Department of
Health, Social Services and Public Safety
www.dhsspsni.gov.uk

LEARNING DISABILITY SERVICE FRAMEWORK

Working for a Healthier People

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Foreword

As Minister for Health I am determined to protect and improve the quality of health and social care services and ensure that these are safe, effective and focussed on the patient. Driving up the quality of services and outcomes for people will be my underlying priority. I am committed to working, not only to improve health but to tackle inequalities in health.

I am particularly pleased, therefore, to launch the Learning Disability Service Framework for implementation. This Framework aims to improve the health and wellbeing of people with a learning disability, their carers and families, by promoting social inclusion, reducing inequalities in health and social wellbeing and improving the quality of health and social care services, especially supporting those most vulnerable in our society.

Service Frameworks aim to set out clear standards of health and social care that are both evidence based and measurable. They set out the standard of care that service users and their carers can expect, and are also to be used by health and social care organisations to drive performance improvement through the commissioning process. The Learning Disability Service Framework is one of five Frameworks to be issued for implementation to date and, that focus on the most significant causes of ill health and disability in Northern Ireland, namely: cardiovascular disease, respiratory disease, cancer, mental health and learning disability. Two further Frameworks, for children and young people and older people are currently at various stages of development.

This latest Framework has been developed actively involving a wide range of people across all aspects of health and social care including, patients, clients and carers, all of whose support has been invaluable. I would like to convey my sincere thanks, to you all, for your immensely important contribution.

Edwin Poots MLA
Minister for Health, Social Services and Public Safety

LEARNING DISABILITY SERVICE FRAMEWORK

Summary of Standards

Safeguarding and Communication and Involvement in the Planning and Delivery of Services

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 1: (Generic) All HSC staff should ensure that people of all ages are safeguarded from harm through abuse, exploitation or neglect.	1. All HSC organisations and organisations providing services on behalf of the HSC have a **Safeguarding Policy** in place, which is effectively aligned with other organisational policies (e.g. recruitment, governance, complaints, SAIs, training, supervision, etc.) The Safeguarding Policy is supported by robust procedures and guidelines. 2. All HSC organisations and organisations providing services on behalf of the HSC have **Safeguarding Plans** in place. 3. All HSC organisations and organisations providing services on behalf of the HSC have **safeguarding champions** in place in order to promote awareness of safeguarding issues in their workplace.	Establish baseline Performance levels to be determined once baseline established Establish baseline Performance levels to be determined once baseline established Establish baseline Performance levels to be determined once baseline established

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 2: People with a learning disability should as a matter of course make choices or decisions about their individual health and social care needs. This needs to be balanced with the individual's ability to make such decisions and then the views of their family, carers and advocates should be taken into account in the planning and delivery of services, unless there are explicit and valid reasons to the contrary agreed with the person.	1. Evidence that people with a learning disability their family and carers have been involved in making choices or decisions about their individual health and social care needs.	Establish baseline Performance levels to be determined once baseline established.
Standard 3: (Generic) All patients, clients, carers and the public should have opportunities to be actively involved in the planning, delivery and monitoring of health and social care at all levels.	1. To be developed by Commissioners	Establish baseline Performance levels to be determined once baseline established.
Standard 4: Adults with a learning disability should be helped by HSC professionals to develop their capacity to give or refuse informed consent.	1. Organisations that care for and support people with a learning disability have organisational strategies and/or policies for person and public involvement. 2. Evidence that robust processes are in place where capacity has been judged to be an issue within HSC services or services commissioned by HSC.	All HSC organisations Develop and implement SAAT Performance levels to be determined based on outcomes of SAAT.

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 5 (Generic) All patients, clients, carers and the public should be engaged through effective communications by all organisations delivering health and social care.	1. To be developed by Commissioners	Establish baseline Performance levels to be determined once baseline established.
Standard 6: People with a learning disability should expect effective communication with them by HSC organisations as an essential and universal component of the planning and delivery of health and social care	1. Percentage of people with a learning disability who do not use speech as their main form of communication who have been supported to establish a functional communication system. 2. Develop and agree a regional training plan for staff in both HSC and services commissioned by HSC to raise awareness of communication difficulties and how they may be addressed.	Develop and implement SAAT Performance levels to be determined based on outcomes of SAAT. Regional Training Plan in place. Training is delivered in accordance with Regional Training Plan.
Standard 7: People with a learning disability should receive information about services and issues that affect their health and social wellbeing in a way that is meaningful to them and their family.	1. All HSC organisations should provide evidence that they are making information accessible to people with a learning disability. 2. Each person with a learning disability can access a named person who can signpost them to relevant services.	Development and implementation of SAAT. Performance levels to be determined once baseline established. Establish baseline of information provided Performance levels to be determined once baseline established.

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 8: People with a learning disability, or their carer, should be able to access self directed support in order to give them more control and choice over the type of care and support they receive.	1 Evidence of provision of accessible information on Direct Payments within HSC organisations.	Develop and implement SAAT. Establish performance levels based on outcomes from SAAT.
	2 Percentage of requests for Direct Payments from people with a learning disability that were approved.	Develop and implement SAAT. Establish performance levels based on outcomes from SAAT.
	3 Number of adults with a learning disability in receipt of Direct Payments expressed as a percentage of those in contact with Trust (regional percentage is 2.25%).	Performance levels to be determined based on available resources and included in final Framework
	4 Number of children with a learning disability in receipt of Direct Payments expressed as a percentage of those in contact with Trust (regional percentage is 3.50%).	Performance levels to be determined based on available resources and included in final Framework
	5 The HSC Board and Trusts have plans in place to extend the range and scope of self directed support including how they will develop skills and expertise in relevant staff.	HSC Board and all Trusts.
Standard 9 (Generic) Service users and their carers should have access to independent advocacy as required.	1. To be developed by Commissioners	Establish baseline Performance levels to be determined once baseline established.

Children and Young People

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 10: From the point at which concerns are raised that a child or young person may have a learning disability, there is an action plan in place to determine the nature and impact of the learning disability	1. Percentage of parents who express satisfaction with the assessment process and how the outcomes were conveyed.	Establish baseline of information provided. Performance levels to be determined once baseline established.
Standard 11: Children and young people should receive child-centred and co-ordinated services through assessment to ongoing care and support from the point at which a determination has been made that they have a learning disability.	1 Percentage of children and young people with a learning disability and carers who have been offered an assessment either under the Family Health Needs Assessment or UNOCINI Assessments. 2 Percentage of children and young people who have an agreed support plan detailing a pathway to receiving appropriate care and support.	Establish baseline Performance levels to be determined once baseline established Establish baseline Performance levels to be determined once baseline established

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 12: HSC services should respond to the needs of children and young people who have a learning disability and complex physical health needs in a manner that is personalised, developmentally appropriate and which support access to appropriate care.	1 Percentage of parents whose child has a learning disability and complex physical health needs who have an identified key worker with co-ordinating responsibility. 2 Percentage of children and young people with complex physical health needs who have effective transition arrangements in place between hospital and community. 3 Percentage of children with a learning disability and complex physical health needs who have received a multi-professional assessment using the regional universal assessment tool. 4 Percentage of children and young people with a learning disability and complex physical health needs who are receiving care under the integrated care pathway.	Scope requirements and produce audit plan. Audit 50% of information available. 100%. Establish baseline Performance level to be established when baseline is established. Fast Trace arrangements for access to hospital/community services to be audited following establishment of baseline. 90% 95% 98% Establish baseline Performance levels to be determined once baseline established

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 13: Any child or young person who cannot live at home permanently should have their placement/ accommodation needs addressed in a way that takes full account of their learning disability.	1 Percentage of looked after children or young people with a learning disability who cannot live with their families who have a Permanency Plan. 2 Percentage of looked after children or young people with a learning disability who cannot live at home, who have access to specialised placements where the need for this is indicated in the Permanency Plan.	Establish baseline Performance levels to be determined once baseline established Establish baseline Performance levels to be determined once baseline established

Entering Adulthood

Standard 14: Young people with a learning disability should have a transition plan in place before their 15th birthday and arrangements made for their transition to adulthood by their 18th birthday.	1. Percentage of young people who express satisfaction that their transition plan has been implemented within 2 years of leaving school. 2. Evidence of transfer to DES, where appropriate, for health checks for children on transition to adult services.	Develop and implement SAAT Performance levels to be determined based on SAAT outcomes 90% 95% 98%.

