration with people with learning disabilities, their families and care workers.

Recommendation 1

The Public Health Institute of Scotland should undertake a Needs Assessment of the health needs of children and adults with learning disabilities in Scotland to inform the development and commissioning of services for the future.

The needs of children and families

Families of children born with a learning disability or who fail to reach developmental milestones need additional help and support. Health professionals, particularly nurses, are well placed to contribute to this endeavour and are able to provide information, practical help and emotional support. They are in a position to work with parents and care workers to advise on the care of children with special needs.

As children's nurses who participated in the Local Area Focus Groups reported (see Chapter 4), there are concerns that the health care needs of young people with learning disabilities are not always considered, recognised or met at the time of transition between children's and adult services. Adult services may have had little experience of young people with learning disabilities, and often feel poorly prepared and equipped to meet their needs, particularly if complex.

For people with learning disabilities who become parents, it is important not only to recognise and address the needs of the new child, but also the needs of the new parents. Some people with learning disabilities may require additional support when becoming parents, and nurses and midwives have an important contribution to make to this.

Good practice – Families First

The number of families headed by a parent with learning disabilities accessing clinical psychology services in Edinburgh has increased in recent years. Funding from the Sure-Start Scotland initiative has allowed a team consisting of Clinical Psychologists, a Health Visitor and a Community Learning Disabilities Nurse to design and implement a parent education programme for people with learning disabilities. The teaching package, Family First, uses a variety of methods to teach parenting skills to people with learning disabilities, such as verbal instruction, modelling and supported behavioural rehearsal. Learning has been reinforced through the use of pictorial workbooks, home visits and practice with a simulator baby doll. Three families consisting of parents with learning disabilities took the course over a 12-week period, and results indicate that their levels of knowledge of childcare have increased, and some positive changes to their parenting practice have been introduced.

The needs of older people

The promotion of the health and wellbeing of older people, including those with learning disabilities, is a national priority. NHS Boards and social work departments must ensure that care staff have the appropriate support and training to meet the needs of older people with learning disabilities. But the needs of family carers must not be ignored.



Many older parents who are caring for a person with a learning disability find it difficult to make plans for the future. Caring for people with learning disabilities on a long-term basis can place strains on wellbeing, health, finance and relationships. This can result in high incidences of stress, anxiety and depression. Healthcare professionals, including nurses, are often the key point of ongoing support for family carers, and are in a position to assess, recognise and support them to sustain their ability to care and to help them plan for the future in partnership with other services.

Providing services

Sound evidence and data on the health needs of children and adults with learning disabilities should be used to inform the development and commissioning of evidence-based services. At present, such information does not exist in Scotland.

Recommendation 9 of *The Same as You?* however will see the development of a database across Scotland. A strategic, Scotland wide assessment of health needs will support and inform the development of this database. The promotion of the general wellbeing and health of all people with learning disabilities needs to be a priority at strategic and local levels. NHS Boards must ensure that there is an appropriate distribution of specialists, including nurses, to support and educate others and to provide interventions and treatment for those with the most complex needs.

Recommendation 2

NHS Boards and Local Health Care Co-operatives should profile the health needs of children and adults with learning disabilities by working collaboratively with colleagues in Community Child Health, Learning Disability Teams, Primary Care, Public Health and other areas, to inform Partnership in Practice Agreements, Health Plans and joint commissioning.

Recommendation 3

NHS Boards should review the funding and resourcing of health services for people with learning disabilities to ensure that the commissioning and development of services are built on sound evidence of the full range of health needs of children and adults with learning disabilities.

The capacity of *all* nurses to contribute to the wider social inclusion and public health agenda affecting people with learning disabilities needs to be developed across Scotland. This is an issue that must be addressed by NHS Boards and by nurses working as part of a wide range of teams, in both specialist and generic roles. Nurses, specifically Public Health and specialist Learning Disability Nurses, should participate in local area developments and projects that promote the inclusion of people with learning disabilities in their community, educating the public and increasing their awareness of people with learning disability, their needs and qualities.

The Key Messages

- ⊕ **Services must be organised and delivered locally in response to sound evidence and assessed need**
- ⊕ **The promotion of good health and wellbeing must be given greater priority at a strategic and local level**
- ⊕ **Joint working must be a priority**



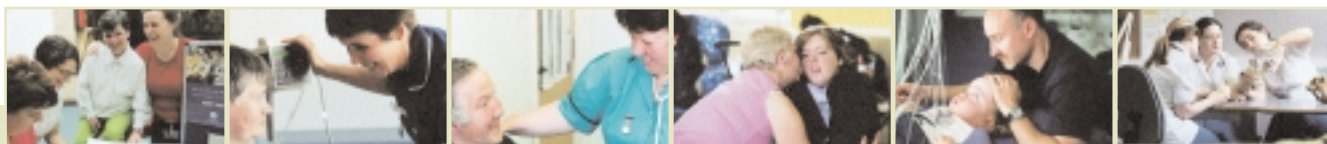
Tier 1

Health services must enable access for all people with learning disabilities to primary care services and directly accessed health services such as community pharmacy, dental and optician services.

People with learning disabilities have everyday health needs, just like everyone else. Some people with learning disabilities, however, face particular problems in having their everyday health needs met, with few health professionals having extensive specialist knowledge on which to base their practice. To make sure that everyday health needs are met, the journey through the health care system needs to be planned and co-ordinated, particularly through transitions.

Good practice – service transitions

A Community Learning Disability Nurse in a project in Forth Valley is identifying the needs of young people with learning disabilities making the transition from children's to adult services. Surveys of parents of young people with learning disabilities has been conducted. They highlight the need for better information, more options in service delivery, better access to staff for support, and education for staff in adult services on the needs of young people with learning disabilities. The project is identifying a range of measures aimed at tackling the main problem areas.



Accessing services in primary care

It is estimated that a GP with 1,500 patients will have on average between 20-30 people with mild learning disabilities, and up to 4-6 people with severe disabilities, on his or her list. A GP practice of five doctors could therefore expect to have about 125 people with mild learning disability and 25 people with severe learning disability registered as patients.

Making the connections recognises that all patients need to be registered with a practice to access primary care services to meet their everyday health needs.¹³ For the majority of patients, the first point of contact with health services is normally the GP or a member of the primary care team.

All people need to be registered with a GP to be included in national screening programmes, to receive appropriate health education and health promotion advice, and to access general hospital and other specialist services. The GP is often described as the 'gatekeeper' of the health service, and is the professional responsible for the overall health and wellbeing of patients in the community.

Almost all GP practices are unaware of the number of people with learning disabilities registered with them. Some GPs have limited involvement in meeting the health care needs of children with learning disabilities, while others may be unaware of older people with learning disabilities on their list and are unfamiliar with their health needs. There is in general across Scotland a lack of data and information about the range of assessed health needs of people with learning disabilities at practice, LHCC and NHS Board levels.

People with learning disabilities have a greater need for health care than the general population, but many needs go undiagnosed, unrecognised and therefore untreated.¹⁴⁻²⁰ They encounter particular problems and barriers in accessing primary care and other health services.²¹⁻²⁴ For some people with learning disabilities, there are barriers to accessing and obtaining health care.²⁵ Some of the barriers include:

- Physical barriers – poor accessibility to health care facilities;
- Administrative barriers – short appointments and long waiting times;
- Communication barriers – inability to describe symptoms, with differential diagnosis difficult and diagnostic overshadowing possible;
- Attitudinal barriers – negative assumptions and attitudes about people with learning disabilities; and
- Knowledge barrier – limited theory and practice experience of the health needs of people with learning disabilities.

The majority of general practices function on a largely reactive rather than proactive basis, relying upon people with learning disabilities, their families or care workers to identify problems and actively seek a consultation – which can be problematic if communication or access difficulties are present.

Good practice – 'Health Matters'

A project funded by the Lothian Primary Care Development Fund, run in partnership with Jewel and Esk Valley College, has led to the development of a course – Health Matters – to teach people with learning disabilities about their health and offer advice on how to access healthcare services. The course, jointly run by a college lecturer and a Community Learning Disabilities Nurse, ran for ten students over an 18-week semester. At the end, the students were evaluated and compared to a control group of students who had learning disabilities, and were found to have a significant increase in knowledge and perception of personal competence in relation to health.

chapter 7: Primary care and directly accessed health services

It is not possible for health care professionals working in primary care to develop all the skills necessary to work with all groups. They need support from, and access to, specialists in learning disabilities and other fields. Partnership working and collaboration between primary care and specialist health services is the key. Exciting and innovative projects have recently been developed in Glasgow and the Western Isles to address the primary care needs of people with learning disabilities.

Good practice – The Glasgow Primary Care Liaison Team

The Primary Care Liaison Team was established in recognition of the need to address health inequality issues. A team consisting of Community Learning Disability Nurses, doctors and Health Promotion Officer works with and supports LHCCs and primary care teams across Glasgow. At the core of the team's work is health assessment, identification of needs, education of and liaison with primary care colleagues and health promotion. This innovative project is seen as an excellent example of collaborative working between services as a means to improve health and enable social inclusion

Good practice – Western Isles Learning Disability Service

Following a successful tender by a primary care practice in Harris in the Western Isles, Personal Medical Services funding was obtained from the Scottish Executive to develop a primary care-based community learning disability nursing services to cover the islands. Two Learning Disability Nurses have been appointed and will work with colleagues from health, social work and the voluntary sector to improve health and well-being of people with learning disabilities in remote and rural areas.

Recommendation 4

All NHS Boards should ensure there are models of health care in place that support a primary care-based approach to developing services for people with learning disabilities. To support this, NHS Boards should ensure there are Community Learning Disability Nurses based in, and working collaboratively as integrated members of primary care teams. The numbers of specialist nurses required will need to take account of geography and population needs, and every NHS Board should have appropriate arrangements in place across all LHCCs.

Preventative health care

Preventative health care has not traditionally been a high priority area in learning disabilities services. This must change as the focus of health care shifts towards health promotion and disease prevention. *Nursing for Health* recognises the important role all nurses and midwives have in improving health and makes recommendations about the role of specialist working with people with learning disabilities.²⁵

Preventative health care includes routine health screening, such as cervical smear and mammography programmes. Uptake and inclusion of women with learning disabilities for these services is lower than in the general population. Sensitive areas such as sexual health and physical, sexual or emotional abuse also tend to be neglected, with potentially serious implications for the person with learning disability.

Research strongly suggests that people with learning disabilities benefit from health assessments and a range of models has been suggested. *The Same as You?* recommends that NHS Boards should offer regular health checks for all people with learning disabilities.^{26–28}



Good practice – Healthy hearts

Community Learning Disabilities Nurses are working closely with health promotion staff to ensure that people with learning disabilities take advantage of the Borders' innovative Healthy Hearts in the Borders campaign. The health promotion department is training the nurses on motivating change to encourage people with learning disabilities to adopt healthier lifestyles, and the nurses are using this as a basis for work with people with learning disabilities in the region. Plans are underway to allow the nurses to present part of the course on an ongoing basis, heightening awareness of the needs of people with learning disability to a wide range of health, social care and health promotion staff.

Health professionals, including nurses, need to pay particular attention to preventative health care for people with complex needs. They must also ensure that the special needs of people with learning disabilities are considered within health promotion programmes. Specialist nurses have a particularly important role to play in co-ordinating preventative health efforts with primary and secondary care sectors and the range of specialist and other services. For this to be achieved, it is necessary to ensure that there are specialists with the relevant underpinning knowledge and clinical experience of the health needs of people with learning disabilities, and the skills to respond appropriately. *The Same as You?* recommends the development of the role of Local Area Co-ordinators, which creates opportunities for collaborative working.

Recommendation 5

NHS Boards should ensure that all people with learning disabilities – particularly those with complex needs – have regular assessments of their health needs and plans of care developed as part of their Personal Life Plan. These should be developed in partnership with Primary Care and Specialist Learning Disability Services. Particular attention should be given to the interface between services at transition stages, such as at the time of diagnosis, commencement of education and transfer between child and adult services, to ensure appropriate co-ordination of health care.

Recommendation 6

The Health Education Board for Scotland and the Scottish Consortium for Learning Disability should work collaboratively with NHS Boards, LHCCs, Public Health Practitioners and Learning Disability Nurses through local and national networks to promote health education and health promotion of people with learning disabilities in public health initiatives.

The Key Messages

- ⊕ **All people with learning disabilities should be enabled and supported appropriately to access primary care-based health services**
- ⊕ **Improving the health of people with learning disabilities by planned and co-ordinated health assessment, health education and health promotion must be a priority**
- ⊕ **Planning and practice must be needs-based**
- ⊕ **Good health enables social inclusion**



Tier 2

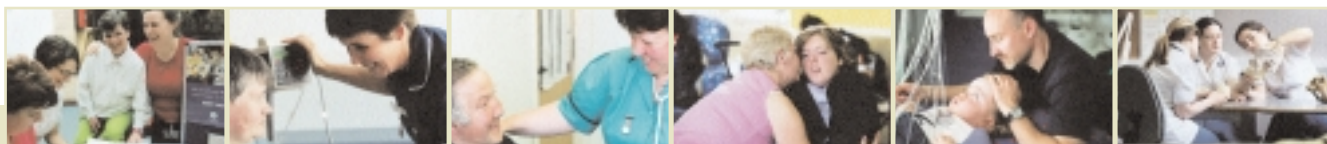
These are health services accessed via primary care and which support and enable primary care to meet general and additional health needs by providing appropriate assessment, treatment and specialist advice. Such services include outpatient, domiciliary and in-patient services delivered from general hospital services, and include palliative care.

Many people with learning disabilities have greater health needs than the general population. Some will require referral from primary care to secondary care and specialist health services, where investigation, diagnosis and treatment can take place.

Extra health needs resulting from a learning disability

Some people with learning disabilities have health needs that are specifically associated with the underlying cause of their learning disabilities. A person with Down syndrome, for example, is more likely to be born with heart problems and cataracts, is at higher risk of acquiring problems with the thyroid gland, and has a greater vulnerability to depression and dementia. However, it is important to understand that this does not apply to all people with learning disabilities.

Many causes of learning disability have associated additional health needs that differ according to the individual syndrome or genetic condition. Knowledge of these associations is important, both to prevent problems occurring and to improve detection of health needs at an early stage to enable appropriate treatments and management to be started. This may reduce unnecessary suffering for some through, for example, the detection of early hypothyroidism in a person with Down syndrome through annual blood testing. Long-term, irreversible damage to health and functioning or premature death may be prevented for others; awareness of the risk of the onset of hydrocephalus in adults with tuberous sclerosis, for example. While some people with learning disabilities resulting from a specific genetic syndromes are more likely to suffer from certain kinds of cancers.²⁹



A brief summary of some of the disorders that appear more commonly in people with learning disabilities than in the general population is given below.

People with Learning disabilities and Health Needs

- ⊕ at least forty per cent of adults with learning disabilities have additional mental health needs^{30,31}
- ⊕ seventy per cent will have an additional physical health need³²
- ⊕ mobility problems are present in about fifteen per cent of people with learning disabilities³³
- ⊕ thirty per cent of people with learning disabilities may have significant visual impairment, while a further ten per cent are blind or partially sighted³⁴
- ⊕ hearing impairment varies from between 28-40 per cent, and it is estimated that seven per cent are totally deaf³⁵
- ⊕ fifty per cent have a significant communication impairment
- ⊕ seventy per cent of people with severe learning disabilities have gastrointestinal reflux disorder
- ⊕ about twenty five per cent of all people with learning disabilities have epilepsy; the risk increases with the level of impairment, as does the severity of the epilepsy.³⁶

These health problems are more common, present differently, are more complex and tend to appear more commonly in clusters among the learning disabilities population. Effective assessment, identification of needs, investigation, care planning and intervention beyond that available from primary and secondary care services are therefore needed by some people with learning disabilities. As a result of the increased presence of these conditions, people with learning disabilities will often require investigation and treatment across a range of health services. Access, co-ordination and support are important issues.

