

Learning Disability Service Framework

Project Initiation Document

V.7

Document History

Version 1	Drafted for discussion at preliminary meeting on 7 th May 2008.
Version 2	Amended following initial meeting for discussion at meeting with DHSSPS on 4 th June 2008.
Version 3	Amended following meeting with DHSSPS on 4 June 2008 for discussion with Learning Disability Co-Directors on 31 July 2008
Version 4	Draft for discussion at meeting with DHSSPS on 1 September 2008
Version 5	Amended as per discussion at meeting with DHSSPS officials on 1 September 2008
Version 6	Revised for submission to Project Board meeting on 9/9/08
Version 7	Approved by DHSSPS Board November 2009

LEARNING DISABILITY SERVICE FRAMEWORK

INTRODUCTION

DHSSPS are taking forward a programme to develop Service Frameworks for Northern Ireland. A Service Framework is a document that contains explicit standards underpinned by evidence and legislative requirements. Service Frameworks will set standards, specific timeframes and expected outcomes designed to:

- improve the health and social wellbeing of the population of Northern Ireland
- reduce inequalities and promote social inclusion
- improve the quality and safety of care
- safeguard vulnerable individuals and groups and
- improve partnership working with other agencies and sectors.

Each Service Framework document will be the subject of public consultation and will be developed in collaboration with Health and Social Care (HSC) staff and through engagement with service users, carers, the wider public and other key stakeholders. The Service Frameworks will be of use to the public, commissioners, service providers and those organisations that are required to report on the performance and quality of services and care.

It is anticipated that the implementation of the Learning Disability Service Framework across Health and Personal Social Services (HPSS) will lead to the adoption of a more standardised, agreed, regional approach to support.

DHSSPS have tasked the Western Board (WHSSB) with taking forward the process of developing the Learning Disability Service Framework. The Association For Real Change (ARC) has agreed to assist in this process by chairing the project, arranging administrative support and managing the work of the Project Manager.

DHSSPS have acknowledged that the Learning Disability Service Framework will involve adaptation of the more clinical aspects of the health - related frameworks given that learning disability is a life state and not solely a health issue.

CONTEXT

The Learning Disability Service Framework will provide standards that are underpinned by robust evidence (where available), regional/national policy, the findings of inquiries, the experience of service users and also relevant legislative requirements.

The Framework will take full account of the Bamford Review of Mental Health and Learning Disability. In particular *Equal Lives: Review of Policy and Services for People with a Learning Disability* will underpin the Learning Disability Service Framework. The project will not repeat the work of this review process but rather will use the findings and recommendations of Equal Lives as the basis for developing the Learning Disability Service Framework.

This Service Framework identifies specific standards for learning disability. Other frameworks that are being developed will also impact on services for adults and children who have a learning disability eg the Mental Health, Older People's and Children's frameworks.

The Learning Disability Service Framework will set out performance standards and indicators in respect of day-to-day service delivery across Health and Personal Social Services (HPSS). However DHSSPS have recognised that major progress in improving the health and social wellbeing of people with a learning disability cannot be achieved in isolation from the contributions of other Government Departments and agencies. DHSSPS will therefore seek to secure the involvement of senior officials from the following Departments, each of which have significant responsibilities in this area: Department For Social Development (DSD), Department For Education (DE) and Department For Employment and Learning (DEL).

DHSSPS has acknowledged that the Learning Disability Service Framework may highlight specific gaps in current service provision and therefore identify areas where future investment is potentially required. The Learning Disability Service Framework is not a mechanism for identifying the resource requirements to address service deficits. However it is appropriate for the Framework development process to include a mechanism for highlighting resource concerns. In the first instance, the standards proposed must by necessity be based upon what can be realistically achieved within existing HPSS

resources. However, taking a longer-term perspective, the standards and associated performance indicators identified within the Framework should be progressive and therefore stretch to reflect future investment in learning disability services.

AIMS & OBJECTIVES

The overall aim of the Learning Disability Service Framework is to improve the health and wellbeing of people with a learning disability and their families in Northern Ireland through promoting social inclusion, reduce inequalities in health and wellbeing, and improve HSC quality of care.

Of particular importance is the need to value the uniqueness of the individual and to promote integration into society so that individuals with learning disabilities can participate in the families and communities in which they live and can access the full range of opportunities open to everyone else.