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 15: People with a learning disability should be supported to have meaningful relationships, which may include marriage and individual, unique, sexual expression within the law, balancing their rights with responsibilities.	1. Regional guidelines on sexuality and personal relationships are developed to ensure a consistent approach. 2. Trusts to facilitate appropriate training for staff. 3. Trusts to facilitate appropriate training for service users and family carers. 4. Increase in the number of people with a learning disability accessing sexual health and reproductive healthcare services.	HSC Board policy developed and agreed. 40% 80% Level to be established pending development of regional policy. Develop and implement SAAT Performance levels to be determined based on SAAT outcomes

Inclusion in Community Life

Standard 16: Adults with a learning disability should be able to access support in order that they can achieve and maintain employment opportunities in productive work.	1. Percentage of school leavers with a learning disability who access work placements or employment within one year of leaving school (as percentage of total learning disabled school leaving population). 2. Percentage of adults with a learning disability who receive HSC support to help them secure employment (as a measure of those who request support).	Establish baseline. Performance levels to be determined once baseline established Establish baseline. Performance levels to be determined once baseline established

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 17: All adults with a severe or profound learning disability should be able to access a range of meaningful day opportunities appropriate to their needs.	1. Percentage of adults with a severe or profound learning disability who have meaningful day opportunities in mainstream community settings. 2. Percentage of adults with a severe or profound learning disability who express satisfaction with the choice of day opportunities they can access.	Establish baseline. Year on year increase to be determined once baseline established. Establish baseline. Year on year increase to be determined once baseline established.
Standard 18: All parents with a learning disability should be supported to carry out their parenting role effectively.	1. Develop and agree a regional protocol between children's and adult services for joint working and care pathways. 2. Percentage of parents with a learning disability who have a multi-professional/agency competence based assessment. 3. Percentage of parents with a learning disability involved in child protection or judicial processes who have received locally based skills training. 4. Percentage of parents with a learning disability involved in child protection or judicial processes who have access to the services of an independent advocate.	HSC Board in collaboration with all Trusts. Establish baseline. Performance levels to be determined once baseline established. 85% 90% 95% Establish baseline. Performance levels to be determined once baseline established.

Meeting General Physical and Mental Health Needs

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 19: All people with a learning disability should have equal access to the full range of health services including services designed to promote positive health and wellbeing.	1. All acute hospitals should have an action plan for implementing the GAIN Guidelines for improving access to acute care for people with a learning disability and be able to demonstrate a clear commitment to the implementation of such a plan. 2. Percentage of GPs who have a system for identifying people with a learning disability on their register. 3. Each GP practice has a designated link professional within local learning disability services. 4. Evidence of reasonable adjustments by health service providers.	All HSC Trusts establish baseline. Performance levels to be determined once baseline established. Baseline as per learning disability DES. Performance levels to be determined once baseline established. Establish baseline. Performance levels to be determined once baseline established. Establish baseline. Performance levels to be determined once baseline established.
Standard 20: (Generic) All HSC staff, as appropriate, should advise people who smoke of the risks associated with smoking and signpost them to well-developed specialist smoking cessation services.	1. Percentage of people accessing smoking cessation services who have heard about the service from an HSC professional. 2. Percentage of people accessing smoking cessation services offered by HSC providers who have quit.	Establish baseline. Performance levels to be determined once baseline established. Establish baseline. Performance levels to be determined once baseline established.

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 21: All people with a learning disability should be supported to achieve optimum physical and mental health.	1. Each HSC Trust has a health improvement strategy for people with a learning disability (children and adults) to address all relevant physical and mental health promotion and improvement needs.	All Trusts have in place a health improvement strategy for people with a learning disability.
	2. Percentage of adults with a learning disability who have an annual health check.	Establish baseline. Performance levels to be determined once baseline established.
	3. Percentage of adults with a learning disability, who have an up to date and active Health Action Plan (HAP) following the annual health check.	Establish baseline. Performance levels to be determined once baseline established.
	4. Percentage of people with a learning disability who have been examined by a dentist in the past year.	Establish baseline. Performance levels to be determined once baseline established.
	5. Percentage of females with a learning disability who access cervical and breast screening services.	Establish baseline. Performance levels to be determined once baseline established.
	6. Percentage of people with a learning disability who have a sight test with an optometrist in the past year.	Establish baseline. Performance levels to be determined once baseline established.

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 22: All people with a learning disability who experience mental ill health should be able to access appropriate support.	1. A regional protocol is developed to ensure that people with a learning disability can access mainstream mental health services. 2. Percentage of people with a learning disability and mental health needs who access mainstream mental health services e.g. psychological and talking therapies where indicated in their treatment plan. 3. Percentage of Health Action Plans and health checks which include mental health assessment and mental health promotion.	Protocol in place. Establish baseline. Performance levels to be determined once baseline established. Establish baseline. Performance levels to be determined once baseline established.
Standard 23: (Generic) All HSC staff, as appropriate, should provide people with healthy eating support and guidance according to their needs.	1. Percentage of people eating the recommended 5 portions of fruit or vegetables each day.	Establish baseline. Performance levels to be determined once baseline established.
Standard 24: (Generic) All HSC staff, as appropriate, should provide support and advice on recommended levels of physical activity.	1. Percentage of people meeting the recommended level of physical activity per week.	Establish baseline. Performance level to be determined once baseline established.

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 25: (Generic) All HSC staff, as appropriate, should provide support and advice on recommended levels of alcohol consumption.	1. Percentage of people who receive screening in relation to their alcohol consumption.	Establish baseline. Performance level to be determined once baseline established.

Meeting Complex Physical and Mental Health Needs

Standard 26: All people with a learning disability whose behaviour challenges should be able to get support locally from specialist learning disability services and other mainstream services, as appropriate, based on assessed need.	1. Percentage of individuals with significant challenging behaviours who have a Behaviour Support Plan including advance directives in place that detail actions to be undertaken in the event of their challenging behaviours escalating. 2. Where challenging behaviours present a significant risk to the individual or others or a risk of breakdown in accommodation arrangements, a specialist assessment has been completed within 24 hours. 3. Where challenging behaviours present a significant risk to the individual, a Management Plan has been developed and implemented within 48 hours. 4. Evidence that HSC has engaged with other relevant delivery partners in developing and implementing consistent approaches in individual cases.	Establish baseline. Performance level to be determined once baseline established. Establish baseline. Performance level to be determined once baseline established. Establish baseline. Performance level to be determined once baseline established. All HSC Trusts

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 26 (continued)	5. Percentage of people labelled as challenging who are not living in a congregate setting described as a challenging behaviour or specialist assessment/treatment service.	Establish baseline Performance levels to be determined once baseline established
Standard 27: All people with a learning disability who come into contact with the Criminal Justice System should be able to access appropriate support.	1. Evidence that the HSC has engaged and developed local protocols with relevant delivery partners to achieve consistent and co-ordinated approaches to working with people with a learning disability who have offended or are at risk of offending.	Protocols in place.

At Home in the Community

Standard 28: HSC professionals should work in partnership with a variety of agencies in order to ensure that the accommodation needs of people with a learning disability are addressed.	1. Percentage of support plans that take account of people's aspirations in relation to future accommodation needs, including independent living. 2. Percentage of parents with a learning disability who have a multi-professional/agency competence based assessment. 3. Percentage of people in receipt of public funding living in households of 5 people or less with a learning disability.	Develop and implement SAAT Performance levels to be determined based on SAAT outcomes Develop and implement SAAT Performance levels to be determined based on SAAT outcomes Develop and implement SAAT Performance levels to be determined based on SAAT outcomes

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 28 (continued)	4. Percentage of people (including the resettlement population) leaving learning disability hospital within one week after treatment has been completed.	95% 97% 100%
Standard 29 (Generic) All HSC staff should identify carers (whether they are parents, family members, siblings or friends) at the earliest opportunity to work in partnership with them and to ensure that they have effective support as needed**.**	1. Number of HSC Trust front line staff in a range of settings participating in Carer Awareness Training Programmes 2. The number of carers who are offered Carers Assessments 3. The percentage of carers who participate in Carers Assessments	Improvement targets set by H&SC Board in conjunction with Carers Strategy Implementation Group
Standard 30: All family carers should be offered the opportunity to have their needs assessed and reviewed annually.	1. Percentage of carers who express satisfaction at their annual review that their needs as identified in the carers' assessment have been met.	Establish baseline. Performance levels to be determined once baseline established.

Ageing Well

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 31: All people with a learning disability should have the impact of ageing taken into account in having their future needs assessed and proactively managed.	1. Percentage of people whose care plan has been reviewed taking account of issues associated with ageing. 2. Percentage of carers aged 65 years and over receiving domiciliary or short break support services.	Develop and implement SAAT Performance levels to be determined based on SAAT outcomes Develop and implement SAAT Performance levels to be determined based on SAAT outcomes
Standard 32: All people with a learning disability should have access to dementia services at whatever age it becomes appropriate for the individual.	1. Percentage of people with a learning disability and dementia who can access appropriate dementia services as required. 2. Percentage of people with a learning disability and dementia who have received additional supports following a dementia diagnosis. 3. Percentage of HSC professionals and other support providers who have received awareness training on the needs of people with a learning disability and dementia.	Establish baseline. Performance levels to be determined once baseline established. Develop and implement SAAT Performance levels to be determined based on SAAT outcomes Establish baseline. Performance levels to be determined once baseline established.

Palliative and End of Life Care

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 33: (Generic) All people with advanced progressive incurable conditions, in conjunction with their carers, should be supported to have their end of life care needs expressed and to die in their preferred place of care	1. Percentage of the population that is enabled to die in their preferred place of care. 2. Percentage of population with a understanding of advance care planning	Establish baseline. Performance levels to be determined once baseline established. Establish baseline. Performance levels to be determined once baseline established.
Standard 34: All people with a learning disability being assessed for supportive and palliative care should have their learning disability taken into account in consultation with them, their carers and learning disability services when appropriate.	1. Palliative care services have mechanisms to identify whether people have a learning disability. 2. Evidence of specific actions in service delivery that make reasonable adjustment for their learning disability.	Establish baseline. Performance levels to be determined once baseline established. Establish baseline. Performance levels to be determined once baseline established.