Good practice – homeless services

Work carried out in 1999 showed that the health needs of homeless people with learning disabilities in Glasgow were not being adequately met. The Glasgow Primary Care NHS Trust responded by appointing two Community Learning Disabilities Nurses to address the health care needs of this client group. Following a wide consultation on the elements of the service and an awareness-raising programme, the service was launched in September 2001. It brings specialist information and advice to frontline services engaging with homeless people with learning disabilities, and offers a comprehensive assessment, care and support service based on health need. Partnerships have been forged with a variety of relevant groups and organisations, and an audit of the service will be commenced later this year.

For some people with learning disabilities, an understanding of individual problems, such as those associated with autism or challenging behaviour, is necessary to ensure that appropriate preparation and support is available. Many health professionals in primary and secondary care settings have limited experience and knowledge of these important issues and as a result some people with learning disabilities have in the past received inadequate health care. This is not acceptable.

As it is not possible for all nurses and health professionals to develop the full range of skills necessary to work with all people with learning disabilities, it is important to ensure that specialists are available locally and are accessible. This should not be seen as optional and clear pathways to access them must be in place.

chapter 8: Health services accessed via primary care

Good Practice – Detection and prevention of cancer

A nurse-led project to assist in the prevention and detection of cancer in people with learning disabilities has been set up in the Forth Valley area. The New Opportunities-funded project aims to identify good models of practice in prevention and detection of cancer, and to produce good practice guidelines and a health promotion package targeted at people with learning disabilities. The project is identifying how mainstream cancer services are currently operating, and will gather information from service users on difficulties they have experienced accessing services. The results of these surveys will be fed into the good practice guide.

Primary and secondary health care staff will have to refer to and liaise with specialist health professionals to meet many of these needs effectively. Specialists commonly work as part of Child Development or Paediatric Teams or in Learning Disability Teams, and include paediatric nurses with interest and knowledge of child development and learning disability nurses, who have knowledge and experience of all the health and nursing needs across the learning disability spectrum.

The challenge is to provide integrated health care encompassing both everyday and specialist health needs, while avoiding the potential for over-medicalisation of management. Nevertheless, it must not be assumed that all people with learning disabilities can and do access services in the same way, and alternative approaches are necessary for some.

Good Practice – Maternity Services in Argyll & Bute

A joint protocol has been developed by midwives and the community learning disability team to ensure that parents with learning disabilities using maternity services, receive additional support and advice if required.

Good practice – Lothian Acute Hospital Project

An acute hospital liaison service established since 1998 has been held up as an example of excellence by SHAS and has been the focus of UK interest since its inception. The service, formed in a partnership between Lothian Primary Care NHS Trust and Lothian University Hospitals NHS Trust, aims to facilitate high quality care for people with learning disabilities who are receiving services from acute hospitals. The service consists of a Liaison Nurse supported by project managers working with designated Link Nurses within the hospitals. It focuses on the needs of people with learning disability throughout the care journey, co-ordinating care, supporting the planning of admissions and discharges, promoting inter-disciplinary and inter-agency collaboration, developing and auditing standards, and providing education for staff on issues around consent. Plans are now underway to extend the service throughout Lothian.

Recommendation 7

NHS Boards should develop and ensure there is access to a Learning Disability Liaison Nursing service within acute general, paediatric and psychiatric hospitals to support children and adults with learning disabilities and their families and care workers throughout the care journey.



Children's and learning disability nurses should develop their roles to ensure that people with learning disabilities are supported appropriately to have their everyday health needs assessed and met, in collaboration with primary and secondary care colleagues. Families and care workers need to be supported to ensure that health assessments, investigations and treatments are taken up and that opportunities for health promotion and health education are maximised. These are complex challenges that require understanding of health needs, how care is delivered across health services and the ability to assess, plan and co-ordinate health care in a primary care setting.

The Key Messages

- ➔ **Many people with learning disabilities have high unmet and unrecognised health needs**
- ➔ **The assessment and treatment of health needs can be complex, requiring access to specialist skills**
- ➔ **Partnership working needs to be developed with primary and secondary care and specialists in learning disabilities to support assessments of health need, provide advice and co-ordinate care**



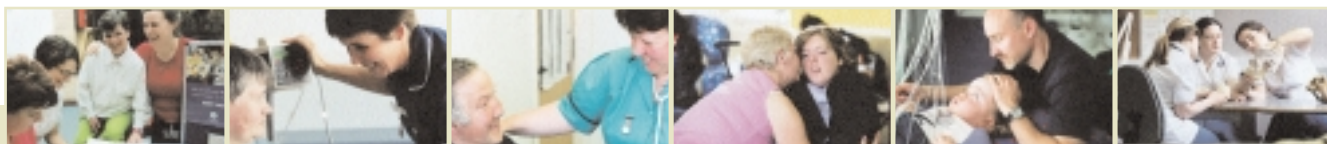
Tier 3

Specialist learning disability/mental health/child health services are usually provided on a locality basis. These services work to support primary care services and others by providing advice, assessment, interventions and treatments for complex specialist learning disability health needs. Specialists provide advice and practical support to people with learning disabilities, their families, and to local authority or voluntary sector providers such as schools, day services and short breaks services.

Complex needs

People with learning disabilities who have complex needs are among some of the most disadvantaged and vulnerable in our society. They have a wide range of needs that will often require additional services and support to those available from mainstream services, including primary and secondary health care.

The term 'complex needs' encapsulates a variety of specific problems which, when combined with learning disabilities either singularly or as a group, creates needs that are challenging to health care systems. Some of the main problems associated with complex needs are shown opposite.



Health Care and Complex Needs

- | | |
|---|--|
| <ul style="list-style-type: none"> ➤ Epilepsy ➤ Syndromes and genetic conditions ➤ Profound and multiple learning disabilities ➤ Mental ill-health ➤ Challenging behaviour | <ul style="list-style-type: none"> ➤ Offending behaviour ➤ Older age learning disabilities ➤ Dementia ➤ Autistic spectrum disorder |
|---|--|

Epilepsy

There is a higher prevalence of epilepsy in children and adults with learning disabilities, with prevalence increasing with the level of impairment. Epilepsy is more likely to be of a multiple-seizure type, and tends to be difficult to control. Accurate history and assessment is vital to ensure a correct diagnosis. The education and support of family carers and care workers is important as some people with learning disabilities will require medication and additional support as a result of their epilepsy.

Syndromes and genetic conditions

Some people with learning disabilities have additional health needs that are specifically associated with genetic factors. Knowledge of these associations is important if early detection and appropriate treatments are to be provided, but it is unlikely that primary care generic staff will have had significant training in the characteristics of syndromes and genetic conditions. There is limited opportunity to acquire and develop such knowledge while working in generic primary care settings. Consequently, additional support from specialists in learning disabilities is required.

Profound and multiple learning disabilities

There is no accepted definition of profound and multiple learning disabilities, but it is commonly associated with pronounced developmental delay with significant physical and sensory impairments and epilepsy. Communication difficulties are also common, and some eighty per cent of affected individuals will have physical disabilities that affect mobility.

It has been reported that 64% of children and 59% of adults with profound and multiple learning disabilities have seizures, either 'frequently' or 'occasionally'.³⁷ Others will experience sleep disturbance, gastrointestinal reflux disorder, respiratory and cardiac problems and have special feeding and nutrition needs.

The health care needs of people with profound and multiple learning disabilities are high and their vulnerability to illness and mortality are well recognised. The co-existence of multiple health needs impacts on the ability of generic services in primary and secondary care to effectively assess, identify and meet the range of needs. Health co-ordination and specialist assessment, interventions and support for primary and secondary care health services are essential.

Good practice – Life plans

Learning Disability Nurses at a unit for adults with profound and multiple learning disabilities have set up a unique Life Plan system for their residents, in line with recommendations within The Same As You? The Personal Life Plan document is carefully tailored to meet the needs of residents of the nursing home, and is based on a thorough assessment of health and social needs. It complements and supports the care philosophy, which is aimed at creating a centre of excellence in the provision of a needs-driven service for adults with profound and multiple learning disabilities.

chapter 9: Specialist locality health services

Factors predisposing people with learning disability to mental ill-health

Biological	Genetically determined factors linked to the underlying cause of the learning disability, termed <i>behavioural phenotypes</i> – Down's syndrome is the most common example. Strong association with mental ill-health and epilepsy and other neurological disorders.
Psychological	Adverse and traumatic experiences during early childhood which affect the development of personality, confidence and coping skills can all predispose to mental ill-health in adult life.
Social	Multiple life events, social disadvantage, isolation, poverty, lack of support, exploitation and abuse are known to impact on the development of mental ill-health.
Developmental	Communication difficulties and difficulties associated with progressing through developmental stages are associated with people with learning disabilities developing mental ill-health.

Mental ill-health

People with learning disabilities across all age-groups are more at risk of developing mental ill-health than the general population.³⁸⁻⁴¹ Thirty- forty two per cent of children require treatment for mental health problems, while as many as 40-50% of adults and 60% of older adults with learning disabilities may have a mental health problem, with higher than average levels of depression, psychoses and dementia.⁴²

There is a wide range of biological, psychological, developmental, social and developmental factors that are specifically associated with the development of mental ill-health in people with learning disabilities (see above).

These risk factors exist in addition to those that affect the general population. Many go undiagnosed, as particular skills are required to recognise and treat mental ill health in the learning disability population. Diagnostic overshadowing, where important health needs are dismissed as being a part of the learning disability, can be avoided by appropriate joint working among family carers, care workers and specialist health services.

Challenging behaviour

It is important to distinguish between challenging behaviour and offending behaviour, while recognising that there may

be a relationship between the two. Challenging behaviours are described as those behaviours that are very challenging to services and those who care for them. The challenging behaviours can be excessively disruptive and aggressive, persisting over time, and may become so severe that they cause major problems for individuals, families, communities and services. Estimates suggest that forty per cent of children with learning disabilities will display challenging behaviour, and that some will not simply 'grow out' of the behaviour, emphasising the need for appropriate early interventions.⁴³

Challenging behaviour can persist into older age.⁴⁴ Studies indicate that as many as 38% of people with learning disabilities will have some degree of challenging behaviour, perhaps as a result of mental ill-health. Differentiating challenging behaviours due to environmental factors from behaviours that are symptoms of mental ill-health requires specialist education and experience. Challenging behaviour is more likely in those with severe learning disability, those with certain syndromes and conditions, and where there is a deficit in social and communication skills and sensory impairment.

It is estimated that about six per cent of people with learning disabilities will show severe challenging behaviour. In a



general population of 100,000, 20 people will have severe challenging behaviour.⁴⁵ A small number of people with challenging behaviour display the behaviour constantly rather than intermittently and require specialist services and support from time to time.

Offending behaviour

An estimated 11 per cent of people in Scottish prisons have an IQ of less than 80, with offending behaviour more likely to be identified in people with a mild learning disability.⁴⁶ Further estimates suggest that between 5–9 per cent of people taken into police custody have received learning disability services.

There are children with learning disabilities being cared for in residential accommodation as a result of offending behaviour. It is important to ensure that their everyday and special health needs are appropriately addressed. This also applies to people with learning disabilities in prisons.

Small numbers of people with learning disabilities who commit offences are at high risk of re-offending. A quarter of the patient population in the State Hospital, Carstairs have a learning disability, while others are detained under the Mental Health and Criminal Procedure Acts in a variety of hospitals.

The Scottish Executive has recently commissioned further research into this area, following a recommendation in *The Same as You?*

Older age and learning disabilities

The increase in lifespan among people with learning disabilities is proportionately greater than in the general population, meaning that people with severe and profound learning disabilities and complex health needs are now living into old age.^{47 48}

Adding Life to Years, the report of the expert group on the healthcare needs of older people recognises the important health issues that affect older people.⁴⁹ The needs of older people with learning disabilities should not be viewed as being distinct from those of other older people. Where older people with learning disabilities are identified as having

complex health needs in addition to their older age health needs, however, the principle of accessing specialist services for people with learning disabilities should be acknowledged. There needs to be links between old age health services and specialist learning disability teams to enable joint assessment and treatment where appropriate.

Further research needs to be undertaken into old age in people with learning disability. In the past, few survived into old age. The caring services therefore have limited experience of their needs.

Dementia

Dementia is found in around forty five per cent of people with Down syndrome who are over 55, in comparison with five per cent of the general population over 65.^{50 51} The prevalence is also higher in people with learning disabilities who do not have Down syndrome, occurring at four times the rate for the age-matched general population.⁵²

Early detection is important to exclude potentially correctable causes of dementia, and access to specialist assessment and pharmacotherapeutic treatments to minimise the progression of the dementia is vital. Specialist nurses have important roles to play in assessing dementia, optimising health, monitoring treatments and providing interventions.

Autistic spectrum disorder and Asperger's syndrome

Autism is a developmental disorder that affects language skills, the ability to relate to others and the capacity to cope with change. It also carries a tendency to ritualistic and repetitive behaviours. The disorder can usually be identified by the third year of life, affects males more commonly than females, and is commonly associated with learning disability.

It is a lifelong disorder that results in severe impairment with many complex needs, such as epilepsy and underlying neurological disorders. Identification and diagnosis can be difficult. The recent Autistic Spectrum Disorder Needs Assessment Report estimates that 60 per 10,000 children have Autistic Spectrum Disorders.⁵³ There is no epidemiological information available on adults.

chapter 9: Specialist locality health services

An autistic type of social impairment affects people with Asperger's syndrome, with intelligence falling in the normal range. Difficulties experienced range from problems with social interaction, possible motor delay and restricted behaviours, interests and activities. The prevalence rate is estimated to be 36 per 10,000 children.⁵⁴ The needs of people with Asperger's syndrome are often not met in mainstream services and specialist services for people with learning disabilities may receive referrals.

Specialist services for people with complex needs

People with learning disabilities are living longer as they benefit from advances and developments in health technology. As a result, there are now more older people with learning disabilities in Scotland than ever before. This in turn impacts upon the number of people with learning disabilities who present with complex health care needs.

As the level of learning disability becomes more severe, so does the likelihood of increasingly complex health needs, and the role of specialists in learning disabilities, including nurses, becomes even more crucial. As complex needs tend to be addressed on an ongoing rather than occasional or episodic basis, specialist nursing interventions may need to be provided within people's normal daily environments. This includes local authority or voluntary sector facilities such as schools, day service and short break provision settings.

Nurses provide education and support for people with learning disabilities, their families and care workers. They use their knowledge of health and social care systems to liaise and co-ordinate care for those with the most challenging and complex needs. Health problems can result in those with the most complex needs being excluded from access to care and opportunities available to others. The knowledge, skills and experience of nurses working as part of specialist teams to assessment, planning care, delivering treatments and health interventions is important for people with learning disabilities with complex needs. By developing nurses to effectively deliver care and support to people with complex needs, health will be improved.

While some of the relevant nursing skills necessary to support people with complex needs may be transferable to social care and education staff, others require underpinning nursing knowledge, clinical judgement and experience. Placements of nursing staff to work alongside education or social care staff complement the principles of multidisciplinary working and help to ensure those comprehensive needs assessments are conducted.

Recommendation 8

NHS Boards should ensure there are specialist health services in place to respond appropriately to people with learning disabilities who have complex health needs. Learning Disability Nurses should contribute to the development and implementation of the Single Shared Assessment for people with learning disabilities, recognising their skills to assess, identify and respond to needs and support mainstream services.

Recommendation 9

All people with learning disability who have complex health care needs, wherever they live, should have a named Children's or Learning Disability Nurse as a member of a specialist team to liaise, co-ordinate and link with all Tiers of health care and other care systems. Integral to this aspect of the role is co-ordination of care, assessment and planning care, providing therapeutic interventions, advocacy, monitoring health and enabling improvement to promote social inclusion and address health inequalities.

The implications of complex needs for individuals and families

Some people with learning disabilities may present particular problems for their family and care workers as they may injure themselves, become aggressive or destructive or display significant socially unacceptable behaviour. Others require an extraordinary amount of additional support and services to help them cope with the consequences of an unusual syndrome or a rare condition.



A particular problem such as epilepsy, a disruptive or disordered sleep pattern, difficulties with eating and drinking or poor physical and mental health may mean that some people with complex health needs require additional health care and support, often for extended periods in their lives.