Achievement of these aims goes beyond traditional health and social care boundaries and is strongly influenced by population/individual attitudes and behaviours, and the contribution of carers and other sectors.

DEFINITION

The Learning Disability Service Framework will be based on:

- enabling people with learning disabilities to live full and meaningful lives and have access to a wide range of continuing education, training, employment, social and leisure opportunities
- promoting independence, self help and self directed support, where appropriate, through the active participation of the individual, their family and the wider community
- securing improvements in the health and wellbeing of those with learning disabilities, with particular reference to complex conditions and the need to promote healthy aging

- supporting families and carers to assist in the development of the individual and in their integration into society
- the best available evidence including the composite research reports conducted by the University of Ulster to inform the Equal Lives review and the views of people with learning disability, family carers and service providers gathered as part of the Equal Lives Review and Framework Development process
- existing policies and strategies already endorsed by the Department through formal publications or circulars and links with national standard setting bodies
- the standardised template as agreed by the Departmental Service Framework Steering Group (this includes a definition of a standard, performance indicators and audit criteria). As noted above the template will need to be modified to take account of the fact that learning disability:
 - is not an illness
 - is a life long condition
 - encompasses both health and social care
 - will be addressed within a social model of disability wherein the responsibilities of agencies beyond HPSS are recognised.

SCOPE

The Learning Disability Service Framework will promote Person Centred Planning and partnership working which spans agencies, sectors and professions. It will promote the independence of the individual and will recognise the need to support the family carer throughout the life of the individual, where appropriate, especially during transition periods.

It will focus on supporting equity of access to primary, secondary and specialist services appropriate to the needs of the individual and the family, in order to promote and maintain health and wellbeing. The Learning Disability Service Framework will include specific standards for the areas detailed below.

1 Children and Young People

To ensure that children and young people with learning disabilities get the best possible start in life and are enabled to access opportunities that are open to others their age.

- Early intervention
- Challenging behaviours
- Complex physical health care and social care needs
- Looked after children (to be reviewed pending consideration of the Children's Service Framework)
- Lifestyle choices including diet, obesity and physical activity
- Social, educational and leisure opportunities
- Transitional arrangements from:
 - hospital to home
 - home to preschool and school
 - childhood to adolescence

2 Fuller Adult Lives

To ensure that the move to adulthood for young people with learning disabilities supports their access to continuing education, employment and training and that they and their families receive continuity of support during the transition period.

- Transition arrangements from adolescence to adulthood that will contribute to enhanced psychological and physiological well-being.

To enable men and women with learning disabilities to lead full and meaningful lives through access to a range of social, work and leisure opportunities and forming and maintaining friendships and relationships.

- Promoting social, educational, employment day opportunities.
- Enabling choice and independence.
- Promoting access to leisure opportunities.

3 Accommodation

To ensure that men and women with a learning disability have their own home in the community and the choice of who they live with.

To ensure that an extended range of housing options is developed.

- Multiagency engagement on accommodation and housing needs
- Adaptations
- Housing options

4 Ageing

To ensure that men and women with learning disabilities are supported to age well in their neighbourhoods.

- Transition arrangements
- Promoting healthy ageing
- Dementia (with reference to the Mental Health Service Framework)

5 Health

To secure improvements in the physical and mental health of people with learning disabilities.

- Prevention and health promotion
- Access to and responsiveness of:
 - primary health services
 - secondary health services
 - tertiary health services
- Specific health improvements- obesity, healthy lifestyles
- Palliative Care including end of life care

In addition to the development of standards in each of these areas the project will ensure that the following 6 overarching themes are addressed in each area.

- (i) Areas where there is an overlapping responsibility with other agencies or departments beyond HPSS will be highlighted.
- (ii) The manner in which the adoption of standards will result in improved personal outcomes for people with a learning disability will be clarified in order to promote person centred approaches across HPSS.
- (iii) Where the introduction of essential standards at this stage is not possible without immediate additional resourcing this will be highlighted to the DHSSPS Board as the project develops.
- (iv) The implications for ensuring appropriate family support including:
 - provision of timely and appropriate information and advice, particularly at transition points
 - access to services
 - respite
 - carers assessment
 - life after caring
- (v) Advocacy
- (vi) Increased control relating to individual budgets, Direct Payments and Self-Directed Services

PROJECT STRUCTURE

The Project Structure is depicted diagrammatically at Appendix B.