A NOTE ON TERMINOLOGY

The following terms will be used throughout this document:

> ‘carer’ will be used to describe a family member including children and young people or informal carers
>
> ‘HSC organisation’ will be used to describe a variety of health and social care providers, such as, the HSC Board, HSC Trusts and the Public Health Agency.
>
> ‘service user’ will be used to describe those who use learning disability services

A glossary of terms used is provided in Annex A

CHAPTER 1: INTRODUCTION TO SERVICE FRAMEWORKS

Background

The overall aim of the Department of Health, Social Services and Public Safety (DHSSPS) (the Department) is to improve the health and social wellbeing of the people of Northern Ireland (NI).

In support of this the Department is developing a range of Service Frameworks, which set out explicit standards for health and social care that are evidence based and capable of being measured.

The first round of Service Frameworks focuses on the most significant causes for ill health and disability - cardiovascular health and wellbeing; respiratory health and wellbeing; cancer prevention, treatment and care; mental health and wellbeing; and learning disability. Work has also commenced to develop Service Frameworks for children and young people and older people.

Service Frameworks have been identified as a major strand of the reform of health and social care services and provide an opportunity to:

- strengthen the integration of health and social care services;
- enhance health and social wellbeing, to include identification of those at risk, and prevent/ protect individuals and local populations from harm and /or disease;
- promote evidence-informed practice;
- focus on safe and effective care; and
- enhance multi-disciplinary and inter-sectoral working.

Aim of Service Frameworks

Service Frameworks will set out the standards of care that service users, their carers and wider family can expect to receive in order to help people to:

- prevent disease or harm;
- manage their own health and wellbeing including understanding how lifestyle affects health and wellbeing including the causes of ill health

and its effective management;

- be aware of what types of treatment and care are available within health and social care; and
- be clear about the standards of treatment and care they can expect to receive.

All Service Frameworks incorporate a specific set of standards that are identified as Generic. These, essentially, are intended to apply to all the population, or all HSC professionals or all service users, regardless of their health condition or social grouping. These include:

- safeguarding (Generic Standard 1);
- involvement (Generic Standard 3);
- communication (Generic Standard 5);
- independent advocacy (Generic Standard 9);
- smoking prevention & cessation (Generic Standard 20);
- healthy eating (Generic Standard 23);
- physical activity (Generic Standard 24);
- alcohol (Generic Standard 25);
- carers (Generic Standard 29); and
- palliative care (Generic Standard 33).

These Generic standards reinforce the holistic approach to health and social care improvement and reflect the importance of health promotion in preventing medical or social care issues occurring in the first place. Their inclusion ensures:

- equality of opportunity for all;
- the communication of consistent messages to service users and providers of HSC; and
- a consistent approach in the design and delivery of services.

Service Frameworks will be used by a range of stakeholders including commissioners, statutory and non-statutory providers, and the Regulation and Quality Improvement Authority (RQIA) to commission services, measure performance and monitor care.

The Frameworks will identify clear and consistent standards informed by expert advice, research evidence and by national standard setting bodies such as the National Institute for Health and Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE). The auditing and measuring of these standards will be assisted by the Guidelines and Implementation Network (GAIN) which will facilitate regional audit linked to priority areas, including Service Frameworks.

The standards, in the context of the 10 year Quality Strategy[1], will aim to ensure that health and social care services are:

i. **Safe** – health and social care which minimises risk and harm to service users and staff;

ii. **Effective** – health and social care that is informed by an evidence base (resulting in improved health and wellbeing outcomes for individuals and communities), is commissioned and delivered in an **efficient** manner (maximising resource use and avoiding waste), is **accessible** (is timely, geographically reasonable and provided in a setting where skills and resources are appropriate to need) and **equitable** (does not vary in quality because of personal characteristics such as age, gender, ethnicity, race, disability (physical disability, sensory impairment and learning disability), geographical location or socioeconomic status).

iii. **Person centred** – health and social care that gives due regard to the preferences and aspirations of those who use services, their family and

[1] Quality 2020: A 10-Year Quality Strategy for Health and Social Care in Northern Ireland

carers and respects the culture of their communities. A person of any age should have the opportunity to give account of how they feel and be involved in choices and decisions about their care and treatment dependent on their capacity to make decisions. In absence of the capacity to make decisions they should listen to those who know and care for the person best.

Involving and communicating with service users, carers and the public

The Department has produced guidance, "Strengthening Personal and Public Involvement in Health and Social Services"[2], which sets out values and principles which all health and social care organisations and staff should adopt when engaging with the public and service users. These include the need to involve people at all stages in the planning and development of health and social care services. This policy position has been strengthened by the introduction of the Health and Social Care (Reform) Act (Northern Ireland) 2009 and the statutory duty it places on HSC organisations to involve and consult with the public. (Art 19)

It is important that the views of service users and carers are taken into account when planning and delivering health and social care. The integration of the views of service users, carers and local communities into all stages of the planning, development and review of Service Frameworks is an important part of the continuous quality improvement and the open culture which should be promoted in HSC.

The Department is committed to involving those who use learning disability services (experts by experience), their carers and wider families. Through the proactive involvement of the service users and carers in the planning of Service Frameworks, it is hoped that concerns and ideas for improvement can be shared and that the standards developed in partnership with service users,

[2] DHSSPS (2007) Guidance on Strengthening Personal and Public Involvement in Health and Social Care (HSC (SQSD) 29/07) http://www.dhsspsni.gov.uk/hsc_sqsd_29-07.pdf

carers and the public will focus on the issues that really matter to them.

It is also important that Service Frameworks provide service users and carers with clear and concise information, which is sensitive to their needs and abilities, so that they can understand their own health and wellbeing needs. To facilitate this, easy access versions will be made available for all Service Frameworks. Service Frameworks will also be made available in various other formats e.g. Braille, large print and audio tape. The Department will also consider requests for other formats or translation into ethnic minority languages.

People are ultimately responsible for their own health and wellbeing and that of their dependents, and it is important that service users, their carers and wider family are made aware of the role they have to play in promoting health and wellbeing.

Involving other agencies in promoting health and wellbeing

Improving the health and wellbeing of the population requires action right across society and it is acknowledged that health and wellbeing is influenced by many other factors such as poverty, housing, education and employment. While Service Frameworks set standards for providers of health and social care services it is essential that HSC services work in partnership with other government departments and agencies both statutory and non-statutory to seek to influence and improve the health and social wellbeing of the public.

People who use health and social care services, including learning disability services, may have complex needs which require inputs from a range of health and social care professionals and other agencies.

The benefits of multidisciplinary team working and multiagency working, including voluntary and community organisations, are well recognised and it is a key component of decision making regarding prevention, diagnosis,

treatment and ongoing care. This will be a key theme underpinning the development and implementation of Service Frameworks.

Data Collection

As Service Frameworks are implemented it is important that timely, accurate information is available to support decision-making and service improvement.

To support this, data sources are identified, early in the development stage, to match the key performance indicator (KPI) data definitions. It is through the data source that progress can be monitored. Where robust baseline data is not available Frameworks will be looking to audits, including Self Assessment Audit Tools (SAATs), to gather information, establish baselines and set future performance levels.

Research and Development

It is important that Service Frameworks are based on valid, relevant published research, where available, and other evidence.

Education and Workforce

Education and workforce development occur at individual, team, organisational, regional and national levels: they are part of the drive to promote quality. The ongoing development and implementation of Service Frameworks will influence the education and training agenda and curricula content for all staff involved in the delivery of health and social care. This will require a commitment to lifelong learning and personal development alongside a focus on specific skill areas to ensure that newly qualified and existing staff are in a position to deliver on quality services.

Leadership

Effective leadership is one of the key requirements for the implementation of Service Frameworks and will require health and social care professionals from primary, community and secondary care to work together across organisational boundaries, including other governmental departments and the voluntary and community sectors. It is essential that Service Frameworks are given priority at senior, clinical and managerial level and implemented throughout all HSC organisations.

Affordability

Extensive discussions have been held with key stakeholders on the overall costs of delivering the Learning Disability Service Framework in the context of the very significant challenges facing health and social care services. Many of the standards do not require additional resources and should be capable of delivery by optimising the use of existing funding. Where there are additional costs associated with specific standards, performance indicators and targets will be reviewed and adjusted as necessary, in the light of the available resources in any one year.

Securing additional funding that may be needed to advance some standards will undoubtedly create challenges. However, Service Frameworks constitute the distillation of the best advice and guidance available and there is great value in setting out our aspirations to improve quality in the care of people with a learning disability, even if we cannot commit to achieving every standard fully or as quickly as we would like. Even in the most difficult of times we must continue to set challenging targets in an effort to improve services.

The Department will work closely with the HSC Board, and other stakeholders, in developing an achievable, prioritised implementation plan for this Service Framework that will deliver real benefits and improved quality of services.

CHAPTER 2: LEARNING DISABILITY SERVICE FRAMEWORK

Introduction

The aim of the Learning Disability Service Framework is to improve the health and wellbeing of people with a learning disability, their carers and their families by promoting social inclusion, reducing inequalities in health and social wellbeing, and improving the quality of care.

The Learning Disability Service Framework sets standards in relation to:

- safeguarding and communication and involvement in the planning and delivery of services
- children and young people
- entering adulthood
- inclusion in community life
- meeting general physical and mental health needs
- meeting complex physical and mental health needs
- at home in the community
- ageing well
- palliative and end of life care

The Learning Disability Service Framework is initially for a three-year period from 2013 – 2016. It will be the subject of further review and continuing development as a living document as performance indicators are achieved, evidence of changed priorities emerge and new performance indicators are identified.