Family carers, care workers, health, social and education professionals are the major contributors to the care and support of people with learning disabilities. Family carers have their own care needs. Many will spend a lifetime of caring which, among other things, can have a damaging effect on their long-term health. They tend to develop more health problems than the general population, most noticeably depression in women and cardiovascular problems in men. Back problems are particularly prevalent in family carers of people with significant physical disabilities, and stress-related illnesses are common. Exclusion from or lack of availability of services can cause additional strains.

Understandably, most family carers place the needs of the person they care for above everything else, including their own health and wellbeing. Long-term effective support for family carers is crucial to ensure that their own health needs are recognised. Family carers in particular expressed the view in the Reference Groups that qualified nurses should be responsible for providing, monitoring and evaluating nursing and health care for adults with profound and multiple learning disabilities, whether in the person's own home or other setting such as respite or day care.

Nurses are in an important position to provide advice and support. When family carers are stressed and in need of additional support, it is frequently nurses who are the first point of contact. The relationship nurses have with family carers is often established and maintained over many years, and is built on trust and respect. Their health knowledge, assessment skills and clinical experience can be helpful in identifying situations where additional support is necessary. Nurses are also in a position to advise on welfare benefits, make referrals to other agencies and arrange for formal Carers Assessments to be undertaken by the Social Work Department. Nursing has a significant contribution to make in supporting family carers and promoting their health and ability to care for as long as they wish.

Recommendation 10

People with learning disabilities, their family and care workers require additional support, information, advice and guidance to utilise mainstream services. NHS Boards should ensure there are effective communication and referral pathways between health care professionals, including nurses, working across health and other services to ensure service users and carers are involved in the planning and delivery of care.

Recommendation 11

NHS Boards and Local Authorities should ensure that Children's and Learning Disability Nurses are available to plan, co-ordinate care and provide practical 'hands-on' nursing care and support across the full range of settings where children and adults with complex health needs receive care. The need for some may be life-long. Nursing support packages should focus on practical home-based support, which may include short breaks and respite for family carers on the basis of assessed need, on a regular basis, for agreed hours during the day and/or overnight. The service should also provide nursing support to families in the event of a crisis such as carer illness to prevent the hospitalisation of the person with complex needs.

The Key Messages

- ➔ **Specialist services, including health, must be in place across the complex needs groups**
- ➔ **Specialist health services have a vital role to play in working with those with the most complex needs**
- ➔ **Nurses should be core members of specialist teams**
- ➔ **People with learning disabilities, their families and care workers need practical care, advice and support when caring for those with complex needs**



Tier 4

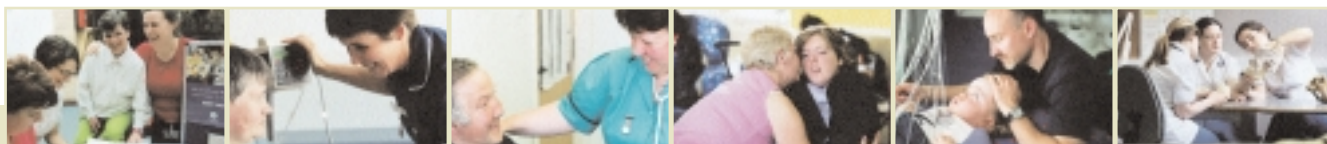
These are specialist area and regional health services. They might be highly special assessment and treatment in-patient units, or area-wide specialist Additional Support Teams for people with complex challenging needs, or forensic services for people with learning disabilities. They may be in-patient as well as in-reach models of care.

Services at this tier are particularly significant for children and adults with complex health needs, their families and care workers. *The Same as You?* recognises that for many with the most complex health needs, the need for care will be life-long. For those with profound and multiple learning disabilities, this might mean complex packages of care provided within the home and day care or employment setting, and identifying and including those with the relevant skills and knowledge to assess and provide care. Children's and Learning Disability Nurses are well placed to provide these services, and have the skills to develop their role within the *Joint Future* context. Their knowledge and experience of working with people with the most challenging and complex needs will be invaluable.

Meeting mental health needs

Some people with complex health needs require specialist mental health assessment, treatment and interventions. Recommendation 23 in *The Same as You?* highlights the need for services to adopt the Care Programme Approach for all people with complex needs – including those with mental health needs. Nurses working with all complex needs groups must develop and strengthen assessments and care planning in order to contribute effectively.

Adults with learning disabilities have access to a range of relatively well-developed mental health services. Throughout the National Nursing Review it became clear, however, that this is not necessarily the case for children. Family carers and professionals highlighted the difficulties in obtaining assessment and treatment for children in the areas of mental health and challenging behaviour. The



Public Health Institute of Scotland, are undertaking a Needs Assessment of Child and Adolescent Mental Health and are reviewing this issue and will include children with learning disabilities and mental ill health.⁵⁵ The Interim Needs report, published in June 2002 by the Public Health Institute, acknowledges that children with learning disabilities have historically been poorly served.

Good practice – awareness of the Mental Health Act

Learning Disability Nurses in Fife are promoting knowledge among their colleagues of the Mental Health (Scotland) Act. Working in partnership with a consultant psychiatrist and mental health officer, the group of nurses developed an information guide and a rolling programme of training for all nursing staff working within Fife Learning Disability Service. They soon discovered that focusing exclusively on the 1984 Act was inadequate, and that training and guidance on other key pieces of legislation – such as the Criminal Procedures (Scotland) Act – was also necessary. They also recognised that the leaflet given to patients explaining their detention and their rights under the Mental Health Act was difficult for people with learning disabilities to understand. A working group of nurses and a speech and language therapist was consequently set up to devise a booklet which contains the same information as the original leaflet, but in simpler written and symbol form.

The Same as You? recommends that four assessment and treatment beds per 100,000 population be provided by NHS Boards. Additionally, there will be a service to those with forensic mental health needs. Additional support team models have been developed in some areas across Scotland. As there is limited data to inform the development and commissioning of health services for people with learning disabilities, additional services, either on an in-patient or in-reach basis may need to be developed in the future for those with the most complex of needs. Nurses will be central in working in partnership with health professionals and others.

Significant changes are being brought about by the implementation of the Adults with Incapacity (Scotland) Act. It is important that *all* nurses, irrespective of their area of clinical practice, have an understanding of the importance of the Act, in particular the management of finances, medical treatment and research, intervention and guardianship orders. Nurses will have an important contribution to make in the assessment of capacity and in facilitating people's wishes. There are also implications for record keeping in nursing practice. It is important to stress that although an individual may lack the legal capacity to make major life decisions this does not mean that he or she is unable to make choices or indicate preferences, and opportunities for self determination should always be maximised.

Nurses with specialist knowledge and expertise in learning disabilities will have an important role in supporting and educating other nurses and professionals in primary and secondary health services to assess capacity and may need to contribute to the assessment of capacity.

chapter 10: Specialist area and regional health services

Autistic spectrum disorder

The Scottish Executive commissioned the Public Health Institute of Scotland to undertake Health Needs Assessment Reports into Autistic Spectrum Disorder (published March 2002) and Child and Adolescent Mental Health (due to be published Autumn 2002).

The autistic spectrum report recognised the important role of health services in early diagnosis and the need for support and information for families. Education for health care professionals is a priority, with opportunities for multiprofessional learning. A range of nurses – public health, children's and learning disability nurses – have a role to play in supporting families and other services from diagnosis and providing essential support through to specific therapy.

Recommendation 12

NHS Boards should ensure that access to specialist multidisciplinary services is available for children and adults with learning disabilities who have the most complex and challenging needs. Children's and Learning Disability Nurses have a distinct contribution to make and must be at the core of specialist teams (such as Paediatric child development centres, Forensic Teams, specialist assessment and treatment units, Mental Health and Challenging Behaviour teams).

Appropriate Adult services

As part of the move to ensure fairness and equity within the justice system, Appropriate Adults schemes have been developed across Scotland. The Schemes focus on the need for people who are thought to have a mental disorder or learning disability to have appropriate representation when facing police investigation and subsequent proceedings.⁵⁶ They are based on an understanding that while some people with learning disabilities may commit crimes, they are more likely to be the victims rather than the perpetrators. Learning Disability Nurses not only act as Appropriate Adults for people with learning disabilities, but also participate in the development of joint training initiatives with colleagues in social work and police departments.

Good practice – Appropriate Adult Scheme

The Fife Appropriate Adult Project has set the benchmark for provision of services to clients with a mental disorder or learning disability who are facing police investigation and subsequent proceedings. The Project, which uses an inter-agency approach involving Community Learning Disability Nurses from the Primary Care Trust, Social Work Department, Fife Constabulary and the Procurator Fiscal, has developed a model of practice, published guidelines, booklets, leaflets and training videos, and is currently developing accredited multi-agency training programmes. The Fife Appropriate Adult Model has been widely adopted throughout Scotland.

Meeting complex health needs

Those with the most complex needs require appropriate, tailored services for them and their families. Recommendations arising from the National Nursing Review aim to strengthen the links between primary and secondary care services and specialist Learning Disability Teams and should enable these services to be appropriately provided in the future.

Participants in the National Nursing Review frequently expressed concerns about the disparity in the delivery of care between health services for children and adults with learning disabilities. Within children's health services, direct nursing care is often provided or directly supervised by qualified Children's or Learning Disability Nurses. Within adult services, the trend is for qualified nurses to teach specific skills to support workers from a range of backgrounds. This is appropriate for some people with learning disabilities, but not all.

Nurses have flexible skills that can be used in a range of settings where people with learning disabilities who have complex needs receive care. The portability of their skills allows for and supports models of care that effectively utilise the nursing resource. This might mean direct nursing care being provided by appropriately qualified nurses, or care workers providing care under their supervision. A number of jointly commissioned services between health and local authorities exist and could be developed in other areas.



Good practice – challenging behaviour

A Borders-based secondment scheme is meeting the needs of people with learning disabilities who have challenging behaviours. Two Learning Disabilities Nurses have been working full-time on secondment within a social care project supporting residents with challenging behaviours. The nurses, working with care workers, are supporting the use of non-aversive approaches to managing challenging behaviours and are ensuring care plans are in place to meet people's needs. The nurses promote residents' health and facilitate access to primary and secondary care, and act as educators and role models for care workers. As an example of the success of the project, one of the residents who previously required hospital admission due to uncontrolled challenging behaviours has not needed crisis intervention since the secondments began.

In the area of treatment, *The Same as You?* recognises the need to ensure that appropriate therapies and interventions, such as Cognitive Behaviour Therapy, are available. Nurses are well placed to provide such therapies and those working within this Tier will need to demonstrate a high level of clinical skills. Post registration education opportunities need to be enhanced to support this.

Recommendation 13

NHS Boards with their partners should develop models of health care, based on evidence, that meet the needs of children and adults with learning disabilities to avoid unnecessary in-patient episodes. Learning Disability Nurses have transferable skills and where there is clinical need, a mix of nurses from learning disabilities, paediatrics and mental health should be developed across a range of settings where children and adults with the most complex needs access in-patient care, day care, short breaks, education, employment and leisure opportunities.

The Key Messages

- ➔ **Specialist services need to be in place for the small yet significant number of people with learning disabilities on an area or region-wide basis**
- ➔ **Nurses have skills that should be utilised in different settings to support people with learning disabilities in the least restrictive way**



Working across all the Tiers

Education and development are issues that run through all the Tiers and include the Common Foundation Programme, Branch programmes and continuing practice development.

All student nurses are required to receive a 'taste and flavour' of learning disabilities within the Common Foundation Programme. But the interpretation of 'taste and flavour' differs from programme to programme across Scotland, and the need to ensure consistency was highlighted frequently throughout the National Nursing Review.

Through discussions at the focus groups and with services users, families and care workers, it was recognised that there is an urgent need to improve and develop the understanding of all nurses and midwives on the needs of people with learning disabilities. A clear message that all nurses and midwives have a responsibility to meet the health needs of children and adults with learning disabilities emerged from the consultation, although it was acknowledged that it is not possible for all to develop the full range of skills and experience necessary.

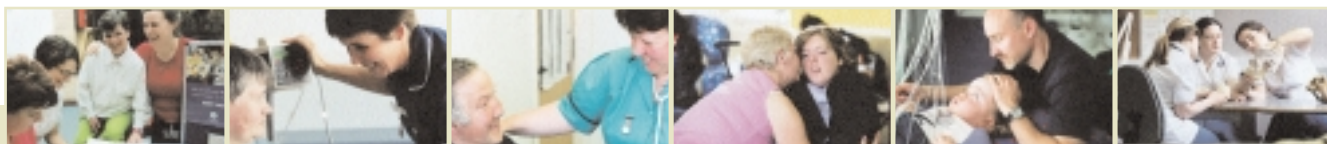
The Scottish Consortium for Learning Disability was established as a result of recommendation 6 of *The Same as You?*, to support the implementation of policy through training, information, research and public education. The Scottish Consortium is therefore in an excellent position to

work collaboratively with Higher Education Institutions and NHS Education for Scotland and others to support the development of a range of education programmes for all health staff, including nurses from all groups. Their involvement will assist with the review and development of education programmes to ensure that they reflect the needs of people with learning disabilities and are sufficiently robust to produce practitioners fit for practice.

NHS Education for Scotland (NES)

This new Special Health Board was formally launched on 1 April 2002, combining the Scottish Council for Postgraduate Medical and Dental Education (SCPMDE), the Post Qualification Board for Health Service Pharmacists in Scotland (PQEB) and the National Board for Nursing, Midwifery and Health Visiting for Scotland (NBS).

The function of NES is to promote multidisciplinary working and learning and educational research and development. It brings together Scottish Executive policies outlined in *Our National Health: A plan for action, a plan for change* to ensure that health professionals are appropriately trained and adopt a culture that includes lifelong learning.



Planning the workforce

NHSScotland needs the right number of nurses with the right competencies, right experiences, right skills, and in the right locations to deliver high quality care. However, the *total number of nurses* is not in itself a guide to quality and efficiency. Much depends on the way nurses are educated, utilised, supported and developed as a skilled resource. Quality services require effective use of the nursing workforce and, in many circumstances, the pursuit of quality will bring changes and extensions to traditional nursing roles and the breaking down of professional barriers.

As part of the ongoing commitment to improve the health of the people of Scotland, the Minister for Health and Community Care hosted a Nursing Convention in November 2001. The Convention had a clear focus on seeking solutions to a range of issues affecting the recruitment and retention of the workforce in Scotland now and in the future. As part of the drive to ensure the availability of a skilled workforce, Regional Workforce Centres are to be established by the Scottish Executive.⁵⁷ The Regional Workforce Centres will assume responsibility for planning to ensure that recruitment reflects local need. Planning the nursing and midwifery workforce, including student nurses, will be an important aspect of their role.

An action plan – *Facing the Future* – was developed from the Convention, focusing on:⁵⁸

- ⊕ careers
- ⊕ flexibility
- ⊕ leadership
- ⊕ education and training
- ⊕ new roles
- ⊕ working conditions and the tools for the job
- ⊕ employment packages
- ⊕ research and evaluation.

The Minister established the Facing the Future Group, supported by the Chief Nursing Officer and the Health Department Director of Human Resources, to take forward the outcomes of the Convention.

Recommendation 14

NHS Boards should identify opportunities for the development clinical leaders, including Nurse Consultants in Learning Disabilities, to develop champions to promote evidence-based practice, as outlined in Facing the Future.

Recommendation 15

The Regional Workforce Centres should take account of the need to identify the local nursing requirements in light of the recommendations of the National Nursing Review, to ensure there are skilled nurses available to meet the needs of people with learning disabilities.

Pre-registration education

Despite the fact that the health service spends around £2.5 billion on all areas of education and development of health professionals, there are concerns about the current UK model of pre-registration nurse preparation.

In 1999, the UKCC's Commission for Nursing and Midwifery Education published *Fitness for Practice*.⁵⁹ The purpose of the review was to ensure that pre-registration nursing and midwifery education produced practitioners fit for practice, based on health and social care need.