Project Board

The Framework development process will be overseen by a Project Board which will be chaired by Dominic Burke, Director of Social Care (WHSSB) and comprise Jim Simpson (Service Planner, WHSSB) and Paul Cavanagh (WHSSB). The Project Board will be accountable to the DHSSPS Service Framework Programme Board for ensuring that the project is completed within agreed timescales and Departmental guidelines.

Project Staff

The Project Director, Siobhan Bogues, (ARC NI), will manage the operational aspects of the project on behalf of the WHSSB. She is tasked with ensuring that the Framework development process proceeds in a timely fashion leading to the production of the required draft Service Framework document by October 2009. Thereafter, following a period of consultation, the subsequent final agreed Framework document will be produced by March 2010.

ARC (NI) has appointed a Project Manager, Edna Dunbar who is accountable to the Project Director and will take forward the Framework development process on a day-to-day basis. The Project Manager will address the range of tasks identified across the Framework Project areas (see below) and be responsible for the development and completion of tasks which are required to support the various project sub groups. She will receive administration support from an Administrator employed by ARC (NI).

Liaison with DHSSPS

To ensure broad compatibility with the range of other Northern Ireland Service Frameworks, the Learning Disability Service Framework will be developed using the agreed template developed by the Programme Board, with the proposed amendments (Framework Template is set out in Appendix A).

Regular liaison with the Department will be undertaken via the DHSSPS Service Framework Coordinator (Veronica Gillen) who is responsible for coordinating the wider programme of Service Frameworks across Northern Ireland.

As has been noted throughout this Project Initiation Document, responsibility for improving the wellbeing of people with learning disabilities goes beyond HPSS. DHSSPS officials have given a commitment to seeking to secure the involvement of suitably senior colleagues from other relevant Government Departments in the Framework development process viz: DSD, DEL and DE. In the first instance this will be achieved by the establishment of an Interdepartmental Liaison Group to which the Project Director will have access. Detailed mechanisms for links between this group and the various service framework project teams will be clarified by DHSSPS at a later stage.

Liaison with the Mental Health and Learning Disability Board of Experts will be provided by Professor Roy McConkey.

External Quality Assurance

Two external experts will be invited to provide external quality assurance.

Each will be acknowledged experts from outside Northern Ireland. They will be invited to comment on the emerging draft standards. Their advice would be considered before the draft consultation document is prepared in September 2009.

Project Team

A Project Team will meet every 6 weeks to manage and direct the development of the Framework. The composition of the Project Team is detailed below.

Project Team

Siobhan Bogues	Chair	ARC
Jim Simpson	Project Board	WHSSB
Veronica Gillen	Service Frameworks Coordinator	DHSSPS
Edna Dunbar	Project Manager	ARC
John Mullen	Service User	Equal Lives Group
Orlaigh Cassidy	Service User	Equal Lives Group
Sandra Harris	Family Carer	Equal Lives Action Group
Bria Mongan	Chair Children and Young People Working Group	SEHSCT
Sam Vallely	Chair Adult Fuller Lives Working Group	NHSCT
Bryce McMurray	Chair Accommodation Working Group	SHSCT
Rosaleen Harkin	Chair Ageing Well Working Group	WHSCT
Miriam Somerville	Chair Health Working Group	BHSCT
Charlie Bamford	DHSSPS	OSS
Gillian Seeds / Patricia Swann	DHSSPS	Policy Branch
Adrian Walsh	Finance Advisor	EHSSB

Tom Smith	Commissioner	SHSSB
Roy McConkey	Mental Health and Learning Disability Board of Experts	

Working Groups

Five working groups will be established each of which will be chaired by a Trust Director of Learning Disability. Each group will meet up to 4 occasions and will be responsible for producing draft standards on the following areas:-

- Children and Young People
- Adult Fuller Lives
- Accommodation and Support
- Ageing Well
- Health

Each working group will ensure representation of key stakeholders including user and carer interests, independent sector and appropriate health and social care professionals which may include pharmacy, psychiatry, psychology, nursing, social work, GP, AHP representation. When appropriate representation of agencies and departments outside HPSS will be sought.