Process for developing the Learning Disability Service Framework

The development of Service Frameworks is overseen by a multi-disciplinary Programme Board, which is jointly chaired by the Chief Medical Officer and the Deputy Secretary of the Department. The Learning Disability Service Framework was lead by a Project Board who were accountable to the

Department's Programme Board for ensuring the completion of the project within agreed timescales and to DHSSPS guidelines. The Project Board was informed by a project team with representation from all aspects of the service including service users, carers, advocates and voluntary organisations. The full project membership is set out in Annex B.

In order to develop the standards, 5 working groups were established which ensured broader representation and expertise. These groups and their membership are set out in Annex C. These groups produced the preliminary reports that informed the development of the standards.

External quality assurance was provided by Mr Rob Greig, National Development Team for Inclusion (NDTi) and Dr Margaret Whoriskey, Scottish Executive.

Equality Screening

The Framework has been screened to take account of Section 75 of the Northern Ireland Act 1998 and any potential impact that the Framework might have on Human Rights. It is the recommendation of the Project Team that the Framework does not negatively impact on equality of opportunity and therefore does not require a full Equality Impact Assessment.

Values

The core values outlined in the Equal Lives Review (2005) have been adopted in full in the development of the Learning Disability Service Framework. These core values when enshrined in practice will ensure that independence is promoted for all people with a learning disability. (Annexe D)

Policy and Legislative Context

The Learning Disability Service Framework is congruent with the legal and policy context for the delivery of supports to people with a learning disability.

This has over recent years increasingly been underpinned by concepts of rights, inclusion and citizenship.

The onus on public authorities to promote equality of opportunity is also enshrined in the Northern Ireland Act (1998) which states that "*a public authority shall, in carrying out its functions in Northern Ireland, have due regard to the need to promote equality of opportunity between persons with a disability and persons without."*

The Reform and Modernisation of Mental Health and Learning Disability Services Review (Bamford - May 2007)

A review of policy, practice and legislation relating to Mental Health and Learning Disability was commissioned by DHSSPS in October 2002. The Review concluded in August 2007 and produced ten reports (Annex E) that detailed the vision for supporting people with a learning disability, promoting mental health and wellbeing at all levels of society and for the delivery of specialist health and social care for everyone who needs it.

The DHSSPS response to Bamford, 'Delivering the Bamford Vision' (2008) (the Action Plan) states, "*the Northern Ireland Executive accepts the thrust of the recommendations"*, and sets out proposals to take the recommendations forward over the next 10 – 15 years.

The Learning Disability Service Framework builds on the approaches to supporting people with a learning disability proposed in the Bamford Review and the subsequent Action Plan.

Consistency with other documents

The Learning Disability Service Framework has taken cognisance of reports and documents that have been or are being developed by DHSSPS and other regional groups, including:

- Transforming Your Care (DHSSPS, 2011)
- *Investing for Health* strategies;
- The Quality Framework – as outlined in *Best Practice Best Care (2001);*

- The *Reform and Modernisation* of HSC;
- Personal and Public Involvement (PPI) (DHSSPS, 2007)
- National Institute for Health and Clinical Excellence guidance (NICE)
- Social Care Institute for Excellence guidance (SCIE)

Human Rights and Social Inclusion

A key priority for health and social care services and the wider community is to tackle stigma, discrimination and inequality and to empower and support people with a learning disability and their families to be actively engaged in the process. This is underpinned by legislation from Europe and the United Kingdom (UK) as well as international law. A summary of all the relevant documentation can be found in "Promoting Social Inclusion" (including the UN Convention on the Rights of People with Disabilities[3] (UNCRPD)), The Reform and Modernisation of Mental Health and Learning Disability Services (Bamford - May 2007) and the "Human Rights and Equality" Report (Bamford - October 2006).

Human rights, as enshrined in the Human Rights Act (1998) UK, derive from the fundamental principles that:

- human beings have value and should be treated equally based on the fact that they are human beings first and foremost; and
- human worth is not based on either capacity or incapacity.

Human rights include the right to life, liberty and security and respect for a private and family life.

As this Framework also aims to address the particular issues facing children and young people with a learning disability and their family carers it is also underpinned by the four core principles of the UN Convention on the Rights of Children:[4]

- non-discrimination;

[3] UNCRPD http://www.un.org/disabilities/default.asp?id=150
[4] UNCRC http://www.article12.org/pdf/UNCRC%20Official%20Document.pdf

- devotion to the best interests of the child;
- the right to life, survival and development; and
- respect for the views of the child.

How to read the rest of this document

Each Service Framework follows an individual's journey from infancy through to end of life care taking into account the different health and social care needs of children, adults and older people. In the Learning Disability Service Framework each standard is accompanied by a statement written from the perspective of a person with a learning disability, in order to make them more meaningful to those for whom the Framework is primarily aimed.

Each standard sets out the evidence base and rationale for the development of the standard, the impact of the standard on quality improvement as well as the performance indicators that will be used to measure that the standard has been achieved within a specific timeframe. Each standard is presented in the same way. Figure 1 shows the information that is included in each standard.

Explaining the Standards

Overarching Standard This is a short statement that outlines what will be delivered and includes a statement written from the perspective of a person with a learning disability
Rationale This is a short section that outlines why/how the standard will make a difference for people using learning disability services. **Evidence** This includes brief references for the research evidence or guidance that the standard is based on.
Responsibility for delivery/implementation
This lists the HSC organisations tasked with responsibility for delivering the standard. It will include partners in care such as other government departments and agencies and voluntary organisations and community groups that have contractual or service level agreements with health and social care organisations.
Quality Dimensions
The impact of the standard on quality improvement is identified in relation to the five core values outlined in the Equal Lives Review (2005) (Annexe D). These include: • Citizenship • Social Inclusion • Empowerment • Working Together • Individual Support

Performance Indicator	**Data Source**	**Anticipated Performance Level**	**Date to be achieved by**
This information will be monitored to show if the standard is being delivered.	This identifies where the information will be derived from.	This describes how well the service must perform against this indicator.	This specifies when the anticipated performance level should be reached.

Figure 1

Many of the standards apply to both adult services and services for children and young people. Each standard has been colour coded for ease of reference. It should be noted that there are some standards that may apply to both adults and young people, for example, Standard 13 (meaningful relationships) but will continue to be colour coded for adult services.

Standard applies to children, young people and adults with a learning disability

Standard applies only to children and young people with a learning disability

Standard applies only to adults with a learning disability

The rest of this document is divided into the following chapters:

- **Chapter 3** sets out the rationale for developing a Learning Disability Service Framework
- **Chapter 4** sets out the standards for safeguarding and communication and involvement in the planning and delivery of services
- **Chapter 5** sets out the standards for children and young people
- **Chapter 6** sets out the standards for entering adulthood
- **Chapter 7** sets out the standards for inclusion in community life
- **Chapter 8** sets out the standards for meeting general physical and mental health needs
- **Chapter 9** sets out the standards for meeting complex physical and mental health needs
- **Chapter 10** sets out the standards for at home in the community
- **Chapter 11** sets out the standards for ageing well
- **Chapter 12** sets out the standards for palliative and end of life care

CHAPTER 3: WHY DEVELOP A SERVICE FRAMEWORK FOR LEARNING DISABILITY?

Introduction

Learning disability may be defined as follows:

> *A learning disability includes the presence of a significantly reduced ability to understand new or complex information or to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood with a lasting effect on development.* (Equal Lives, 2005)

Prevalence of Learning Disability

In determining the prevalence of learning disability in NI the Bamford Review (2005) cited a study based on information held by the former Health and Social Services Trusts, which estimated the numbers as shown in Table 1.

Table 1: Prevalence Rates (per 1,000) (15)

Age Bands	Mild/Moderate	Severe/Profound	Total
0-19	6432	1718	8150
20-34	2504	1047	3551
35-49	1489	949	2438
50+	1473	753	2226
Totals	**11,898**	**4468**	**16,366**

However, the Review notes that these figures may be an underestimate as many people classed as *possibly having learning disability* may not be making any demands on health and social care services at present but could do so in the future.

Nonetheless, the overall prevalence rate of 9.7 persons per 1000 is higher than that reported for the Republic of Ireland (RoI) and for regions of Great Britain (GB).

The Review also anticipates that there will be increased numbers of people with a learning disability in the next 15 years. In addition, it notes the likelihood that higher proportions of these individuals will have increased care and support needs due to old age or additional complex needs.

Of particular importance to their quality of life is the need to promote their inclusion in society so that individuals with a learning disability can participate in the communities in which they live and access the full range of opportunities open to everyone else.

Developing a Service Framework for people with a learning disability serves a number of functions:

- For people with a learning disability, it details what it is they can expect in terms of care and support to meet their individual needs in ways that they understand and are accessible.
- For carers and families of people with a learning disability, it outlines what it is they can expect in terms of access to services for their family member and of their involvement as partners in the planning processes.
- For staff in front line service delivery, it enables them to communicate effectively in assisting people with a learning disability to access mainstream and specialist HSC services appropriately.
- For commissioners and those with responsibility for the delivery of services in the statutory and independent sectors, it assists them in achieving an integrated model of services and supports around the person in line with the expectations of service users and their families.