Changes were introduced to the pre-registration nursing programmes as a result of the report. Longer-term work was identified in other areas, with perhaps the most significant being a review of the current model of four branches of nursing. The UKCC published *Fitness for Practice and Purpose* in 2001 and set out six possible models for future pre-registration preparation in the United Kingdom.⁶⁰

chapter 11 Working across all the Tiers: Education and development

1. retaining the current branch structure with practice experience divided equally between hospital and community;
2. integrating the four current branches with social care;
3. extending to six branches of nursing, including new separate branches for care of older people and community nursing;
4. reducing to two branches of nursing – child and adult;
5. reducing to two branches of nursing – hospital and community; and
6. enabling all entrants to register as generalist nurses, with specialisation following registration.

The Nursing and Midwifery Council has responsibility for taking forward the recommendations contained within *Fitness for Practice and Purpose*, and the National Nursing Review can help to stimulate discussions that inform the wider debate.

The Scottish Executive contract funds pre-registration programmes for up to four years. This creates the opportunity to develop a range of options on the possible range of qualifications that could be developed at pre-registration level. A number of options in relation to the shape of the pre-registration learning disability programme have been identified and considered as part of the National Nursing Review:

Option 1 – Three year programme leading to diploma or degree and registered nurse [Learning Disabilities] qualification

Option 2 – Three or four year programme leading to a first degree and registered nurse [Learning Disabilities] + social work qualification

Option 3 – Four year programme leading to a diploma or degree + registered nurse [Learning Disabilities] + a second registered nurse qualification [adult, mental health or children's]

Option 4 – Three-year programme leading to a diploma or degree + registered nurse [Learning Disabilities] qualification by distance learning

Option 5 – Higher National Certificate in Health Care completed flexibly at a further education college, followed by a two-year learning disability branch programme delivered by a range of distance learning options.

By developing a range of options for Scotland, nurses working with people with learning disabilities can lead the way and help identify possible models that could have relevance to other branches of nursing.



Increasing access

Difficulties are experienced in some areas in recruiting learning disability trained nurses to enable services to develop. On the branch programme, learning disabilities is one of the less popular options and in some areas there is a short fall in recruitment. In part this may be attributed to the location and model of course delivery – the course is currently provided by four, largely centrally based, universities – which is thought to dissuade potential entrants who might otherwise opt for the branch.

The focus groups suggested that recruitment could be improved by developing a delivery model that promotes open learning from learning centres based within Higher Education Institutions across Scotland. A “Centre of Excellence” could be developed to lead the development of the core branch material, which could then be delivered locally via learning centres situated within existing Departments of Nursing.

A network of lecturer/practitioners could be developed to support students and existing lecturers to deliver course material locally. Such an approach creates the opportunity to fully utilise local options to promote staff development and career options, encourages flexibility and addresses workforce planning needs. The approval of the Higher National Certificate in Health Care to provide exemption from the Common Foundation Programme creates the potential for further local flexibility.

The contribution of people with learning disabilities and family carers

All nurses and midwives have much to learn from people with learning disabilities, who have a wealth of knowledge and experience that can be shared. The need to develop the capacity of people with learning disabilities and family carers to participate in the planning and delivery of nurse education programmes was raised at the National Nursing Review Consensus Conference.

People with learning disabilities can be employed by Higher Education Institutions as Associate Lecturers and can participate in the delivery of programme material and the assessment of students. They can work alongside lecturers in nursing skills laboratories to provide students with a positive experience, as well as learn and develop a range of nursing skills.

Recommendation 16

The Scottish Executive will invite NHS Education for Scotland in collaboration with the Scottish Consortium for Learning Disability and other key stakeholders to establish a multiagency working group to develop core material to address the needs of people with learning disabilities for incorporation within the pre-registration nursing Common Foundation Programme. These developments should incorporate the development of a network of people with learning disabilities and family carers to act as trainers and educators within nurse education programmes.

It will therefore be necessary, in light of the deliberations arising from *Fitness for Practice and Purpose* and until the model of nurse education across the United Kingdom is determined, to develop a sustainable learning disability nursing branch programme across Scotland. This will ensure that a part of the nursing workforce is prepared for working with children and adults with learning disabilities, and that students continue to be recruited. The refocusing of both the Children’s and Learning Disability Nursing branch programmes will contribute to ensuring all people with learning disabilities have the opportunity to receive the very best health care in the future.

chapter 11 Working across all the Tiers: Education and development

Recommendation 17

The Scottish Executive will invite NHS Education for Scotland to review immediately the existing pre-registration Children's and Learning Disability branch programmes in light of the recommendations of the National Nursing Review, to ensure that nurses in training are fit for practice.

Recommendation 18

The Scottish Executive will review the contractual arrangements and consult with provider universities to determine the most effective model of delivery of the Learning Disability Nursing branch programme to enable a Scotland-wide focus to meet local workforce needs. The Chief Nursing Officer will establish a working group of key stakeholders to take this forward immediately.

Post-registration education and continuing professional development

Nurses and midwives have a mandatory requirement to keep themselves professionally updated to maintain their professional registration. In addition, nurses and midwives in NHSScotland are encouraged to develop their professional skills and knowledge and endorse the culture of lifelong learning through *Learning Together*, the Scottish Executive's strategy for lifelong learning for all staff. Under the provisions of this strategy, employers must make education and training opportunities available to all staff, and each employee must have a personal development plan.⁶¹

A key issue that has arisen as part of the National Nursing Review is the need to ensure that all nurses and midwives, wherever their area or place of practice, receive education on antidiscrimination, the Right to care, Adults with Incapacity and points of access to specialist services and advice. This needs to be part of their core nurse induction and ongoing practice development programmes. Links between nursing groups and networks offer the opportunity to share best practice and information that promotes the need to recognise and include children and adults with learning disabilities in mainstream health and other services.

Recommendation 19

Directors of Nursing should utilise the knowledge and skills of Learning Disability Nurses to ensure that an awareness of learning disabilities is included in all nurse induction and continuing development programmes.

Opportunities exist for nurses and midwives to undertake further education beyond initial pre-registration programmes, to enable them to practice at a higher level. Higher Education Institutions offer a range of Specialist Practitioner Qualifications (SPQs) and other courses across Scotland within their higher award frameworks, or as independent stand-alone courses. In addition, a number of Higher Education Institutions such as Strathclyde University and St. Andrew's University offer courses on specific issues affecting people with learning disabilities. In addition to these opportunities, many nurses take further academic study at first degree, post-graduate and doctorate level.

A framework of approved SPQs has been developed, which includes two specifically in the area of learning disabilities – a Specialist Community Learning Disability Nursing award and a Specialist Forensic Nursing award. It is also possible for all first-level registered nurses to train as Public Health Nurses, but this is not currently a common option for learning disability nurses. With the developments resulting from *Nursing for Health*, it is timely and appropriate for some learning disability nurses to develop their role and adopt a public health nursing approach.

A number of methods are used to deliver SPQ courses, including open and distance learning. A framework that supports open and distance learning was supported by nurses who attended the focus groups, as geographical constraints were seen to prevent nurses in some areas from accessing post registration education opportunities.



Recommendation 20

The Scottish Executive will invite NHS Education for Scotland to enhance and develop the Specialist Practitioner Qualification framework available for all nurses in the area of complex health needs of children and adults with learning disabilities.

An enhanced SPQ framework of learning disabilities courses and qualifications should be developed across Scotland. The framework needs to be delivered using flexible routes that enable nurses from all parts of Scotland to obtain access.

The Key Messages

- ⊕ **All nurses, midwives, health care support workers and students need to develop their knowledge around the needs of people with learning disabilities**
- ⊕ **Models of delivering the branch programme need to be reviewed**
- ⊕ **Continuing practice development opportunities in the complex needs areas must be developed as a priority**



Working across all the Tiers

Services for people with learning disabilities need to be monitored and reviewed to ensure a high standard of care is provided and services developed. Research initiatives and evidence-based practice are required to improve and inform service developments, treatment and care.

Quality and standards are important issues that cut across all tiers identified in the National Nursing Review. Clinical governance is the accountability for clinical performance. It incorporates a range of issues that seek to improve standards of care and outcomes locally and throughout the NHSScotland. Key among these are:

- ⊕ Improving standards of care by monitoring the implementation of national care standards
- ⊕ Nursing research activity in the area of learning disabilities to promote the development of evidence based practice.
- ⊕ The on-going development of nursing practice through life long learning and continuing practice development to ensure that all nurses are equipped with the skills necessary to provide high quality care.
- ⊕ Clinical Audit to evaluate care and improve standards.
- ⊕ Risk Assessment.

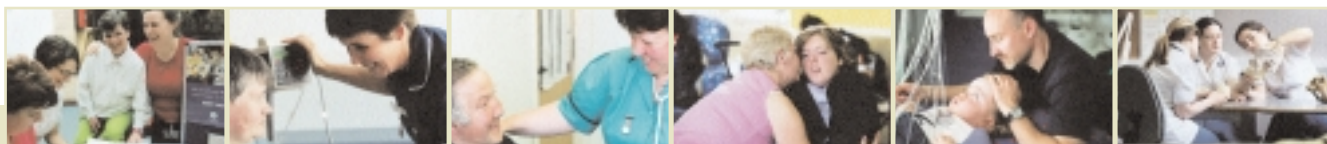
Regulation, standards, quality and monitoring

The National Care Standards Committee (NCSC) was set up in 1999 to develop draft national standards for the new Scottish Commission for the Regulation of Care.⁶²

The standards make explicit what each individual can expect from a service provider and have been developed in collaboration with users, carers, staff, professional organisations, independent service providers and regulators of health and social care.

Specific National Care Standards relating to care homes for people with learning disabilities have been developed.⁶³

Increasingly, people with learning disabilities are being cared for in Registered Care Homes (which now incorporate those establishments previously listed as Registered Nursing Homes). The contributions of nurses working in Registered Care Homes will impact upon the quality of care people with learning disabilities will receive. Nurses are also important and integral members of teams responsible for the inspection and monitoring of Registered Care



Homes, and have the vital role of maintaining and promoting standards and quality.

Links should be developed between primary care and learning disability teams to ensure that the full range of health and nursing needs of people with learning disabilities in care homes are assessed and appropriate care planned. Continuing practice development programmes within Registered Care Homes need to take account of the health needs of people with learning disabilities.

Quality and Standards

A Quality and Standards Board for Health in Scotland (QSBS) is shortly to be established by the Scottish Executive. A consultation paper, (Scottish Executive (March 2002) *A Quality and Standards Board for Health in Scotland*) outlined proposals for improving the quality of healthcare in Scotland through the creation of a single NHS body with responsibility for clinical standards and clinical governance at a national level. The QSBS will be charged with the development of a national strategy for improving the quality of patient care and with co-ordinating the work of the Scotland's clinical effectiveness organisations. The new Board will incorporate the current functions and work of Scottish Health Advisory Service (SHAS), the Clinical Standards Board for Scotland (CSBS), as well as taking over responsibility for work undertaken by other groups such as the Nursing and Midwifery Practice Development Unit (NMPDU).

- ⊕ *The Clinical Standards Board for Scotland* was established as a statutory body in April 1999 to ensure that NHSScotland delivers the highest possible standard of care. The key function of the CSBS is to promote public confidence in NHSScotland by driving forward quality and improving standards. A process of accreditation, based on a system of external peer review, is used to evaluate performance of NHS service providers. Written standards, designed to assess the quality of an activity, service or organisation, guide the process.
- ⊕ *The Scottish Health Advisory Service (SHAS)* was established as an independent body in 1970 and has authority to carry out mandatory visits to establishments

to review the quality of services for people with learning or physical disabilities, people with mental illness and frail older people. SHAS has developed quality indicators for evaluating community and in-patient health services for people with learning disabilities and the other care groups. As services change and develop in line with policy, it will be important to consider the ongoing nursing contribution to meeting these standards.

- ⊕ The *Nursing and Midwifery Practice Development Unit (NMPDU)* was developed to ensure there is an inclusive approach to work-based projects, which are designed to review and lead improvements in clinical practice. This had brought about many benefits in areas of shared nursing practice and facilitated learning and practice development.

Recommendation 21

The monitoring of standards and care undertaken by the Scottish Health Advisory Service within the Quality and Standards Board of Scotland should take account of the outcomes of this National Nursing Review to enhance and improve care in the future.

Recommendation 22

The Nursing and Midwifery Practice Development Unit will support nurses to develop an awareness of integrated health care pathways and identify the range of nursing contributions required to improve health and wellbeing.

Research

Our National Health: A plan for action, a plan for change places high priority on the need for service improvement underpinned by evidence based practice. *Caring for Scotland: The Strategy for Nursing and Midwifery* sets out the rationale and importance of a sound research base for nursing and midwifery practice. Central to this is the capacity of nurses and midwives to undertake research appropriate to their level, knowledge and experience.

In June 2001, the Chief Nursing Officer established a working group to develop a research and development strategy for nursing and midwifery in Scotland. The Strategy will underpin evidence-based practice in the future and inform service development, and will be launched in Autumn 2002.

A number of mechanisms and opportunities support research development and activity in NHSScotland at national and local levels. Nurses and midwives have access to a range of organisations that provide support and funding to enable research activity within the health services, including:

➤ **Chief Scientist Office (CSO)**

As part of the Scottish Executive Health Department, the CSO encourages and supports health-related research to improve the health of the people of Scotland and the services provided by NHSScotland. The CSO published the Research Strategy for the National Health Service in Scotland in 1998.

➤ **Scottish Higher Education Funding Council (SHEFC)**

The main strand of the Scottish Executive's support for research in the Higher Education Institutions is through the Scottish Higher Education Funding Council (SHEFC). The Council supports research capacity in Scottish Higher Education Institutions by distributing selectively on the basis of quality of research in each institution as measured by the Research Assessment Exercise (RAE). SHEFC funding research infrastructures also underpins the investment in research projects by others, such as Research Councils, European Union, charities and the private sector. There is an on-going challenge for nursing and midwifery in getting into and being successful within the cycle of funding.

➤ **School of Primary Care**

The School of Primary Care was established in June 2000 to promote and develop evidence-based practice and decision making in primary care in Scotland and to increase research capacity. The School aims to provide the high quality research evidence needed to inform decisions made by service users, practitioners, managers and policy makers as a means to increase access to education and training in primary care research. Links could be developed with Primary Care

and Learning Disability Services to promote joint research initiatives.

➤ **The Nursing Research Initiative for Scotland (NRIS)**

The Nursing Research initiative is one of the seven core units funded by the Chief Scientist Office. The unit has a multiprofessional focus and comprises health researchers from Speech and Language Therapy, Psychology, Nursing and Midwifery, who undertake specific projects that will inform and enhance care.

These resources are available to nurses, but they have experienced difficulties in competing for funding and have lacked a well co-ordinated support system. The combination of a research-focus in pre-registration training and the framework for nursing research, which will appear in the Strategy, suggests that nurses will soon be in a stronger position to take advantage of the opportunities offered.

Within Scotland there is a need to develop the academic workforce to focus their attention on the opportunities to undertake research in the area of learning disabilities. This was highlighted frequently in the National Nursing Review. At present, Psychiatrists and Clinical Psychologists publish the main body of research in the area of learning disabilities. There is a need for nurses to work collaboratively with experienced researchers to develop their skills to undertake joint and independent research. The work of nurses caring and supporting people with learning disabilities is an area rich for research and nurses should take a lead in contributing to the development of the body of knowledge. An active research community that includes nurses and midwives will add to and enhance the quality of the lives of children and adults with learning disabilities.



Recommendation 23

The Nursing and Midwifery Practice Development Unit will work with nurses and midwives across Scotland to develop a network for and database of best practice of nurses working in the area of Learning Disability.

Recommendation 24

The Nursing and Midwifery Practice Development Unit will, in collaboration with Directors of Nursing, support the development and co-ordination of Trust-wide audits to identify the practice development, training needs and career pathways of all groups of nurses and inform workforce planning.