Methodology

The Framework development process will proceed in 5 broad stages:

Stage 1 Establishing the Project (April – October 2008)

During this stage the basic project infrastructure will be established to include:

- design and secure approved budget
- appointment of Administrator and Project Manager
- confirmation of Project Team membership and initial scoping meeting
- approval secured from DHSSPS to PID.

Stage 2 Establish Project Working Groups (October – November 2008)

After the initial set up phase the main Framework development process will be taken forward by the following project Working Groups.

- Children and Young People

- Adult Fuller Lives
- Accommodation and Support
- Ageing Well
- Health

During this phase the Working Groups will be established as follows.

Generic Terms of Reference Produced

In order to ensure that each Working Group adopts an appropriate approach, their work will be directed by a very specific terms of reference drawn up by the Project Team that meets both the DHSSPS Template requirements and avoids the risk of the process being unnecessarily complicated or prolonged. The terms of reference will include guidance on the overarching themes that must be addressed by each group viz:

- Areas where there is an overlapping responsibility with other agencies or government beyond HPSS
- The manner in which the adoption of standards will result in improved personal outcomes for people with a learning disability
- Resource issues highlighted to the DHSSPS Board
- Family Support
- Advocacy
- Increased control

Representation Secured

Appropriate representation will be drawn from across the HPSS, service users, family carers and other agencies/sectors as deemed appropriate. Each Working Group will include as a minimum the following:

- Chair
- HPSS Board representative
- Health and social care professionals as appropriate – this may include pharmacy, nursing, social work, GP, AHP representation
- Service User
- Family Carer

- Independent Sector
- Other Government Department/Agency officials as relevant to the work of the Working Group

Preliminary Scoping of Evidence Base

Information resources for each sub group will be developed to include links to existing policy documents, relevant research and standards from other parts of the UK. The Project Manager will be tasked with seeking out literature which includes evidence based and/or national level standards proposed or already in place elsewhere. This will largely be a tabletop exercise undertaken within the 5 Working Group themes. It is understood that much of this material has already been gathered by DHSSPS and that the research base for the Equal Lives review will also be a prime source of evidence.

Stage 3 Developing the Framework (January 2009 – April 2009)

The main activities during this phase will be taken forward within the Working Groups as they distil the available evidence into proposed standards using the template provided. The Project Team will meet regularly during this phase to receive updates on progress and where required steer the Working Groups' activities.

Stage 4 Production of Initial Draft Framework (May – August 2009)

During this phase the Project Team will work closely to bring together the various Working Groups proposals into a coherent draft Framework. This draft will be shared with key stakeholders in a series of consultation meetings prior to the submission of the initial draft to DHSSPS in August 2009.

Stage 5 Refinement of the Framework (September – November 2009)

This phase will involve close liaison with DHSSPS officials on editing the initial draft and completing the necessary final documents including an Affordability Analysis, Equality Impact Assessment and check for compliance with legislation and policy.

Stage 6 Consultation and production of final, approved framework (March 2010)

It is understood that arrangements for public consultation and production of the final Framework will be the responsibility of DHSSPS officials. During this phase the Project

Team will be available to meet and provide feedback and advice to officials on issues raised by the consultation process.

Project Timeline

STAGE	PRODUCTS	TIME SCALE
1 Establish the Project		April – July 2008
<ul style="list-style-type: none"> • Design and secure approved budget • Appointment of Administrator and Project Manager • Establish Project Board • Confirmation of Project Team membership and initial meeting • Approval secured to PID 	Approved budget Job descriptions and personnel specifications Terms of reference and membership of Project Team Approved final PID	
2 Establish Project Working Groups		October – November 2008
<ul style="list-style-type: none"> • Produce Terms of Reference • Representation Secured • Preliminary Scoping of Evidence Base • Initial meetings of each Working Group 	Information resource for each Working Group Terms of reference for each Working Group	
3 Develop the Framework		January 2009 – April 2009
<ul style="list-style-type: none"> • Distillation of evidence • Draft standards 	Draft standards for each Working Group theme	
4 Production of the initial, draft Framework		May – August 2009
<ul style="list-style-type: none"> • Collation of standards • Initial consultation with key stakeholders 	Draft Service Framework document	