Relating the Learning Disability Service Framework to other Service Frameworks

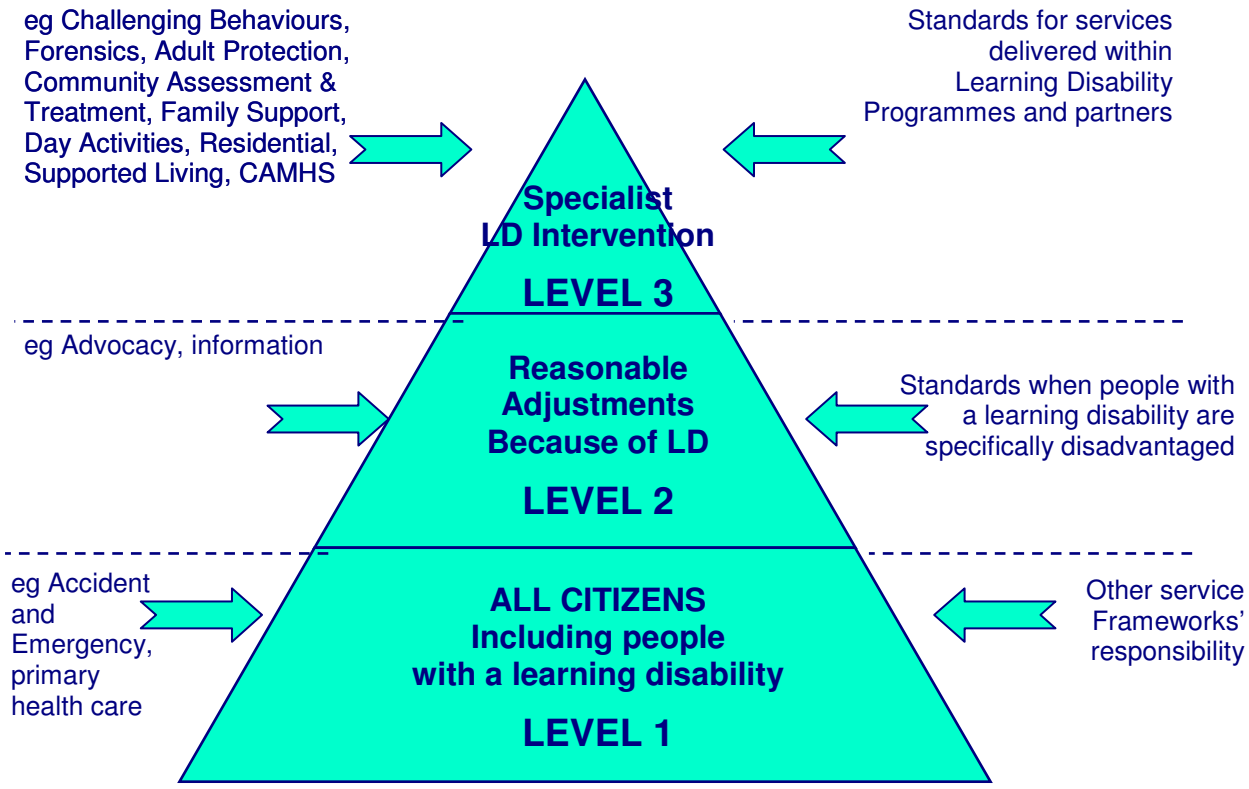

Figure 2

Figure 2 above describes the relationship between the Learning Disability Service Framework and other service frameworks. Each service framework identifies standards related to a specific aspect of health and social care. The needs of people with a learning disability will also be addressed through these frameworks (Level 1).

In many instances HSC providers will need to make adjustments to the care and support they offer in order to make them accessible to people with a learning disability and their families. Current evidence indicates that these necessary adjustments are not consistently in place within HSC services. Standards in the Learning Disability Service Framework will therefore require all HSC services to take the needs of people with a learning disability into account when designing and delivering services (Level 2).

While the basic premise of the Learning Disability Service Framework is that people with a learning disability should access the same HSC services as other people, there are occasions when special expertise or support is required. As services become more inclusive it is anticipated that the volume and range of separate services will decrease as learning disability expertise is developed within mainstream HSC services.

The Learning Disability Service Framework identifies a range of minimum standards that reflect the current service configuration in order to ensure that people with a learning disability and their families are clear about the care and support they can expect from these services (Level 3). Services provided through the non-statutory sector through contractual or service level agreements with HSC Trusts are also expected to meet these standards.

CHAPTER 4: SAFEGUARDING AND COMMUNICATION AND INVOLVEMENT IN THE PLANNING AND DELIVERY OF SERVICES

A wide range of people, for a variety of reasons, have been shown to be at risk of harm through abuse, exploitation or neglect. People of all ages, and from all social groupings, have the right to be safeguarded from such harm; to have their welfare promoted; and their human rights upheld. All HSC staff and staff providing services on behalf of the HSC have a dual responsibility with regard to safeguarding: (a) to ensure that all service users are treated with respect and dignity and are kept safe from poor practice that could lead to harm; and (b) that all staff are alert to the indicators of harm wherever it occurs and whoever is responsible; and know how and where to report concerns.

Effective communication is fundamental to the delivery of high quality health and social care. Without it there can be no meaningful partnership with service users and carers. Poor communication is often a significant contributory factor in complaints against HSC organisations and underpins many of the negative user experiences reported in research.

Involving people with a learning disability and their carers in the planning, delivery and monitoring of services helps to ensure that the care and support received meets their needs and aspirations. Involvement has to occur at all levels in HSC from ensuring service users' and carer's views are represented in organisational structures for the design and delivery of services, to securing a person-centred approach in all individual care and support arrangements.

There are particular challenges in meaningfully involving people with learning disability given the communication impairments they may experience and the legacy of discrimination which has served to exclude them from decision making fora in the past. Effective service user involvement needs to be underpinned by access to advocacy and information, alongside a clear understanding of issues related to capacity and informed consent.

Standard 1: (Generic)
All HSC staff should ensure that people of all ages are safeguarded from harm through abuse, exploitation or neglect.

Service user perspective:

"I am protected from harm"

Rationale:
A wide range of people, for a variety of reasons, have been shown to be at risk of harm through abuse, exploitation or neglect. People of all ages have the right to be safeguarded from such harm; to have their welfare promoted; and their human rights upheld. At the same time, they have the right to choose how to lead their lives, provided their lifestyle choices do not impact adversely on the safeguarding needs of others or, within the requirements of the law, of themselves. Decision making in this regard will have to pay due consideration to the age, maturity and capacity of the person. In this Standard, the term safeguarding is intended to be used in its widest sense, that is, to encompass both **preventive** activity, which aims to keep people safe and prevent harm occurring, and **protective** activity, which aims to provide an effective response in the event that there is a concern that harm has occurred or is likely to occur.

All HSC staff and staff providing services on behalf of the HSC have a dual responsibility with regard to safeguarding: (a) to ensure that all service users are treated with respect and dignity and are kept safe from poor practice that could lead to harm; and (b) that all staff are alert to the indicators of harm from abuse, exploitation or neglect wherever it occurs and whoever is responsible; and know how and where to report concerns about possible harm from abuse, exploitation or neglect whether these relate to the workplace or the wider community.

Effective safeguarding can ensure that people are safeguarded and their welfare promoted whether in their own homes; in the community; in families; and in establishments such as children's homes; secure accommodation; residential care and nursing homes; and hospitals. Through safeguarding, and in conjunction with positive engagement of individuals (and as appropriate their family and carers), effective prevention and potential for early intervention is enhanced and promoted and care and service plans are supported to deliver better outcomes. Where safeguarding is promoted, staff are empowered to act as advocates to safeguard vulnerable individuals and professional advocacy and counselling services are provided where required. A learning culture is also evident and staff are knowledgeable about safeguarding and keep abreast of local and national developments and learning, including enquiries, serious case reviews, case management reviews, inquiries and reports.

The quality of outcomes is more consistent, regardless of age, disability, gender, ethnic origin, religion, language, sexuality, political opinion, who pays for their care or their access to HSC provided or purchased services. Application in the wider community of knowledge and expertise gained in the

workplace serves to safeguard people more broadly and more generally.
The cycle of abusive behaviour(s) and/or neglect is broken.

Evidence:

World Health Organisation (2011) European Report on Preventing Elder Maltreatment
http://www.euro.who.int/__data/assets/pdf_file/0010/144676/e95110.pdf

OFMDFM (2009) Report of the Promoting Social Inclusion Working Group on Disability
http://www.ofmdfmni.gov.uk/report_of_the_promoting_social_inclusion_working_group_on_disability__pdf_1.38mb_.pdf

DHSSPS (2008) Improving the Patient & Client Experience 5 Standards: Respect, Attitude, Behaviour, Communication and Privacy and Dignity
http://www.dhsspsni.gov.uk/improving_the_patient_and_client_experience.pdf

The Joint Committee on Human Rights (2008) A Life Like Any Other? Human Rights of Adults with Learning Disabilities, Seventh Report of Session 2007-08 Volume 1
http://www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/40/40i.pdf

Council of Europe (2007) Convention on the Protection of Children against Sexual Exploitation and Sexual Abuse
http://conventions.coe.int/Treaty/EN/treaties/html/201.htm

OHCHR (2006) UN Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment http://www2.ohchr.org/english/law/cat-one.htm

OFMDFM (2005) Ageing in An Inclusive Society – Promoting the Social Inclusion of Older People (currently under review)
http://www.ofmdfmni.gov.uk/ageing-strategy.pdf

DHSSPS (2003) Co-operating to Safeguard Children
http://www.dhsspsni.gov.uk/show_publications?txtid=14022