The Key Messages

- ⊕ **Nurses and midwives have an important part to play in improving quality of care and monitoring services**
- ⊕ **Best practice and clinical networks need to be developed to promote nursing practice and improve care**
- ⊕ **Nurses and midwives should be supported to develop their capacity to participate in research in the area of learning disabilities**

Context

The National Review has been undertaken to take account of and reflect the important changes and developments that are impacting significantly upon the lives of people with learning disabilities and their families. It is set within the current context of the need to promote and enable social inclusion and address fundamental health inequalities.

Background

People with learning disabilities frequently have complex health, social and education needs that require high levels of support. Failure to recognise and meet their needs often leads to their exclusion from services and facilities; it may also prevent them from gaining access to many recreational, educational and occupational opportunities, reinforcing their social isolation.

People with learning disabilities have health needs like the rest of the population. Some also have health needs as a result of their learning disabilities, while others have additional complex needs that may require specific interventions and support from specialist staff, including nurses. For a small but significant number of people with very complex needs, area and region-wide specialist services are necessary.

As the largest group of care providers in NHSScotland, nurses and midwives have a vital role in ensuring that people with learning disabilities have their health needs met and gain access to services.

All nurses and midwives – not just those who have chosen to specialise in caring for people with learning disabilities – have an important contribution to make, working in partnership with people with learning disabilities and their family carers across health, social and education systems and within the *Joint Future* context.

The contributions of Nurses and Midwives

The Review found many examples of practice developments involving nurses and midwives working in partnerships with nursing colleagues from specialist learning disability teams, primary care and acute care settings.

Much of the work, however, has been developed locally on an *ad hoc* basis and is not co-ordinated in a way that encourages sharing and wider implementation. In addition, significant deficiencies in current knowledge, practice and service provision were also identified.

Expectations of what can be delivered by nurses who are not specifically trained in the care of people with learning disabilities must be realistic. They have received no significant education on the health needs of people with learning disabilities, and tend to have little clinical experience in assessing, identifying and meeting their health needs.

It is nevertheless reasonable to expect that all nurses should have knowledge of where to access specialist nursing support, and that all nurses are able to demonstrate appropriate attitudes when caring for people with learning disabilities. Education programmes for all nursing students must reflect a positive value base, and the group of students who elect to specialise in caring and supporting people with learning disabilities must be seen as a valuable resource who are appropriately prepared for the challenges ahead.

Meeting needs through the Tiered model approach

The National Review considered the health needs of all children and adults with learning disabilities in the context of the Tiered Model of care. Five 'Tiers' (0-4) are set out in the model:

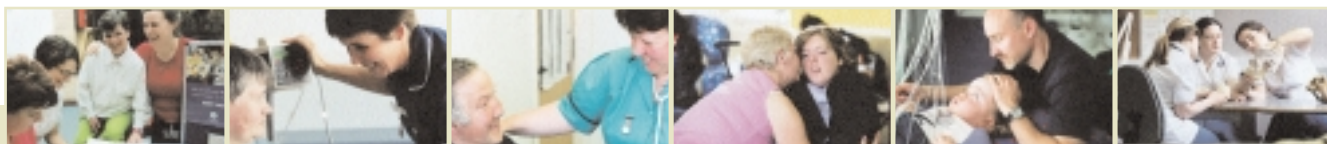
Tier 0 – Community, public health and strategic approaches to care

Tier 1 – Primary care and directly accessed health services

Tier 2 – Health services accessed via primary care

Tier 3 – Specialist locality health services

Tier 4 – Specialist area health services.



Community, public health and strategic approaches to care

A significant number of people with learning disabilities have health needs beyond those that can be met by primary care alone. Some require referral to specialist services. Services must recognise this and work in partnership to ensure that the assessment of needs is planned, co-ordinated and managed through the person's life course, in collaboration with people with learning disabilities, their families and care workers.

Families of children born with a learning disability or who fail to reach developmental milestones need additional help and support. Health professionals, particularly nurses, are well placed to contribute to this endeavour and are able to provide information, practical help and emotional support. Some people with learning disabilities may require additional support when becoming parents, and nurses and midwives have an important contribution to make to this.

There are concerns that the health care needs of young people with learning disabilities are not always considered, recognised or met. This is often the case for young people with learning disabilities at the time of transition between children's and adult services. Adult services may have had little experience of young people with learning disabilities, and often feel poorly prepared and equipped to meet their needs, particularly if complex.

The promotion of the health and wellbeing of older people, including those with learning disabilities, is a national priority. NHS Boards and social work departments must ensure that care staff have the appropriate support and training to meet the needs of older people with learning disabilities.

Nurses are often the key point of ongoing support for carers, and are in a position to assess, recognise and support them to sustain their ability to care and to help them plan for the future in partnership with other services.

The capacity of *all* nurses to contribute to the wider social inclusion and public health agenda affecting people with learning disabilities needs to be developed across Scotland.

This is an issue that must be addressed by NHS Boards and by nurses working as part of a wide range of teams, in both specialist and generic roles.

The Key Messages

- ➔ **Many people with learning disabilities have unrecognised and unmet health needs**
- ➔ **Services must be organised and delivered locally in response to sound evidence and assessed need**
- ➔ **The promotion of good health and wellbeing must be given greater priority at a strategic and local level**

Primary care and directly accessed health services

There is a general lack of data and information across Scotland about the range of health needs of people with learning disabilities at practice, LHCC and NHS Board levels.

The majority of general practices function on a largely reactive rather than proactive basis, relying upon people with learning disabilities or their carers to identify problems and actively seek a consultation – which assumes they have the knowledge necessary to recognise changes in health.

It is not possible for health care professionals working in primary care to develop all the skills necessary to work with all patient/client groups. They need support from, and access to, specialists in learning disabilities and other fields. Partnership working and collaboration between primary care and specialist health services is the key.

Preventative health care has not traditionally been a high priority area in learning disabilities services. This must change as the focus of health care shifts towards health promotion and disease prevention. Health professionals, including nurses, need to pay particular attention to preventative health care for people with complex needs. They must also ensure that the special needs of people with learning disabilities are considered within health promotion programmes.

The Key Messages

- ⊕ **All people with learning disabilities should be enabled and supported appropriately to access primary care-based health services**
- ⊕ **Improving the health of people with learning disabilities by health assessment, health education and health promotion must be a priority**
- ⊕ **Planning and practice must be needs based**
- ⊕ **Good health enables social inclusion**

Health services accessed through primary care

Some people with learning disabilities have additional health needs that are specifically associated with the underlying cause of their learning disabilities and differ according to the individual syndrome or genetic condition. Knowledge of these associations is important, both to prevent problems occurring and to improve detection of health needs at an early stage to enable appropriate treatments and management to be started.

As a result of the increased presence of these conditions, people with learning disabilities will often require investigation and treatment across a range of primary and secondary care health services. Many health professionals in primary and secondary care settings have limited experience and knowledge of these important issues. As a result, some people with learning disabilities have received inadequate care.

Children's and learning disability nurses should develop their roles to ensure that people with learning disabilities are supported appropriately to have their everyday health needs assessed and met, in collaboration with primary and secondary care colleagues.

The Key Messages

- ⊕ **Many people with learning disabilities have greater health needs than the general population**
- ⊕ **The assessment and treatment of health needs can be complex, requiring access to specialist skills**
- ⊕ **Partnership working needs to be developed with primary and secondary care and specialists in learning disabilities to support assessments of health needs, provide advice and co-ordinate care**

Locality health services

People with learning disabilities who have complex needs will often require additional services and support to those available from mainstream services, including primary and secondary health care.

The health care needs of people with profound and multiple learning disabilities are high and their vulnerability to illness and mortality well recognised. The co-existence of multiple health needs impacts on the ability of generic services in primary and secondary care to effectively assess, identify and meet the range of needs. Specialist assessment, interventions, co-ordination, monitoring and support for primary and secondary care health services are essential.

- ⊕ **People with learning disabilities across all age groups are more at risk of developing mental ill-health than the general population. Particular skills are required to recognise and treat mental ill health in the learning disability population.**
- ⊕ **Children with learning disabilities may display challenging behaviour that they will not 'grow out' of, emphasising the need for early intervention.**
- ⊕ **A range of nurses – public health, children's and learning disability – have a role to play in supporting families of children with autistic spectrum disorders and other services from diagnosis through to specific therapy and the provision of essential support.**



- ⊕ A small significant numbers of people with learning disabilities commit offences are at high risk of re-offending. Specialist support, assessment and treatment need to be available.
- ⊕ The needs of older people with learning disabilities should not be viewed as being distinct from those of other older people. There should be links between old age health services and specialist learning disability teams to enable joint assessment and treatment of older people with learning disabilities where appropriate.
- ⊕ Specialist nurses have important roles to play in assessing dementia in people with learning disabilities, optimising health, monitoring treatments and providing interventions.

Nurses provide education and support for people with learning disabilities, their families and carers. They use their knowledge of health and social care systems to liaise and co-ordinate care for those with the most challenging and complex needs. As complex needs tend to be addressed on an ongoing rather than occasional or episodic basis, specialist nursing interventions may need to be provided within people's normal daily environments. They understand that health problems in people with the most complex needs can result in them being excluded from access to the services and opportunities available to others. The knowledge, skills and experience of nurses, working as part of specialist teams in assessing and planning care, in delivering treatments and health interventions, enable them to improve health and consequently support social inclusion.

Nurses are in a key position to provide advice and support to family carers. Their health knowledge, assessment skills and clinical experience can be helpful in identifying situations where additional support is necessary. Nurses are also in a position to advise on welfare benefits, make referrals to other agencies and arrange for formal Carers Assessments to be undertaken by the Social Work Department.

The Key Messages

- ⊕ **Specialist services, including health, must be in place for people with complex needs**
- ⊕ **Specialist health services have a vital role to play in working with those who have the most complex needs**
- ⊕ **Nurses should be core members of specialist teams**
- ⊕ **People with learning disabilities, their families and carers need practical care, advice and support when caring for those with complex needs**

Specialist area and region health services

The Same as You? recognises that for many with the most complex health needs, the need for care will be life long. The range of services necessary to effectively support people with the most complex needs will be highly specialised and be provided on an area wide or regional basis. A variety of models are in place and new ones need to be developed that will meet needs in the future. Area and regional highly specialised assessment and treatment units, in-reach and out-reach teams are being developed to ensure that services and support are available for those with the most complex needs. For a small number, this will need to be in secure accommodation.

For those with profound and multiple learning disabilities, this might mean complex packages of care provided within the home and day care or employment settings, and identifying and including those with the relevant skills and knowledge to assess and provide care.

Carers and professionals highlighted to the Review the difficulties in obtaining assessment and treatment for children in the areas of mental health and challenging behaviour. This is not such a major issue in adult services where appropriate specialist units and teams are available. It is now recognised that the issue of children's services requires urgent attention.

People with learning disabilities with the most complex needs require appropriate, tailored services for them and their families. Recommendations arising from the National Review aim to strengthen the links between primary and secondary care services and specialist Learning Disability Teams and should enable these services to be appropriately provided in the future. This might mean direct nursing care being provided by appropriately qualified nurses, or health care support workers providing care under their supervision.

Children's and Learning Disability Nurses are well placed to provide these services, and have the skills to develop their role in care management within the *Joint Future* context. Their knowledge and experience of working with people with the most challenging and complex needs will be invaluable.

Nurses have flexible skills that can be used in a range of settings where people with learning disabilities who have complex needs receive care. The portability of their skills allows for and supports models of care that effectively utilise the nursing resource. A number of jointly commissioned services between health and local authorities exist and could be developed in other areas. In the area of treatment, *The Same as You?* recognises the need to ensure that appropriate therapies and interventions, such as Cognitive Behaviour Therapy, are available. With higher level education, nurses are well placed to provide such therapies. Post registration education opportunities need to be enhanced to support this.

The Key Messages

- ⊕ **Specialist services need to be in place on an area or region-wide basis for a small, but significant, number of people with learning disabilities**
- ⊕ **Nurses have skills that should be utilised in different settings to support people with learning disabilities in the least restrictive way**

The education of all nurses and midwives

Nurses, other professionals, service-users, families and carers have highlighted an urgent need to improve and develop the understanding of all nurses and midwives on the needs of people with learning disabilities.

Quality services require effective use of the nursing workforce and, in many circumstances, the pursuit of quality will bring changes and extensions to traditional nursing roles and the breaking down of professional barriers. As part of the drive to ensure the availability of a skilled workforce, Workforce Development Centres are to be established by the Scottish Executive. The Workforce Development Centres will assume responsibility for planning to ensure that recruitment reflects local need. Planning the nursing and midwifery workforce, including student nurses, will be an important aspect of their role.

A number of options in relation to the shape of the pre-registration learning disability programme have been identified and considered as part of the National Review. By developing a range of options for Scotland, nurses working with people with learning disabilities can lead the way and help identify possible models that could have relevance to other branches of nursing.

Until decisions on the model of nurse education to be used across the United Kingdom in the light of *Fitness for Practice and Purpose* are made by the Nursing and Midwifery Council, it will be necessary to develop a sustainable learning disability nursing branch programme across Scotland. Recruitment to the Learning Disabilities Nursing branch programme could be improved by developing a delivery model that promotes open learning from learning centres based within Higher Education Institutions across Scotland.



People with learning disabilities can be employed by Higher Education Institutions as Associate Lecturers and can participate in the delivery of programme material and the assessment of nursing students. They can work alongside lecturers in nursing skills laboratories to provide students with a positive experience, as well as learn and develop a range of nursing skills.

All nurses and midwives, whatever their area or place of practice, should receive education on anti-discrimination, the Right to Care and points of access to specialist services and advice. This needs to be part of their core nurse induction and ongoing practice development programmes.

An enhanced Specialist Practitioner Qualification Framework of learning disabilities courses and qualifications should be developed across Scotland. The framework needs to be delivered using flexible routes that enable nurses from all parts of Scotland to obtain access.

The Key Messages

- ⊕ **All nurses, midwives, health care support workers and students need to develop their knowledge about the needs of people with learning disabilities**
- ⊕ **Models of delivering the branch programme need to be reviewed**
- ⊕ **Continuing professional development opportunities in complex needs areas must be developed as a priority**

Standards and monitoring and research

The contributions of nurses working in Registered Care Homes will impact upon the quality of care people with learning disabilities will receive. Nurses are also important and integral members of teams responsible for the inspection and monitoring of Registered Care Homes, and have the vital role of maintaining and promoting standards and quality.

Links should be developed between primary care and learning disability teams to ensure that the full range of health and nursing needs of people with learning disabilities in care homes are assessed and appropriate care planned. Continuing professional development programmes within Registered Care Homes need to take account of the health needs of people with learning disabilities.

Within Scotland, there is a need to develop the academic workforce to focus their attention on the opportunities to undertake research in the area of learning disabilities. The work of nurses caring for and supporting people with learning disabilities is an area rich for research, and nurses should take a lead in contributing to the development of the body of knowledge. A number of mechanisms support research development and activity in NHSScotland at national and local levels.

The Key Messages

- ⊕ **Nurses and midwives have an important part of play in improving quality of care and in monitoring services**
- ⊕ **Best practice and clinical networks need to be developed to promote nursing practice and improve care**
- ⊕ **Nurses and midwives should be supported to develop their capacity to participate in research in the area of learning disabilities**

appendix 1: The Recommendations

Recommendation 1

The Public Health Institute of Scotland should undertake a Needs Assessment of the health needs of children and adults with learning disabilities in Scotland to inform the development and commissioning of services for the future.

Recommendation 2

NHS Boards and Local Health Care Co-operatives should profile the health needs of children and adults with learning disabilities by working collaboratively with colleagues in Community Child Health, Learning Disability Teams, Primary Care, Public Health and other areas, to inform Partnership in Practice Agreements, Health Plans and joint commissioning.

Recommendation 3

NHS Boards should review the funding and resourcing of health services for people with learning disabilities to ensure that the commissioning and development of services are built on sound evidence of the full range of health needs of children and adults with learning disabilities.