STAGE	PRODUCTS	TIME SCALE
Stage 5 Refinement of the Framework <ul style="list-style-type: none"> • 		September – November 2009
<ul style="list-style-type: none"> • Complete Equality Impact Assessment • Check for compliance with Human Rights Legislation • Ongoing edit and final draft 	Draft Learning Disability Service Framework to DHSSPS	
5 Consultation and production of final, approved framework	Learning Disability Service Framework	March 2011

APPENDIX A

TEMPLATE FOR SERVICE FRAMEWORKS

All Service Frameworks will be developed using the attached template. Where appropriate, there will be areas of overlap between the different frameworks eg lifestyle factors and health promotion topics. In recognition of this and in acknowledgement of the considerable amount of information and guidance that is already available, it is proposed that the Department will develop a frameworks website. This will allow linkages and cross referencing between the frameworks and to other documents or websites. Such an approach will facilitate the regular updating of frameworks, and will provide the service user with easy access to further information.

The frameworks should contain sections relating to

- A** Background/epidemiology/statistics/standards table;
- B** Prevention/Health Promotion/Lifestyle Factors/risk and choice/rights and responsibilities;
- C** Condition specific chapters eg CHD, asthma and care pathways;
- D** End-of-life Care/Palliative Care/discharge; and
- E** Process of review.

Sections **B** to **D** will follow the format of table 1 below. They will describe the evidence based standards and rationale, quality dimensions and performance indicators.

Table 1

Overarching Standard
Rationale/evidence and reference to existing guidance eg NICE, CREST and SCIE

Quality Dimensions		Responsibility for delivery/ implementation	
Performance Indicator	Data Source for PI	Expected Performance Level	Date to be achieved by

As the frameworks will be available to the public, the Project Teams will develop them in line with flow chart 1 (below), using easily understandable language and terminology. It is anticipated that the health promotion/prevention/lifestyle factors (eg smoking, obesity etc) and end-of-life care/palliative care/discharge, will be similar for most of the specific conditions identified within a single service framework and shared, where appropriate, between other relevant Service Frameworks eg cardiovascular and respiratory health and wellbeing, and cancer care. Hence, there will be general chapters (B and D) to address these issues, but any condition specific issues can also be addressed within the appropriate chapter. The aim of this approach is to avoid duplication of effort.

Flowchart 1 – Template for Development of Service Frameworks

Section B

Section C

Section C

Section D

Section C/D

Section D

The standards will be colour co-ordinated throughout the documents for ease of reference eg standards related to assessment and diagnosis will be yellow.

Appendix 1 Heart Failure

Overarching standard:

All patients should have an accurate diagnosis of heart failure and timely access to diagnostic tests.

Rationale:

Early detection of heart failure enables appropriate and clinically effective treatments to be commenced in a timely way, enabling support for patients to maintain as healthy a lifestyle as possible with minimum hospitalisation.

NICE Guidelines on the Management of Heart Failure were produced in 2003. CREST Guidelines on the management of Chronic Heart Failure In Northern Ireland were produced in 2005.

Both NICE and CREST guidelines represent best practice for the management of chronic heart failure. This is available on www.nice.org and www.crestni.org.uk

Quality Dimension		Responsibility for delivery/ implementation	
Patients with a diagnosis of heart failure should have had an Echocardiography (ECHO).		GP HSSA/LCG Trusts	
Patients who are referred to ECHO should have had an abnormal BNP test or ECG		GP HSSA/LCG Trusts	
Performance Indicator:	Data source	Expected Performance Level	Date to be achieved by
Percentage of patients	Heart failure		

<p>referred for ECHO for investigation of heart failure who have had an abnormal BNP* or abnormal ECG.</p> <p>Percentage of patients with heart failure who have had an ECHO** to confirm the diagnosis.</p>	<p>minimum data set</p> <p>Quality and Outcomes Framework (QOF)</p>		
<p>Article I. <u>Data Source for Performance Indicator</u></p> <p>Heart Failure minimum data set</p> <p>QOF</p>			

* B-type natriuretic peptide is a blood test that is helpful to determine the diagnosis of heart failure

** ECHO cardiogram is an ultrasonic scan of the heart used as part of the assessment and diagnosis of heart failure

APPENDIX B PROJECT STRUCTURE