United Nations (2000) The Protocol to Prevent, Suppress and Punish Trafficking in Persons, especially Women and Children
http://www.uncjin.org/Documents/Conventions/dcatoc/final_documents_2/convention_%20traff_eng.pdf

European Convention on Human Rights http://www.hri.org/docs/ECHR50.html

Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• HSC Board & LCGs • Public Health Agency (PHA) • HSC Trusts • Primary Care	• PCC • RQIA • SBNI, NIASP & LASPs • PSNI • Other statutory agencies & voluntary, community & private sector

Quality Dimension
Citizenship People of all ages will be safeguarded from harm and have their welfare promoted and their human rights upheld. Safeguarding responses are non-discriminatory, and seek to ensure that people of all ages at risk of harm are offered support to keep them safe from harm and to protect them when harm occurs. **Empowerment** Safeguarding interventions must be tailored to the presenting circumstances and to the needs and choices of the individual (provided these do not impact adversely on the safeguarding needs of others or, within the requirements of the law, of him or herself) and his/her circumstance. Decision making in this regard will have to pay due consideration to the age, maturity and capacity of the person. **Working Together** Promotion of self-reliance and personal and professional safeguarding behaviours; builds personal and professional safeguarding capacity; promotion of the welfare of individuals; protection from mistreatment; impairment of health and development is prevented; and individuals are kept safe from harm. **Individual Support** Promotion of self-aware practice; supportive of person-centred engagement; fosters awareness and opportunity for early intervention in poor practice/potentially abusive dynamics; and promotion of individualised safety plans where these are indicated, thereby enhancing services and safeguarding awareness and responses

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1. All HSC organisations and organisations providing services on behalf of the HSC have a **Safeguarding Policy** in place, which is effectively aligned with other organisational policies (e.g. recruitment, governance, complaints, SAIs, training, supervision, etc). The Safeguarding Policy is supported	HSC and provider Organisation annual reports HSC Governance Reviews, e.g. Complaints; SAIs, etc HSC Statutory Functions Reports and Corporate Parent Reports SBNI, NIASP & LASP Annual Reports RQIA Reports &	Establish baseline Performance levels to be determined once baseline established	Year 1 Year 2

by robust procedures and guidelines	Reviews Case Management Reviews (CMRs) Serious Case Reviews (SCRs)		
2. All HSC organisations and organisations providing services on behalf of the HSC have **Safeguarding Plans** in place	As above	Establish baseline Performance levels to be determined once baseline established	Year 1 Year 2
3. All HSC organisations and organisations providing services on behalf of the HSC have **safeguarding champions** in place to promote awareness of safeguarding issues in their workplace	As above	Establish baseline Performance levels to be determined once baseline established	Year 1 Year 2

Standard 2:
People with a learning disability should as a matter of course make choices or decisions about their individual health and social care needs. This needs to be balanced with the individual's ability to make such decisions and then the views of their family, carers and advocates should be taken into account in the planning and delivery of services unless there are explicit and valid reasons to the contrary agreed with the person.

Service user perspective:

"I am involved as a matter of course in making choices or decisions about my health and social care needs."

"My family, other carers and advocates are involved as partners."

"Staff ask for my views and the views of family carers when they are planning and delivering services."

Rationale:
People with a learning disability and family carers report a lack of engagement and exclusion from the planning and decision-making processes, which can result in services being unresponsive to individual needs, strengths and aspirations. It is important to ensure that people with a learning disability and their families are involved as partners in their health and social care.

Services must be delivered in ways that appropriately manage risk for service users, carers and their families. It is acknowledged, however, that in some situations, living with an identified risk can be outweighed by the benefit of having a lifestyle that the individual really wants and values. In such circumstances, risk taking (when it is appropriately managed) can be considered to be a positive action. HSC staff need to work in partnership with service users and carers to explore choices, identify and assess risks and agree on how these will be managed and minimised for the benefit of individual service users, their carers and families.

Evidence:
DHSSPS (2010) Care Management, Provision of Services and Charging Guidance http://www.dhsspsni.gov.uk/hsc-eccu-1-2010.pdf

DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011)
http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability
http://www.dhsspsni.gov.uk/equallivesreport.pdf

DHSSPS (2005) A Healthier Future: A Twenty Year Vision for Health and Well

being in Northern Ireland 2005-2025 http://www.dhsspsni.gov.uk/healthyfuture-main.pdf	
Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• HSC Trusts	• Other service providers • Advocacy organisations • Families and carers

Quality Dimension

Citizenship
Service users will be involved as partners in the planning and delivery of health and social care services.

Social Inclusion
Involvement will ensure that service users are enabled to access mainstream services and be fully included in the life of the community.

Empowerment
Involving service users in the design and delivery of HSC services ensures that their expertise effectively informs the development of appropriate services.

Working Together
Partnership with service users, their families and carers is only possible if they are proactively involved in decision-making processes. Effective partnerships will contribute to positive health and social care outcomes.

Individual Support
Person-centred support relies on individuals being supported to share their views, hopes and concerns. Involvement is a necessity for the development of person-centred approaches and planning.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1 Evidence that people with a learning disability, their family and carers have been involved in making choices or decisions about their individual health and social care needs.	HSC Trust reports (care plans)	Establish baseline Performance level to be determined once baseline established	Year 1 Year 2

Standard 3: (Generic)
All patients, clients, carers and the public should have opportunities to be actively involved in the planning, delivery and monitoring of health and social care at all levels.

Service user perspective:

"I will have an opportunity to be actively involved at all levels of health and social care."

Rationale:
Actively involving patients and the public in the planning and provision of health care in general has been noted to bring many advantages to both those who receive and those who provide care. These include:

- Increased patient satisfaction and reduction in anxiety with positive health effects
- Improved communication between service users and professional staff
- Better outcomes of care with greater accessibility and acceptability of services
- Bridging of the gap between those who avail of services and those who provide care
- Recognition of the expertise of the recipient of care developed through experience

Evidence:
DHSSPS (2007) Guidance on strengthening Personal and Public Involvement in Health and Social Care http://www.dhsspsni.gov.uk/hsc_sqsd_29-07.pdf

NHS (2006) Healthy Democracy
http://www.nhscentreforinvolvement.nhs.uk/index.cfm?content=90

DHSSPS (2005) A Healthier Future: A Twenty Year Vision for Health and Well being in Northern Ireland 2005-2025
http://www.dhsspsni.gov.uk/healthyfuture-main.pdf

Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003
http://www.dhsspsni.gov.uk/hpss_qi_regulations.pdf

Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• HSC Board • HSC Trusts • Primary Care	• Other Service providers • Advocacy organisations • Families & carers

Quality Dimension

Citizenship
Effective involvement ensures that the diverse needs of people with a learning disability are taken account of in service planning and delivery. The development of partnerships with service users and carers ensures that their views and aspirations are respected and valued.

Social Inclusion
Involvement helps to address the legacy of disadvantage for people with a learning disability which has led to their voices not being heard effectively in service planning.

Empowerment
Involvement gives a voice to the people most directly affected by decisions within health and social care. Involving them will enable them to have an influence over decisions made that affect their lives.

Working Together
Partnership with service users and carers is only possible if they are proactively involved in decision-making processes. Effective partnerships will contribute to positive health and social care outcomes.

Individual Support
Person-centred support relies on individuals being supported to share their views, hopes and concerns. Involvement is a necessity for the development of person-centred approaches and planning.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
To be developed by Commissioners		Baseline to be established Performance levels to be determined once baseline established	Year 1 Year 2

Standard 4:
Adults with a learning disability should be able helped by HSC professionals to develop their capacity to give or refuse informed consent.

Service User Perspective*:*

"I am helped to give or refuse my consent when decisions are being made that will affect my health or well being"

Rationale:
Respecting peoples' right to determine what happens to them is a fundamental aspect of good practice and a legal requirement. Research shows that people with a learning disability are often denied this right. Health and social care staff report uncertainty about how to ensure capacity and informed consent. This covers a wide range of areas from managing personal finances to consenting to surgery and other medical interventions. A major legislative reform process is underway that will strengthen the legal framework for work in the area of mental capacity and consent. HSC organisations should be working within the spirit of this legislative direction.

Evidence:
DHSSPS (2009) Legislative Framework For Mental Capacity And Mental Health Legislation In Northern Ireland – A Policy Consultation Document www.dhsspsni.gov.uk/legislative-framework-for-mental-capacity.pdf

Equality Commission Northern Ireland (2008) – A Formal Investigation under Disability Discrimination Legislation to Evaluate the Accessibility of Health Information in NI for People with a Learning Disability www.equalityni.org/archive/pdf/FormalInvestDisability(Full).pdf

SCIE (2008) Healthcare for All: The Independent Inquiry into Access to Healthcare for People with Learning Disabilities (The Michael Inquiry) Tizard Learning Disability Review, 13(4), December 2008, pp.28-34. http://www.scie-socialcareonline.org.uk/profile.asp?guid=4f9f7333-2539-4004-af21-26ed14db5f5d

Mencap (2007) Death by Indifference www.mencap.org.uk/case.asp?id=52&menuId=53&pageno

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability http://www.dhsspsni.gov.uk/equallivesreport.pdf

DHSSPS (2003) Reference Guide to Consent for Examination, Treatment or Care www.dhsspsni.gov.uk/consent-referenceguide.pdf

DHSSPS (2003) Seeking Consent: Working with People with Learning Disabilities: http://www.dhsspsni.gov.uk/consent-guidepart4.pdf

Responsibility for delivery/implementation	Delivery and Implementation Partners
• HSC Board • Public Health Agency (PHA) • HSC Trusts • Primary & Acute Care Teams	• DHSSPS • Independent sector • Service users, carers and families

Quality Dimension

Citizenship
The right to self determination is respected and capacity to consent is presumed to exist unless proven otherwise

Empowerment
Paying attention to correct processes for securing consent ensures that the views of people with a learning disability are adequately addressed in decision making.