Recommendation 4

All NHS Boards should ensure there are models of health care in place that supports a primary care-based approach to developing services for people with learning disabilities. To support this, NHS Boards should ensure there are Community Learning Disability Nurses based in, and working collaboratively as integrated members of primary care teams. The numbers of specialist nurses required will need to take account of geography and population needs, and every NHS Board should have appropriate arrangements in place across all LHCCs.

Recommendation 5

NHS Boards should ensure that all people with learning disabilities – particularly those with complex needs – have regular assessments of their health needs and plans of care developed as part of their Personal Life Plan. These should be developed in partnership with Primary Care and Specialist Learning Disability Services. Particular attention should be given to the interface between services at transition stages, such as at the time of diagnosis, commencement of education and transfer between child and adult services, to ensure appropriate co-ordination of health care.

Recommendation 6

The Health Education Board for Scotland and the Scottish Consortium for Learning Disability should work collaboratively with NHS Boards, LHCC's, Public Health Practitioners and Learning Disability Nurses through local and national networks to promote health education and health promotion of people with learning disabilities in public health initiatives.

Recommendation 7

NHS Boards should develop and ensure there is access to a Learning Disability Liaison Nursing service within acute general, paediatric and psychiatric hospitals to support children and adults with learning disabilities and their families and care workers throughout the care journey.

Recommendation 8

NHS Boards should ensure there are specialist health services in place to respond appropriately to people with learning disabilities who have complex health needs. Learning Disability Nurses should contribute to the development and implementation of the Single Shared Assessment for people with learning disabilities, recognising their skills to assess, identify and respond to needs and support mainstream services.

Recommendation 9

All people with learning disability who have complex health care needs, wherever they live, should have a named Children's or Learning Disability Nurse as a member of a specialist team to liaise, co-ordinate and link with all Tiers of health care and other care systems. Integral to this aspect of the role is co-ordination of care, assessment and planning care, providing therapeutic interventions, advocacy, monitoring health and enabling improvement to promote social inclusion and address health inequalities.

Recommendation 10

People with learning disabilities, their family and care workers require additional support, information, advice and guidance to utilise mainstream services. NHS Boards should ensure there are effective communication and referral pathways between health care professionals, including nurses, working across health and other services to ensure users and carers are involved in the planning and delivery of care.

Recommendation 11

NHS Boards and Local Authorities should ensure that Children's and Learning Disability Nurses are available to plan, co-ordinate care and provide practical 'hands-on' nursing care and support across the full range of setting where children and adults with complex health needs receive care. The need for some may be life long. Nursing support packages should focus on practical home-based support, which may include short breaks and respite for family carers on the basis of assessed need, on a regular basis, for agreed hours during the day and/or overnight. The service should also provide nursing support to families in the event of a crisis such as carer illness to prevent the hospitalisation of the person with complex needs.

Recommendation 12

NHS Boards should ensure that access to specialist multidisciplinary services is available for children and adults with learning disabilities who have the most complex and challenging needs. Children's and Learning Disability Nurses have a distinct contribution to make and must be at the core of specialist teams (such as Paediatric child development centres, Forensic Teams, specialist assessment and treatment units, Mental Health and Challenging Behaviour teams).

Recommendation 13

NHS Boards with their partners should develop models of health care, based on evidence, that meet the needs of children and adults with learning disabilities to avoid unnecessary in-patient episodes. Learning Disability Nurses have transferable skills and where there is clinical need, a mix of nurses from learning disabilities, paediatrics and mental health should be developed across a range of settings where children and adults with the most complex needs access in-patient care, day care, short breaks, education, employment and leisure opportunities.

Recommendation 14

NHS Boards should identify opportunities for the development clinical leaders, including Nurse Consultants in Learning Disabilities, to develop champions that promote evidence based practice, as outlined in Facing the Future.

Recommendation 15

The Regional Workforce Centres should take account of the need to identify the local nursing requirements in light of the recommendations of the National Nursing Review, to ensure there are skilled nurses available to meet the needs of people with learning disabilities.

appendix 1: The Recommendations

Recommendation 16

The Scottish Executive will invite NHS Education for Scotland in collaboration with the Scottish Consortium for Learning Disability and other key stakeholders to establish a multiagency working group to develop core material to address the needs of people with learning disabilities for incorporation within the pre-registration nursing Common Foundation Programme. These developments should incorporate the development of a network of people with learning disabilities and family carers to act as trainers and educators within nurse education programmes.

Recommendation 17

The Scottish Executive will invite NHS Education for Scotland to review immediately the existing pre-registration Children's and Learning Disability branch programmes in light of the recommendations of the National Nursing Review, to ensure that nurses in training are fit for practice.

Recommendation 18

The Scottish Executive will review the contractual arrangements and consult with provider universities to determine the most effective model of delivery of the Learning Disability Nursing branch programme that enables a Scotland-wide focus to meet local workforce needs. The Chief Nursing Officer will establish a working group of key stakeholders to take this forward immediately.

Recommendation 19

Directors of Nursing should utilise the knowledge and skills of Learning Disability Nurses to ensure that an awareness of learning disabilities is included in all nurse induction and continuing development programmes.

Recommendation 20

The Scottish Executive will invite NHS Education for Scotland to enhance and develop the Specialist Practitioner Qualification framework available for all nurses in the area of complex health needs of children and adults with learning disabilities.

Recommendation 21

The monitoring of standards and care undertaken by the Scottish Health Advisory Service within the Quality and Standards Board of Scotland should take account of the outcomes of this National Nursing Review to enhance and improve care in the future.

Recommendation 22

The Nursing and Midwifery Practice Development Unit will support nurses to develop an awareness of integrated health care pathways and identify the range of nursing contributions required to improve health and wellbeing.

Recommendation 23

The Nursing and Midwifery Practice Development Unit will work with nurses and midwives across Scotland to develop a network for and database of best practice of nurses working in the area of Learning Disability.

Recommendation 24

The Nursing and Midwifery Practice Development Unit will in collaboration with Directors of Nursing support the development and co-ordination of Trust-wide audits to identify the practice development, training needs and career pathways of all groups of nurses and inform workforce planning.

appendix 2: Reference Groups and Subgroup

The Chief Nursing Officer established two Reference Groups (one of professionals, the other of service-users, family carers and carers organisations) to inform and guide the National Nursing Review process. They included representatives from user and carer organisations, academic and education

sectors, health and social care professions, professional nursing organisations and trades unions. The Groups adopted a strategic position and provided guidance and direction to the Review.

Professional Reference Group

Members	Organisation
Ms Anne Jarvie [Chair]	Chief Nursing Officer, Scottish Executive Health Department
Ms Alison Aitken	Nursing Director, Borders Health Board
Ms June Andrews	Director of Nursing, Forth Valley Acute NHS Trust
Mr Michael Brown	National Nursing Review Project Manager, Scottish Executive Health Department
Mrs Mary Boyle	Professional Officer, NHS Education for Scotland
Ms Jane Campbell	UNISON
Mr Martin Campbell	Tutor in Learning Disability, University of St Andrews
Dr Sally Cheseldine	Consultant Clinical Psychologist, Royal Hospital for Sick Children, Edinburgh
Professor Sally Ann Cooper	Department of Psychological Medicine, Academic Centre, University of Glasgow
Ms Pauline Craig	Project Manager, Public Health Institute
Ms Lisa Curtice	Director, Scottish Consortium for Learning Disability
Ms Kay Eastwood	Director of Nursing, Lomond & Argyll Primary Care NHS Trust
Dr Andrew Fraser	Deputy Chief Medical Officer, Scottish Executive Health Department
Professor Colin Espie	Department of Psychological Medicine, Academic Centre, University of Glasgow
Mrs Anne Haddow	Parent, Profound and Multiple Impairment Service (PAMIS)
Ms Annie Hair	MSF
Professor James Hogg	Director, White Top Research Centre, University of Dundee
Dr Martyn Jones	Senior Lecturer, School of Nursing & Midwifery, University of Dundee
Mr Alex Joyce	UNISON
Mr Ian Kerr	Social Work Services Inspectorate, Scottish Executive
Ms Juliet MacArthur	Senior Nurse – Research, Lothian University Hospitals NHS Trust
Ms Kim Milledge	MSF
Ms Eileen Moir	Director of Nursing, Borders Primary Care NHS Trust
Mr Joe Nichols	Nursing and Midwifery Council
Ms Ann Paul	Royal College of Nursing
Mr Colin Poolman	Professional Officer, Royal College of Nursing
Mr Michael Proctor	Nursing Officer [Primary Care Division], Scottish Executive Health Department
Ms Lindsay Reid	Royal College of Midwives
Mr Pete Ritchie	Director, Scottish Human Services Trust
Ms Jessie Roberts	Co-ordinator, Profound and Multiple Impairment Service (PAMIS), University of Dundee
Dr Pauline Robertson	Consultant Psychiatrist, Lothian Primary Care NHS Trust
Mr Robert Samuel	Nursing Officer, Scottish Executive Health Department
Mr Tommy Starrs	Head of Department, School of Nursing & Midwifery, University of Stirling
Mr Thomas Stevenson	Professional Nurse Advisor, Ayrshire & Arran Primary Care NHS Trust
Dr Margaret Whoriskey	Advisor Disability Services, Scottish Health Advisory Service

appendix 2: Reference Groups and Subgroup

User and Carer Reference Group

Mr Robert Samuel (Chair)	Nursing Office
Ms Sylvia Allardyce	Partners in Advocacy
Mrs Karen Bain	ENABLE
Mr Michael Brown	Project Manager, Scottish Executive Health Department
Mr Bill Gibson	People First
Mrs Anne Haddow	PAMIS
Ms Monica Hunter	People First
Mr Jodie Sloan Murphy	Partners in Advocacy
Mrs Ena Murray	National Carers Association
Mrs Pam Spence	Scottish Society for Autism
Ms Julia Pennicuik	ENABLE
Ms Jessie Roberts	PAMIS
Mrs Doreen Walkinshaw	ENABLE
Mr John Wallace	Shared Care Scotland
Mr Douglas White	ENABLE

Presentations were given to the Reference Groups from experts in the field of learning disabilities, including:

- ⊕ Professor Sally Ann Cooper, Department of Psychological Medicine, Academic Centre, University of Glasgow
- ⊕ Mrs Mary Boyle, Professional Officer, NHS Education for Scotland
- ⊕ Mr Mark Feinmann, Joint General Manager, Learning Disability Service, Glasgow
- ⊕ Mrs Linda Allan, Lead Nurse, and Team members, The Glasgow Primary Care Liaison Team, Glasgow
- ⊕ Mrs Juliet MacArthur, Senior Nurse-Research, Lothian Acute Hospital Project, Western General Hospital, Edinburgh

Complex Health Needs Subgroup

The Chief Nursing Officer established a group to focus on the health needs of children and adults with learning

disabilities. The group consisted of carers, academics and practitioners from the field of learning disabilities.

The Complex Health Needs Group explored relevant research evidence and practice to identify health needs of children and adults with learning disabilities. They adopted a tiered model approach to considering:

- ⊕ strategic and public health needs
- ⊕ everyday health needs
- ⊕ health needs resulting from the learning disability
- ⊕ complex health needs.

From this, they were able to make recommendations to the National Nursing Review on the developments and changes needed to help nurses and midwives to contribute effectively to meeting the care needs of children and adults with learning disabilities.

Members	Organisation
Dr Margaret Whoriskey Committee Chair Professor Sally Ann Cooper	Adviser Disability Services Scottish Health Advisory Service Professor of Learning Disabilities Department of Psychological Medicine, Academic Centre, University of Glasgow
Dr Sally Cheseldine	Consultant Clinical Psychologist Royal Hospital for Sick Children, Edinburgh
Mrs Ann Haddow	Parent, PAMIS
Mrs Jessie Roberts	Co-ordinator, PAMIS, University of Dundee
Robert Samuel	Nursing Officer, Scottish Executive Health Department
Michael Brown	Project Manager, Scottish Executive Health Department

appendix 3: The Review process

Context

The commitment to carry out a Review of the contribution all nurses and midwives make to the care and support of people with learning disabilities was made in *Caring for Scotland – The Strategy for Nursing and Midwifery in Scotland (2001)*. This built on the work carried out in *The Same as You? A review of services for people with learning disabilities*, published a year earlier. The National Nursing Review commenced in June 2001.

Legislative framework

Health care legislation in Scotland is not developed in isolation. The Review took account of the legislative and policy direction in Scotland, but also recognised the importance of wider UK and international developments and recommendations.

At international level, the United Nations' Convention on the Rights of the Child (1991), the World Health Organisation's Health 21 Initiative (WHO, 1999) and the European Convention on Human Rights impact upon the development and direction of services in Scotland and the UK. European, UK and Scottish legislation relating to health and safety, employment and community care is all relevant.

However, there are specific pieces of legislation that have direct relevance to the care and support of children and adults with learning disabilities in Scotland. These were closely scrutinised in the Review, and included:

- ⊕ The Mental Health (Scotland) Act (1984) *⁶⁴
- ⊕ The Children's (Scotland) Act (1995)
- ⊕ The Disability Discrimination Act (1995)
- ⊕ The Criminal Procedures Act (Scotland) (1995)
- ⊕ The Carers (Recognition & Services) Act (1995)
- ⊕ The Adults with Incapacity (Scotland) Act (2000)
- ⊕ Vulnerable Adults Bill (2002) *

Relevant legislation is summarised in Appendix 3.

Policy context

A wide range of policies from departments of the Scottish Executive and UK Government and beyond were reviewed, including:

- ⊕ Designed to Care (1997)
- ⊕ The Framework for Mental Health Services (1997)
- ⊕ The Acute Services Review (1998)
- ⊕ Towards a Healthier Scotland (1999)
- ⊕ Learning Together (1999)
- ⊕ Report into the education of children with severe low incidence disabilities (1999)
- ⊕ Aiming for Excellence (1999)
- ⊕ Social Inclusion – Opening the door to a better Scotland (1999)
- ⊕ Our National Health – A plan for action, a plan for change (2000)
- ⊕ The Same as You? (2000)
- ⊕ Protecting Children – A shared responsibility (2000)
- ⊕ Community Care: A Joint Future (2000)
- ⊕ For Scotland's Children (2001)
- ⊕ Caring for Scotland (2001)
- ⊕ Nursing for Health (2001)
- ⊕ Patient focus and public involvement (2001)
- ⊕ Fair for all (2001)
- ⊕ Framework for Maternity Services (2001)
- ⊕ Access to primary care services in Scotland (2001)
- ⊕ Making the connections – Report from the Primary Care Modernisation Group (2002)
- ⊕ Adding life to years – Report of the expert group on healthcare of older people (2002)

appendix 3: The Review process

Appendix 4 offers brief outlines of these policies.

Review of nursing and midwifery practice in Scotland

The wide range of contributions currently made by all nurses and midwives throughout the lives of children and adults with learning disabilities were considered. Nurses, midwives, social workers, therapists, doctors, clinical psychologists, service-users, family carers, care workers and many others from all areas of Scotland were asked to provide a picture of the nursing contributions.

The process of reviewing nursing and midwifery practice included:

- ⊕ encouraging wide involvement to create a sense of ownership of the National Nursing Review at local level
- ⊕ holding local area focus groups throughout Scotland (Appendix 6)
- ⊕ identifying best nursing and midwifery practice for people with learning disabilities
- ⊕ identifying innovations and developments in nursing and midwifery practice to inform the National Nursing Review recommendations.

Nursing literature review

The Scottish Executive Library Service undertook a review of the literature on the range of contributions of nurses and midwives. While not exhaustive, a wide range of sources written by authors from a variety of different professional backgrounds was identified. Appendix 6 outlines the themes identified in the review.

Commissioned research

The Scottish Executive commissioned a report from Monash University, Melbourne, Australia, to identify key policy changes implemented in the State of Victoria in relation to health, and specifically the nursing contributions to the care and support of people with learning disabilities. A summary of the report can be found in Appendix 7.