Individual Support
All health and social care interventions are based on best practice in capacity and consent issues.

Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
1 Develop and agree a regional training plan that ensures that relevant HSC staff are trained in consent and capacity issues.	HSC reports	All HSC Organisations	Year 2
2 Evidence that robust processes are in place where capacity has been judged to be an issue within HSC services or services commissioned by HSC	SAAT	Development and implementation of SAAT Performance levels to be determined based on outcomes of SAAT	Year 1 Year 2

Standard 5: (Generic)
All patients, clients, carers and the public should be engaged through effective communications by all organisations delivering health and social care.

Service user perspective:

"I am supported by staff who can communicate well with me."

Rationale:
Effective communication (clear, accessible, timely, focused and informative) has a significant impact on all aspects of care provision from disease prevention, to diagnosis, to self-management of long-term conditions.

Poor communication is a significant factor in most complaints against HSC organisations.

Evidence:
DHSSPS (2007) Guidance on strengthening Personal and Public Involvement in Health and Social Care http://www.dhsspsni.gov.uk/hsc__sqsd__29-07.pdf

GMC (2006) Good Medical Practice
http://www.gmc-uk.org/guidance/good_medical_practice/index.asp

Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland Order) 2003: www.dhsspsni.gov.uk/hpss_qi_regulations.pdf

Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• HSC Board • Public Health Agency (PHA) • HSC Trusts • Primary Care	• DHSSPS • DE • Other service providers • Service Users & carers

Quality Dimension

Citizenship
As a universal requirement, good communication helps to ensure input by all service users on all aspects of the services they receive assisting in the highlighting of gaps in provision and areas for improvement.

Social Inclusion
Good communication helps to deliver and sustain appropriate patient/client/carer access to services and a clear understanding of the role and responsibilities of the service user in achieving health and care outcomes.

Empowerment
Good communication with patients/clients/carers enables adequate understanding of, consent to and compliance with treatment and care and contributes to audit and monitoring

Working together
Health and care outcomes themselves are enhanced through improved patient partnership and dialogue, including, but not limited to – diagnosis, self-referral, health promotion, disease prevention and management of long term conditions

Individual Support
Person-centredness cannot be delivered or claimed in the absence of good communication with service users. Good communication is a prerequisite of person-centredness.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
To be developed by Commissioners		Baseline to be established Performance levels to be determined once baseline established	Year 1 Year 2

Standard 6:
People with a learning disability should expect effective communication with them by HSC organisations as an essential and universal component of the planning and delivery of health and social care

Service user perspective:

"I am supported by staff who can communicate well with me."

Rationale:
Between 50% and 90% of people with a learning disability have some form of communication difficulty. Effective communication has a significant impact on all aspects of care and support provision across the full range of activities that promote health and social wellbeing. Poor communication is often a significant contributory factor in complaints against HSC organisations.

People with speech, language and communication needs, in addition to their learning disability, are amongst the most vulnerable and most in need of effective care and support to reach their potential. Early identification and effective intervention are essential. The current system is characterised by high variability and a lack of equity.

Evidence:
DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011)
http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

Equality Commission (2008) A Formal Investigation under the Disability Discrimination Legislation to Evaluate the Accessibility of Health Information in Northern Ireland for People with a Learning Disability
http://www.equalityni.org/archive/pdf/FormalInvestDisability(Full).pdf

DSCF (2008) Bercow Report: A Review of services for children and young people (0-19) with speech, language and communication needs
www.dcsf.gov.uk/bercowreview/docs/7771-DCSF-BERCOW%20Summary.pdf

DoH (2008) Better Communication: Improving services for children and young people with speech, language and communication needs. Action Plan to the Bercow Report
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_091972

DHSSPS (2007) Guidance on Strengthening Personal and Public Involvement in Health and Social Care (HSC (SQSD) 29/07)
http://www.dhsspsni.gov.uk/hsc__sqsd__29-07.pdf

GMC (2006) Good Medical Practice
http://www.gmc-uk.org/guidance/good_medical_practice/index.asp

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability
http://www.dhsspsni.gov.uk/equallivesreport.pdf

Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003
http://www.dhsspsni.gov.uk/hpss_qi_regulations.pdf

Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• HSC Board • Public Health Agency (PHA) • HSC Trusts • Primary Care	• DHSSPS • DE • Other Service Providers • Service users and carers

Quality Dimension

Citizenship
Good communication helps to ensure input by people with a learning disability on all aspects of the services that they receive, assisting in the highlighting of gaps in provision and areas for improvement.

Social Inclusion
People with communication difficulties are supported to access mainstream leisure and social activities that promote their integration into mainstream community living and promote their psychological and emotional wellbeing.

Empowerment
Good communication with service users, carers and family enables adequate understanding of, and consent to, the care, support and treatment arrangements offered.

Working Together
There is evidence of good communication between professionals that can determine early identification of communication difficulties and planning to provide the necessary supports to the person with a learning disability, their carer and family and that this is reviewed regularly with particular attention at transition points.

Individual Support
Good communication is a prerequisite of person-centredness.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1 Percentage of people with a learning disability who do not use speech as their main form of communication,	SAAT	Develop and implement SAAT Performance level to be determined based on SAAT outcomes	Year 1 Year 2

who have been supported to establish a functional communication system.			
2 Develop and agree a regional training plan for staff in both HSC and services commissioned by HSC to raise awareness of communication difficulties and how they may be addressed	HSC reports	Regional Training Plan in place Training is delivered in accordance with Regional Training Plan.	Year 1 Year 2

Standard 7:
People with a learning disability should receive information about services and issues that affect their health and social wellbeing in a way that is meaningful to them and their family.

Service user perspective:

"I receive information about services and issues that affect my health and wellbeing in a way that my family and I can understand."

Rationale:
The particular communication difficulties experienced by many people with a learning disability create additional challenges in accessing information on which to make informed choices and access appropriate supports. Access to HSC services depends on people having information on what is available and how the care and support offered will impact on them. This places an onus on HSC organisations to ensure that people with a learning disability, their carers and their families are informed in a way that takes account of their particular circumstances.

This process will be enhanced by the availability of a named staff member to assist people in understanding the services available.

Evidence:
DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011)
http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

Equality Commission (2008) A Formal Investigation under the Disability Discrimination Legislation to Evaluate the Accessibility of Health Information in Northern Ireland for People with a Learning Disability
http://www.equalityni.org/archive/pdf/FormalInvestDisability(Full).pdf

DHSSPS (2007) Guidance on Strengthening Personal and Public Involvement in Health and Social Care (HSC (SQSD) 29/07)
http://www.dhsspsni.gov.uk/hsc__sqsd__29-07.pdf

Foundation for People with Learning Disabilities (2005) Communication for person-centred planning
http://www.learningdisabilities.org.uk/?view=Search+results&search=Communication+for+person-centred+planning

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability
http://www.dhsspsni.gov.uk/equallivesreport.pdf

Responsibility for delivery/implementation	Delivery and Implementation Partners
• HSC Board (including Commissioning Groups) • Public Health Agency (PHA) • HSC Trusts	• DHSSPS, DSD, DE, DEL, DoJ • Other service providers • Advocacy partners • Service users and carers

Quality Dimension

Citizenship
People with a learning disability can only exercise their rights as citizens if they have accessible information about entitlements and services offered.

Social Inclusion
A major barrier to inclusion is the lack of information on which to base informed decision making.

Empowerment
Access to information enables people to speak out about what they need and what is being offered.

Working Together
Provision of information in an accessible manner is a key step towards enabling effective partnership between those who work in services and those who use them.

Individual Support
The development of effective person-centred support relies on individuals being well informed about choices that are open to them.

Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
1 All HSC organisations should provide evidence that they are making information accessible to people with a learning disability	SAAT	Development and implementation of SAAT Performance levels to be determined once baseline established	Year 1 Year 2
2 Each person with a learning disability can access a named person who can signpost them to relevant services.	Sample survey of families and service users.	Establish baseline of information provided Performance levels to be determined once baseline established	Year 2

Standard 8:
People with a learning disability, or their carer, should be able to access self directed support in order to give them more control and choice over the type of care and support they receive.

Service user perspective:

"I, or my carer, can request self-directed support in order to give me more control and choice over the type of care and support I receive."

Rationale:
There is growing evidence of the positive outcomes that may be gained by people with a learning disability when they have direct financial control over their supports. Access to Direct Payments as a means of delivering social services in NI has been available since 1996 under the Personal Social Services (Direct Payments) (Northern Ireland) Order 1996. The Carers and Direct Payment Act (NI) 2002 extended access to a much wider group of people. Direct Payments increase choice and promote independence. They provide for a more flexible response than may otherwise be possible for the service user and carer. They allow individuals to decide when and in what form services are provided and who provides them, who comes into their home and who becomes involved in very personal aspects of their lives. Direct Payments put real power into the hands of service users and carers, and allow them to take control over their lives. Whilst uptake of this provision has been low, it has been steadily increasing over recent years.