Consensus Conference

The Chief Nursing Officer hosted a National Nursing Review Consensus Conference on 31 January 2002 at the James Watt Conference Centre, Heriot Watt University, Edinburgh. Delegates from all areas of Scotland attended, with participants including users, family carers, nurses, midwives, social workers, academics, doctors and many others. A series of workshops was held as part of the conference.

appendix 4: Legislation relating to people with learning disabilities

Mental Health (Scotland) Act (1984) People with learning disabilities are included in current mental health legislation, but it is recognised that there is a need for a thorough review of the appropriateness of including people with learning disabilities within mental health law. This will be considered in due course.

It is important that all nurses, whatever their areas of clinical practice, have a general awareness of the mental health legislation and its relevance to people with learning disabilities. Learning Disability and Mental Health Nurses have particular responsibilities and roles in relation to nurse holding powers. Nurses with specialist knowledge and expertise in learning disabilities will contribute to the assessment of people with learning disabilities, in collaboration with mental health colleagues, and will be consulted about detention and the implications of the Mental Health Act.

The United Nations Convention on the Rights of the Child (1991) sets out the principles to be taken into account in any legislation, policy and practice which impacts on children. The key principles focus on:

- ⊕ the best interest of the child
- ⊕ respect for the child's privacy
- ⊕ the need to listen to the child's views
- ⊕ enabling children to enjoy the highest standard of health
- ⊕ ensuring access to treatment
- ⊕ the provision of special care for the disabled child
- ⊕ protection against neglect, treatment and abuse
- ⊕ a child's right to play and recreation.

The Children's (Scotland) Act (1995) sets out parental rights and responsibilities in relation to children. The powers and duties of public authorities to support children and their families is laid out, with indications on when to intervene when the welfare of a child demands. The Act is in four main parts and includes issues such as parental rights and responsibilities, the promotion of children's welfare by public authorities and amended adoption laws.

Carers (Recognition & Services) Act (1995) sets out the right to an assessment of the ability of a carer to care, where they care for a substantial amount of time on a regular basis, and when the person they care for is being assessed or reassessed.

The importance of the role played by carers is well recognised and is high on the agenda of Government in Scotland. In 1999, the Scottish Executive set up a Carer's Legislation Working Group to draw up legislative proposals for public consultation.

The Disability Discrimination Act (1995) and associated guidance describes responsibilities for services, including the requirement to provide fully accessible buildings and information to people. All staff will need to be aware of and comply with the legislation and organisations will be responsible for providing disability awareness and equality training.

The Criminal Procedures (Scotland) Act (1995) is relevant in relation to the small number of people with learning disabilities who engage in offending behaviour. Nurses with specialist knowledge and expertise in learning disabilities will contribute to the assessment and treatment of people with learning disabilities who may be subject to the Criminal Procedures Act; they therefore need an understanding of the legislation.

The Human Rights Act (2000) provides an overarching framework around the rights of individuals and sets out how they can exercise these rights. This is of particular relevance to people with learning disabilities, given their experience over many years.

The Adults with Incapacity (Scotland) Act (2000) provides for decisions to be made on behalf of adults who lack the capacity to act for themselves and will apply to many (but not all) adults with learning disabilities. The decisions concerned may be about the individual's property or financial affairs, or about their personal welfare, including medical treatment. It will be important that personal care plans include statements about the individual's capacity to make such decisions. For example, if an individual is assessed as having the requisite capacity to decide about financial issues or medical treatment, their wishes cannot be overruled on the grounds that it is 'in their best interests'.

Changes in legislation through the Community Care and Health (Scotland) Bill came into effect on 1 April 2002.

appendix 5: Policy documents relating to people with learning disabilities

Designed to Care (1997) raised awareness of the need for patient and public involvement in health services in Scotland. Clinical Governance was introduced to improve quality and service delivery, with social justice and equity of care being seen as central to health care. *Designed to Care* recommended the setting up of the Nursing and Midwifery Practice Development Unit (NMPDU) to complement the work of the Nursing Research Initiative for Scotland (NRIS).

The Framework for Mental Health Services (1997) sought to bring about collaborative working among health, social work and housing departments to develop integrated mental health services. The need to work with users, carers and voluntary agencies was recommended.

The Acute Services Review (1998) presented the framework for acute services in Scotland and brought about the introduction of the Clinical Standards Board for Scotland (CSBS) and managed clinical networks.

Towards a Healthier Scotland (1999) signalled the need to promote health and prevent illness in Scotland and the importance of addressing issues such as smoking, improving diet and increasing activity levels.

Learning Together (1999) focused on the importance of ongoing professional education and a culture of lifelong learning to ensure that health professionals are prepared to meet the needs of patients. Working and learning together and in partnership is seen as the key to delivering a modern, high quality, responsive health service.

Report into the education of children with severe low incidence disabilities (1999) reviewed special educational needs provision in Scotland for children with severe low incidence disabilities. The report attaches great importance to the need for good working practices between all agencies concerned in delivery of services for children with severe low incidence disabilities, including health services.

Aiming for Excellence (1999) set out proposals for the establishment of the Scottish Commission for the Regulation of Care to regulate care services, and a Scottish Social Services Council to regulate the social services workforce. This has led to the development and implementation of standards with independent inspection.

Social Inclusion: Opening the door to a better Scotland (1999) sets out the programme to promote social inclusion in Scotland. It is intended to inform practitioners who are engaged in promoting social inclusion at a local level and for policy implementers at a national level.

Nursing for Health (2000) was a recommendation arising from *Towards a Healthier Scotland* and examines the public health contribution of nurses, midwives and health visitors to improving the public's health. Specific reference is made to specialist learning disability nurses and emphasis is placed on the need to develop and improve links and services for people with learning disabilities and those with complex needs.

Our National Health: A plan for action, a plan for change (2000) is the key government strategy which signals the importance of improving patients' experiences within health services, increasing their involvement in decisions about their care and encouraging team working among staff. All these strategies have an impact upon nurses and midwives and underline the need to ensure that all nurses and midwives focus their efforts on improving the public's health.

Health is not merely the absence of illness or disease; it also embraces physical, mental and spiritual wellbeing. The wider health contribution in relation to people with learning disabilities is to enable them to live their lives fully and be included in society. From a nursing perspective, there needs to be full recognition that all nurses and midwives have an important contribution to make in improving public health in the widest sense. This contribution cannot be considered in isolation and needs to be considered alongside those of doctors, teachers, social workers, health promotion workers, carers, volunteers and many others.

A framework for Maternity Services in Scotland (2001) promotes a modern community-based maternity service and considers policy development and planning based on populations and their needs. The framework recognises the special needs of people with learning disabilities and the importance of developing links with specialist learning disabilities services.

Access to primary care services in Scotland (2001) was the result of the Scottish Executive commissioning the Scottish Consumer Council to look at the experience of the Scottish population using primary care services and the impact on their health and well being. Access to health services is seen as the key issue and factors that can prohibit this were identified. Ways of improving primary care services are recommended in the report.

Patient focus and public involvement (2001) outlines the commitment to involving people more in decision making about their care and in influencing future service provision. The aim is to improve patients' experiences within health services and ensure that people are treated with respect as individuals, regardless of race, class and culture.

Fair for all (2001) states that health care should be equitable and accessible to all and that services design must reflect diversity and are able to respond and meet the needs of multiracial and multicultural society. The intention is to impact on accessible information, communication and understanding of needs, awareness of specific dietary requirements and overall uptake of services in ethnic minority groups.

Making the connections (2002) focuses specifically on the actions required to improve the health of patients in the primary care setting and highlights the need for an integrated approach to the delivery of multiprofessional and multagency services.

Adding life to years (2002) is the report of the Chief Medical Officers expert group on the healthcare of older people and gives a clear multiprofessional commitment to improving the way in which older people can enjoy longer and healthier lives in the community.

appendix 6: Local area focus groups in the National Nursing Review

A series of local area focus groups were hosted throughout Scotland and attended by nurses, midwives and others from all areas of clinical practice. The focus groups showed that in addition to interest from nurses and midwives, there was high levels of support for the Review from clinical psychologists, doctors, allied health professionals, social workers in residential, field and day care settings, voluntary organisation, providers and many others. Local area focus groups were held with student nurses at Napier University, University of Stirling and Glasgow Caledonian.

The focus groups were held in the following areas:

- ➔ Borders
- ➔ Edinburgh
- ➔ Dumfries & Galloway
- ➔ Argyll and Clyde
- ➔ Forth Valley
- ➔ Grampian
- ➔ Lanarkshire
- ➔ Shetland
- ➔ Western Isles
- ➔ Greater Glasgow
- ➔ Ayrshire & Arran
- ➔ Tayside
- ➔ Lomond & Argyll
- ➔ Fife
- ➔ Highland
- ➔ West Lothian
- ➔ Orkney
- ➔ The State Hospital

appendix 7: The Nursing Literature Reviewed

As part of the National Nursing Review process, the Scottish Executive Library service undertook a review of the literature (mainly in nursing journals) to identify some of contributions made by nurses and midwives to the care of people with learning disabilities. While the literature review was not

exhaustive, a wide range was identified, much written by nurses or in collaboration with others such as doctors and clinical psychologists.

Nursing literature reviewed	
Area of publication	Themes identified from the literature
Public Awareness of Learning Disabilities	Attitudes of professionals poor; role of learning disability specialists vital; further work and research required.
Health Promotion and Health Education	Drop-in clinics could offer a way forward; limited focus on health promotion and prevention; exclusion from health promotion; health screening must be a priority; Community Learning Disability Nurses have a key role to play.
Interface with Specialist Services	Community Learning Disability Teams and Primary Care Teams need to improve their links; Learning Disability Nurses pivotal in promoting collaborative working; Learning Disabilities not seen as a priority for Primary Care; issue of knowledge, training, liaison, role definitions and clinical care responsibilities within Primary Care need to be clarified; Learning Disability and Primary Care Nurses must work together to improve health; what Primary Care Nurses need to do to help people with learning disabilities access health care; Learning Disability Nurses must become key partners with Primary Care Teams in shaping health services; Learning Disability Nurses must develop and shape their role around health needs; need to review the effectiveness of Primary Care consultations for people with learning disabilities; Primary Care Teams can have poor awareness of the health needs of people with learning disabilities due to poor education; attitudes and collaboration with specialist teams.
Clinical Networks	The development of clinical networks to share and develop practice needs to be improved.
Mental Health and Learning Disabilities	National Mental Health Strategies continue to fail to consider the needs of children and adults with learning disabilities; Learning Disability Nurses have an important role in meeting mental health needs; Learning Disability Nurses need to improve their skills in assessment and treatment of dual diagnosis; the closure of long-stay hospitals means it is important to recognise mental health needs as distinct from social care needs.

appendix 7: The Nursing Literature Reviewed

Area of publication	Themes identified from the literature
Learning Disability Nursing	The diversity of skills and experience of Learning Disability Nurses needs to be recognised and strengthened for the future; Learning Disability Nurses offer an excellent example of holistic care that other nurses can learn from; Learning Disability Nurses, like Health Visitors and Midwives work in a health promotion and well being model of health care; Learning Disability Nurses need to develop their role as client advocates; Learning Disability Nurses can support people with learning disabilities access health care; Learning Disability Nurses have a community focus and can form effective links with Primary Care; Learning Disability Nurses have responded to change over the last 10 years; More education and support is required from nurses to help parents who have a learning disability; research needs to be undertaken to develop a conceptualised framework of the work undertaken by Learning Disability Nurses; a profile of learning disability nurses.
Community Learning Disability Nursing	Work with Primary Care; family carers around health needs of people with learning disabilities suggests locating Community Learning Disability Nurses within Primary Care could be part of the answer; Community Learning Disability Nursing roles need to be developed to meet health needs; an analysis of the core skills required to practice; Degree level education required for all Community Learning Disability Nursing; Community Learning Disability Nurses should have a profile in health promotion within Primary Care; health screening in Northern Ireland.
Palliative Care	Some people with learning disabilities will use palliative care services – the role of District Nurses and their education needs must be identified; what are the professional needs of District Nurses around learning disabilities?
Acute Nursing and General Hospital Care	The experience of people with learning disabilities in general hospitals; users critical of acute hospitals – more research needed; Liaison Nursing in Edinburgh improves the health outcomes for people with learning disabilities in acute hospitals; General Nurses have negative views and poor attitudes than would be expected from caring professionals.
Education of Nurses	Generalist and specialist debate – the need to consider models in relation to all nurses and avoid focusing in isolation; users not involved in developing nurse education programmes; Nurse education programmes need to be improved about health needs of people with learning disabilities.
Sexual Health	Sexual health needs of people with learning disabilities; the nurse's role in sexual health care and education; sex and health promotion; health care for women with learning disabilities; a holistic perspective to human sexuality; is the sexual health of people with learning disabilities being denied; should nurses support people with learning disabilities to have sex?; sexuality and the relevance to learning disability nurses; preventing rape and sexual assault of people with learning disabilities; how far gay? Politics and HIV in learning disabilities; assessing and meeting needs in HIV and learning disabilities; sexual awareness.

appendix 8: Summary of Report commissioned by the Scottish Executive from Monash University, Melbourne, Australia

A report to the Scottish National Review of the Contribution of Nurses to the Care and Support of People with a Learning Disability

Prepared by:

Associate Professor Robert Davis, MBBS, FRACGP, GDEB, Centre for Developmental Disability Health Victoria, Monash University

Ms Alex Phillips, RMRN, B.App.Sci.(Intellectual Disability), B.App.Sci.(Disability) (Hons), Centre for Developmental Disability Health Victoria, Monash University

Dr Karen Nankervis, RMRN, RPN, B.Ed, PhD, Department of Psychology and Disability Studies, RMIT University

About the Report

This report reviews the contribution of disability specialist professionals to the care and support of people with an intellectual disability (learning disabilities). While the report provides information in relation to services across Australia, specific detail has been given to the State of Victoria, which is largely representative of the other States and Territories. The report provides an overview of the characteristics, definition and prevalence of the target group. Also discussed is the evolution of disability services including the progression of staff training and roles.

Main recommendations for Scotland

Staff qualifications and competencies:

It is important to retain a group of “registered professionals” with expertise in the skills required to meet the higher than average health, mental health, challenging behaviour and developmental needs of people with an intellectual disability. They also require the skills associated with supervising and training direct care staff, managing services, planning support services, ensuring community participation, and the promoting of self determination for people with an intellectual disability. If Scotland makes the decision to no longer have Learning Disability Nurses, then a new disability profession should be established to ensure that the gaps in service delivery experienced in Victoria do not occur.

Staff development and career path:

Services need to have a core group of professionals who are able to gain experience and enhance their ability to contribute in the delivery, planning and management of services. There should be a policy that establishes and maintains career pathways to attract and retain staff committed to maintain high professional standards.

Medical services:

The particular health needs of people with an intellectual disability benefit from services geared to deal with this group.

Generic health professionals, i.e. medical practitioners and nurses, will need training and support from services experienced in delivering services to people with an intellectual disability and this needs to be anticipated and planned for. Training in caring for people with disabilities should be a core component of the curricula of courses preparing health professionals. Generic services should also have access to professionals with training and expertise in disability to enhance service delivery.

Multi disciplinary teams:

The complex nature of the medical, psychiatric and behavioural problems often require a multi-disciplinary or interdisciplinary approach. The availability of and increase in the number of “Disability Professionals” with specific training in intellectual disability and some nursing skills would facilitate the effectiveness of these teams.

Glossary

Advocate	A person who helps others to make their own decisions and say what they need
Accountability	Responsible for something or to someone
Asperger's Syndrome	A type of autism that affects people of average intelligence. They find it hard to understand information and situations, which can make it hard for them to act appropriately and communicate
Autism	A lifelong developmental disability that affects the way a person communicates and relates to others around them. Some may also have a learning disability.
Challenging Behaviour	One of the terms used to describe when someone is acting in a way that might do themselves or others harm
Commissioning	The identification of services needed and the contracting for their delivery
Complex Health Needs	Extra health needs that a person has such as physical or mental health needs, that are over and above everyday health needs.
Diagnostic overshadowing	The inability to see possible see ill-health and conditions that may be present beyond the learning disability
Differential diagnosis	The possible diagnostic options within a range of conditions and diseases
Directly Accessed Health Services	Health services that can be accessed by everyone and that do not require referral from a health care professional, for example, a pharmacists and an optometrist
Dual Diagnosis	Someone who has a learning disability and a mental health need
Everyday health needs	General health needs that affect everyone
Forensic mental health	The assessment, diagnosis and treatment of individuals suffering from mental disorder who have been charged with, or convicted of a criminal offence and others who are considered to have the potential to exhibit similar behaviour.
Generic	The word used to describe a whole group of people
Genetics	The biological inherited individual characteristics
Holistic care	Care and treatment of the whole person rather than a symptom or an illness
Learning Disability	A significant lifelong condition that started before adulthood that affects development and which means they need help to understand information, learn skills and cope independently.
Local Health Care Co-operative [LHCC]	A multidisciplinary, multiagency GP-led group within a specific geographical area set up to meet with health needs of local communities
Mainstream	Generally available to all members of the community
NHS Board	A statutory body with the responsibility of managing health services within a defined area and budget

NHS Education for Scotland (NES)	A new Special Health Board formed on 1 April 2002 to meet the post-registration education needs of nurses, doctors, pharmacists and dentists in Scotland
Nursing and Midwifery Council (NMC)	The body responsible for the regulation of the nurses and midwives in the UK
Partnerships in Practice [PIPs]	A plan that shows how agencies will work together to carry out the recommendations of The Same as You?
Profound and Multiple Learning Disability	Someone who has a very severe degree of learning disability which may have additional complex needs, for example, physical disabilities and sensory impairments
Registered Nurse	A person who following a formal period of education and clinical experience is registered with the Nursing and Midwifery Council to practice as a nurse
Single Shared Assessment	An assessment of care needs that may be carried out by professionals to assist with the planning of care
Social Inclusion	Enabling people to be a part of the community they live in, free from injustice, discrimination and poverty
Social Worker	A person who following a formal period of education and practice is qualified to practice as a Social Worker
Specialist	A professional who following education and training is devoted to a particular occupation or branch of study or research
Strategy	A plan or policy to achieve something
Student Nurse	A person undertaking one of the four nursing branch programmes in order to register with the Nursing and Midwifery Council and practice as a qualified nurse
Syndrome	A group of symptoms or characteristics that indicate the existence of a specific condition, for example Down's Syndrome
Therapeutic Interventions	Any form of treatment, for example drugs, physical or psychological therapy, to promote wellbeing
Offending Behaviour	Actions, which are against the criminal law, regardless of whether or not the individual is caught or convicted.
Clinical Psychologist	A professional who is trained to undertake psychological testing and therapy
Psychiatrist	A medical doctor who has completed further specialist education in psychiatry
UKCC	The body previously responsible for the regulation of nurses, midwives and health visitors. It was replaced by the Nursing and Midwifery Council on 1 April 2002

appendix 9: Examples of services across the Tier

Tier 0	Tier 1	Tier 2
<p>Promotion of general health and well being in the wider community, for example:</p> <ul style="list-style-type: none"> ⊕ Social Inclusion projects ⊕ Healthy eating groups ⊕ Community Education initiatives ⊕ Evening classes ⊕ College courses 	<p>General Health Services:</p> <ul style="list-style-type: none"> ⊕ General practitioners ⊕ General Dental Services ⊕ Optometrists ⊕ Accident & Emergency Services ⊕ NHS 24 ⊕ Community Pharmacists <p>Primary Care based Services, including:</p> <ul style="list-style-type: none"> ⊕ Practice nursing ⊕ District nursing ⊕ Health Visiting ⊕ Treatment Room Nursing ⊕ Community Midwives ⊕ PAMs e.g., Physiotherapists 	<p>Health Services accessed via primary care services, for example:</p> <ul style="list-style-type: none"> ⊕ Specialist Primary Care based Epilepsy services ⊕ Primary Care Liaison service ⊕ Acute Hospital Liaison Service ⊕ General psychiatric Services ⊕ General hospital services – out patient clinics, investigation & treatment units ⊕ Palliative care services

Tier 3	Tier 4
<p>Specialist Locality health Services, for example:</p> <ul style="list-style-type: none"> ⊕ Paediatric Development Assessment services ⊕ Community Learning Disability Teams ⊕ Learning Disability Psychiatric domiciliary & Out patient services ⊕ Specialist epilepsy services ⊕ Child & Family Psychiatric Services ⊕ Community Child Health Services ⊕ Learning Disability Dual Diagnosis clinics ⊕ Orthotic & equipment clinics 	<p>Specialist Area & Regional Health Services, for example:</p> <ul style="list-style-type: none"> ⊕ Specialist Learning Disability Assessment & Treatment Services ⊕ Learning Disability Additional Support Teams ⊕ Specialist Paediatric Assessment & Treatment services ⊕ Intensive Psychiatric Units (IPCU) ⊕ Forensic Assessment & treatment services ⊕ State Hospital, Carstairs

References

- ¹ PUBLIC HEALTH INSTITUTE OF SCOTLAND (2002) *Delivering better health: A report from the Scottish Directors of Public Health Group and the Public Health Institute of Scotland.*
- ² PUBLIC HEALTH INSTITUTE OF SCOTLAND (2002) *Health inequalities in the new Scotland.*
- ³ McCrother, C.; Thorp, C; Taub, N.; Machado, (2001) Prevalence, disability and need in adults with severe learning Disability. *Tizard Learning Disability Review* 6, 4-13.
- ⁴ SCOTTISH EXECUTIVE (2001) *The Same as You? A review of services for people with learning disabilities.*
- ⁵ DEPARTMENT OF HEALTH (2001) *Valuing People: A new strategy for learning disabilities for the 21st century* HMSO.
- ⁶ SCOTTISH EXECUTIVE (2001) *Fair for all.*
- ⁷ SCOTTISH EXECUTIVE (2001) *Caring for Scotland: The strategy for nursing and midwifery in Scotland.*
- ⁸ WELSH ASSEMBLY GOVERNMENT (2002) *"Inclusion, partnership and innovation": A framework for realising the potential of learning disability nursing in Wales* Briefing paper 3.
- ⁹ SCOTTISH EXECUTIVE (2000) *Our National Health: A plan for action, A plan for change.*
- ¹⁰ SCOTTISH EXECUTIVE (2000) *Community Care: A Joint Future: Report of the Joint Future Group.*
- ¹¹ ENGLISH NATIONAL BOARD FOR NURSING, MIDWIFERY AND HEALTH VISITING (2001) *Diversity and Change: The changing roles and education of learning disability nurses*
- ¹² HM Treasury (2002) *Securing our future health: Taking a long-term view. Final Report.*
- ¹³ SCOTTISH EXECUTIVE (2002) *Making the connections: Report from the Primary Care Modernisation Group.*
- ¹⁴ Espie, C. et al (1999) *The role of the NHS in meeting the health needs of people with learning disabilities.* Report for the Scottish Executive Learning Disability Review.
- ¹⁵ Howells, G. (1996) Situations vacant: doctors required to provide care for people with learning disability. *British Journal of General Practice* 46, 59-60.
- ¹⁶ Royal College of General Practitioners Working Party (1990). *Primary Care for people with a mental handicap: Occasional Paper 47.* London: RCGP.
- ¹⁷ Wilson, D., N., Haire, A. (1990) Health care screening for people with mental handicap living in the community. *British Medical Journal* 301, 1379-1381.
- ¹⁸ Whitfield, M.L., Russell, O. (1996) Assessing general practitioners' care of adult patients with learning disabilities: case control study. *Quality in health care* 5, 31-35.
- ¹⁹ Lennox, N.G., & Kerr, M.P. (1997) Review: Primary health care and people with an intellectual disability: the evidence base. *Journal of Intellectual Disability Research* 41, 365-372.
- ²⁰ Webb, O.J., Rogers, L. (1999) Health screening for people with intellectual disability: the New Zealand experience. *Journal of Intellectual Disability Research* 43, 497-503.
- ²¹ Lennox, N.G. (1999) *Comprehensive Health Assessment Programme.* University of Queensland: Brisbane.
- ²² Mencap (1998) *The NHS – Health for all? People with Learning Disabilities and Health care.* Mencap National Centre: London.
- ²³ Lennox, N., G., Diggins, J., N., Ugoni, A., M. (1997) The general practice care of people with intellectual disabilities: barriers and solutions. *Journal of Intellectual Disability Research* 41, 380-390.
- ²⁴ Howells, G. (1997) A General Practice Perspective in O'Hara J. and Sperlinger A. (eds.) *Adults with Learning Disabilities: A Practical Approach for health Professionals* Wiley and sons.
- ²⁵ SCOTTISH EXECUTIVE (2000) *Nursing for Health: A review of the contribution of nurses, midwives and health visitors to improving the public's health.*

References

- ²⁶ Martin, D.M., Roy, A., Wells, M., B. (1997) Health gain through health checks: improving access to primary health care for people with intellectual disability. *Journal of Intellectual Disability Research* 41, 401-408.
- ²⁷ Webb, O.J., Rogers, L. (1999) Health screening for people with intellectual disability: the New Zealand experience. *Journal of Intellectual Disability Research* 43, 497-503.
- ²⁸ Lennox, N.G, Green, M., Diggins, J., Ugoni, A. (2001) Audit and comprehensive assessment programme in the primary healthcare of adults with intellectual disability: a pilot study. *Journal of Intellectual Disability Research* 45, 226-232.
- ²⁹ Hogg, J., Northfield. J., Turnbull. J., (2002) *Cancer and people with learning disabilities* BILD.
- ³⁰ Cooper, S-A. Bailey N.M. (2001) Psychiatric disorders amongst adults with learning disabilities – Prevalence and relationship to ability level. *Irish Journal of Psychological Medicine* 18, 45-53.
- ³¹ Cooper, S-A. (1997) Epidemiology of psychiatric disorders in elderly compared with younger adults with learning disabilities. *British Journal of Psychiatry* 170, 375-380.
- ³² Mansell, J.(1993) *Services for People with Learning Disability and Challenging Behaviour and Mental Health Needs; A Report of a Project Group*. London: HMSO.
- ³³ Royal College of General Practitioners Working Party (1990). *Primary Care for people with a mental handicap: Occasional Paper 47*, London: RCGP.
- ³⁴ Warburg, M. (1994) Visual Impairment among people with developmental delay. *Journal of Intellectual Disability Research* 38, 423-432.
- ³⁵ Yates, S (1995) The incidence and importance of hearing loss in people with severe learning disabilities: the evolution of a service. *British Journal of Learning Disabilities* 23, 79-84.
- ³⁶ Cooper, S-A. (1998) A clinical study of the effects of age on the physical health of people with intellectual disabilities. *American Journal on Mental Retardation* 102, 582-589.
- ³⁷ Hogg, J (1999) People with Profound Intellectual and Multiple Disabilities. Understanding and realising their needs and those of carers. *Report for the Scottish Executive Learning Disability Review*.
- ³⁸ Borthwick-Duffy S. (1994) Epidemiology and prevalence of psychopathology in people with mental retardation. *Journal of Consulting and Clinical Psychology* 62, 17-27.
- ³⁹ Corbett, J., A. (1979) Psychiatric morbidity and mental retardation. In: *Psychiatric Illness and Mental Handicap*, Eds. James, S., E. Snaithe, R., P. London: Gaskill, 11-25.
- ⁴⁰ Patel, P. Goldberg, D., Moss, F. (1993) Psychiatric morbidity in older people with moderate and severe learning disabilities II: The prevalence study. *British Journal of Psychiatry* 163, 481-491.
- ⁴¹ Cooper, S-A. Bailey N.M. (2001) Psychiatric disorders amongst adults with learning disabilities – Prevalence and relationship to ability level. *Irish Journal of Psychological Medicine* 18, 45-53.
- ⁴² Cooper, S-A. (1997) Epidemiology of psychiatric disorders in elderly compared with younger adults with learning disabilities. *British Journal of Psychiatry* 170, 375-380.
- ⁴³ Enfield S., Tongue B. (1996) Population prevalence of psychopathology in children and adolescents with intellectual disability: Epidemiological findings. *Journal of Intellectual Disability Research* 40, 99-109.
- ⁴⁴ Reid, A., H., Ballinger, B., R. (1995) Behaviour symptoms among severely and profoundly mentally retarded patients: A 16-18 year follow-up study. *British Journal of Psychiatry* 167, 452-455.

- ⁴⁵ Kiernan, C.; Quershi, H. (1993) *Challenging Behaviour – Research to Practice. Implications of Research on the challenging behaviour of people with learning disabilities*. Clevedon. Avon: BILD.
- ⁴⁶ Davidson, M.; Humphreys, M., Johnstone, E.; Cunningham-Owens, D. (1995). Prevalence of psychiatric morbidity among remand prisoners in Scotland. *British Journal of Psychiatry*, **167**, 545-548.
- ⁴⁷ Janicki, M., P., Dalton, A., J., Henderson, C., M. Davidson, P.W. (1999) Mortality and morbidity among older adults with intellectual disability: Health services consideration. *Disability and Rehabilitation* **21**, 284-294.
- ⁴⁸ Puri, B.K., Lekh, S. K., Langa, A., Zaman, R., Singh, I. (1995) Mortality in a hospitalised mentally handicapped population: A 10 year survey. *Journal of Intellectual Disability Research* **39**, 442-446.
- ⁴⁹ SCOTTISH EXECUTIVE (2002) Adding life to years: *A report of the expert group on healthcare of older people*.
- ⁵⁰ Visser, N. (1997) Aging and Cognitive Decline in People with Downs Syndrome. *British Journal of Developmental Disability* **43**, 79-84.
- ⁵¹ Prasher, V. P. (1995) Age Specific Prevalence, Thyroid Dysfunction and Depressive Symptomatology in Adults with Down's Syndrome and Dementia. *International Journal of Geriatric Psychiatry* **10**, 25-31.
- ⁵² Cooper, S-A. (1997) High prevalence of Dementia amongst people with learning disabilities not attributed to Down's Syndrome *Psychological Medicine* **27**, 609-616.
- ⁵³ PUBLIC HEALTH INSTITUTE OF SCOTLAND (2001) *Autistic Spectrum Disorders Needs Assessment Report* (p.19).
- ⁵⁴ PUBLIC HEALTH INSTITUTE OF SCOTLAND (2001) *Autistic Spectrum Disorders Needs Assessment Report* (p.17).
- ⁵⁵ PUBLIC HEALTH INSTITUTE OF SCOTLAND (2002) *Needs Assessment Report on Child and Adolescent Mental Health – Interim Report*.
- ⁵⁶ SCOTTISH OFFICE (1998) *Interviewing People Who Are Mentally Disordered “Appropriate Adult” Schemes*.
- ⁵⁷ SCOTTISH EXECUTIVE (2002) *Planning Together: Report of the Scottish Integrated Workforce Planning Group*.
- ⁵⁸ SCOTTISH EXECUTIVE (2001) *Facing the Future*.
- ⁵⁹ UNITED KINGDOM CENTRAL COUNCIL FOR NURSES, MIDWIVES AND HEALTH VISITORS (1999) *Fitness for Practice*.
- ⁶⁰ UNITED KINGDOM CENTRAL COUNCIL FOR NURSES, MIDWIVES AND HEALTH VISITORS (2001) *Fitness for Practice and Purpose*.
- ⁶¹ SCOTTISH EXECUTIVE (1999) *Learning Together*.
- ⁶² SCOTTISH EXECUTIVE (1999) *Aiming For Excellence*.
- ⁶³ SCOTTISH EXECUTIVE (2001) *National Care Standards: Care Homes for People with Learning Disabilities*.
- ⁶⁴ *New legislation in development.

Acknowledgements

The children and adults with learning disabilities photographed for the review.

The nurses from Western General Hospital, Edinburgh.

The nurses from Sighthill Health Centre, Edinburgh.

The Team from the Glasgow Primary Care Liaison Service.

The student midwives from Napier University, Edinburgh.

The nurses at The Royal Hospital for Sick Children, Edinburgh.

© Crown Copyright 2002

Further copies of this report are available from

The Stationery Office Bookshop
71 Lothian Road · Edinburgh EH3 9AZ
Tel 0870 606 5566

Astron B25209-07-02