In England, direct payments have paved the way for investigation into how individual budgets could work to promote choice and control for people using adult social care services. The introduction of individual or personal budgets is part of the wider personalisation agenda in adult social care. At the time of preparing the Learning Disability Service Framework an equivalent policy directive relating to the use of individual budgets is not in place. However, DHSSPS have indicated its commitment, in the Bamford Action Plan, to exploring the benefits of increasing users' direct control over services. The implementation (and review) of this standard will, therefore, evolve alongside future policy developments in this area.

Evidence:
HSC Board/ PHA (2011) Draft Commissioning Plan 2011/12
http://www.publichealth.hscni.net/sites/default/files/Draft%20HSCB%20PHA%20Commissioning%20Plan%202011-2012_0.pdf

DoH (2009) New Horizons: A Shared Vision for Mental Health
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_109708.pdf

DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011)

http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

SCIE (2009) Research briefing 20: The implementation of individual budget schemes in adult social care. Published Jan 2007, Updated Feb 2009, Addendum March 2009
http://www.scie.org.uk/publications/briefings/briefing20/index.asp

PSSRU (2007) Direct Payments: A National Survey of Direct Payments Policy and Practice http://www.pssru.ac.uk/pdf/dprla_es.pdf

DoH (2007) Valuing People Now: From Progress to Transformation – A consultation on the next three years of learning disability policy
http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Consultations/LiveConsultations/DH_081014

DHSSPS (2005) Direct Payments: Policy and Practice Review Report
http://www.dhsspsni.gov.uk/direct_payments_policy_and_practice_review_report.pdf

Bamford (2005) Equal Lives (Chapter 10 - Ensuring Personal Outcomes): Review of Mental Health and Learning Disability
http://www.dhsspsni.gov.uk/equallivesreport.pdf

DoH (2005) Independence, Wellbeing and Choice: Our Vision for the Future of Social Care for Adults in England – Social Care Green Paper
http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Consultations/Closedconsultations/DH_4116631

Joseph Rowntree Foundation (1999) Implementing Direct Payments for People with Learning Disabilities http://www.jrf.org.uk/sites/files/jrf/F349.pdf

Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• HSC Board • Public Health Agency (PHA) • HSC Trusts	• Welfare Rights Advisers • Advocacy organisations • DEL/DHSSPS/DCAL • Service users and carers.

Quality Dimension

Citizenship
Increased equity exists between service users and service providers where human rights have been respected.

Social Inclusion
Quality of life and wellbeing are improved through being able to have direct control over funding available to support social inclusion activities

Empowerment
Service users and carers experience more choice and control within processes and access services that they have requested and, where necessary, have the support of independent advocates.

Working Together
Change in attitudes and culture with renewed engagement between agencies on joint support planning providing greater flexibility in the way in which supports can be accessed.

Individual Support
People demonstrate improved health and wellbeing from having greater control over how they are supported and having their aspirations met in a more individualised way.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1 Evidence of provision of accessible information on Direct Payments within HSC organisations.	SAAT	Develop and implement SAAT Establish performance levels based on outcomes from SAAT	Year 1 Year 2
2 Percentage of requests for direct payments from people with a learning disability that were approved	SAAT	Develop and implement SAAT Establish performance levels based on outcomes from SAAT	Year 1 Year 2
3 Number of adults with a learning disability in receipt of Direct Payments expressed as a percentage of those in contact with Trust (regional percentage is 2.25%)	HSC Board and Trust Reports	Performance levels to be determined based on available resources and included in final Framework	
4 Number of children with a learning disability in receipt of Direct Payments expressed as a percentage of those in contact with Trust (regional percentage is 3.50%)	HSC Board and Trust Reports	Performance levels to be determined based on available resources and included in final Framework	

5 The HSC Board and Trusts have plans in place to extend the range and scope of self directed support including how they will develop skills and expertise in relevant staff	HSC Board and Trust reports	HSCB and all Trusts	Year 3

Standard 9: (Generic)
Service users and their carers should have access to independent advocacy as required.

Service user perspective:

"I can get an advocate to support me to speak out about worries I have about the care and support I receive"

Rationale:
People engage with health and social care services at times in their lives when they might be vulnerable or in need of support and / or guidance in relation to decisions about their health and wellbeing. For a whole raft of reasons (age, disability, mental health issues, gender, ethnic origin, sexual orientation, social exclusion, reputation, abuse and family breakdown and living away from home or in institutions), they may also feel discriminated against or simply excluded from major decisions affecting their health and wellbeing. It is at such times that independent advocacy can make a real difference because it gives people a voice; helps them access information so that they can make informed decisions and participate in their own care or treatment.

Independent advocacy is also a means of securing and protecting a person's human rights; representing their interests; and ensuring that decisions are taken with due regard to a person's preferences or perspectives where, for whatever reason, they are unable to speak up for themselves. In strategic terms independent advocacy can contribute to increased social inclusion and justice; service improvements in health and wellbeing; reductions in inequalities across the health and social care sector; and enhanced safeguarding arrangements. Independent advocacy can be delivered in a number of different ways and people may need different types of advocacy at different times in their lives. The most common models are self/group advocacy; peer advocacy; citizen advocacy; and individual/issue-based advocacy (also known as professional advocacy).

In this context, independence means structurally independent from statutory department or agency providing the service. The advocacy provider must be free from conflict of interest as possible both in design and operation and must actively seek to reduce any conflicting interests.

Independent advocacy should be available throughout the care pathway and, in particular, should be available early in the process as this may prevent a crisis developing. An advocacy service should apply not just to service users but to their carers and families. To be effective users need to be aware of advocacy services. Therefore they need to be promoted through accurate and accessible information. Relevant health and social care staff should be aware of the benefits of independent advocacy and the particular importance of independence from service provision.

There is currently a proposal to introduce a statutory right to an independent

advocate in the proposed Mental Capacity Bill. Guidance on this right will be issued once the Bill has been finalised.

Evidence

DHSSPS (2012) Developing Advocacy Services – A Policy Guide for Commissioners
http://www.dhsspsni.gov.uk/developing-advocacy-services-a-guide-for-commissioners-may-2012.pdf

DHSSPS (2010) Advocacy Research: Summary Paper
http://www.dhsspsni.gov.uk/advocacy-research-summary-paper-of-advocacy-provision-october-2010.pdf

Knox, C. (2010) Policy Advocacy in Northern Ireland. University of Ulster, Jordanstown

Alzheimer's Society (2009) Listening Well http://www.alzheimers.org.uk

Horton, C (2009) Creating a Stronger Information, Advice and Advocacy System for Older People. London; Joseph Rowntree Foundation

SCIE (2009) At A Glance 12: Implications for Advocacy Workers available at http://www.scie.org.uk/publications/ataglance/ataglance12.asp

Seal, M. (2007) Patient Advocacy and Advance Care Planning in the Acute Hospital Setting – Australian Journal of Advanced Nursing Vol 24, No 4, pp29-36

Wright, M. (2006) A Voice That Wasn't Speaking: Older People Using Advocacy and Shaping it's Development, Stoke-on-Trent, OPAAL UK (Older People's Advocacy Alliance)

Bamford Review (2006) Review of Mental Health and Learning Disability (NI), Human Rights and Equality of Opportunity Available at www.dhsspsni.gov.uk/bamford

Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• HSC Board • HSC Trusts • Public Health Agency (PHA)	• Local Commissioning Groups • Primary Care Partnerships • GPs • Voluntary and Community Sector • Independent Sector • PCC

Quality Dimensions

Citizenship
An advocacy service can promote equality, social justice and inclusion of the most vulnerable and disadvantaged. Advocacy can enhance capacity building

at a community and individual level, which can ultimately reduce dependency on other health and social care services.

Empowerment
Advocacy services can enable individuals to access information, express their views and wishes and make informed choices about their own health and well being. The service is geared to needs of the individual. The service user will receive a service that best meets their needs at a time, which evidence shows, to be effective and to have maximum impact.

Individual Support
Advocacy services can safeguard users from abuse and exploitation by ensuring that their rights are upheld and their voice heard. An advocacy service can promote equality, social justice and inclusion of the most vulnerable and disadvantaged.

Performance Indicator	**Data Source**	**Anticipated Performance Level**	**Date to be achieved by**
To be developed by commissioners		Baseline to be established Performance levels to be determined once baseline established	Year 1 Year 2

CHAPTER 5: CHILDREN AND YOUNG PEOPLE

Work is ongoing in the development of a Children and Young People's Service Framework. It is anticipated that that Framework will address the universal needs of children and young people in Northern Ireland.

This chapter aims to address the particular issues facing children and young people with a learning disability and their family carers and acknowledges the role played by schools and Education and Library Board in the assessment, intervention, support and onward referral of children & young people who may or do have a learning disability. This chapter should be read alongside the other standards set out in this Framework.

Support to families tends to be fragmented and parents report difficulty in accessing services and understanding the range of roles and services that are in place.

It is crucial when concerns emerge that a child may have a learning disability, that a clear action plan is agreed as to how the concerns will be investigated. It is essential that planning and support systems are used to wrap around the child and family to ensure a seamless and co-ordinated approach. Where children have to live away from their family the arrangements in place must take account of their learning disability.

The Learning Disability Service Framework reflects the fundamental position that regardless of diagnosis, a child/young person is a child/young person first, and that children and their families should be fully supported to participate in valued childhood experiences. They should also have access to the same opportunities, life experiences and services as other children and families.

Standard 10:
From the point at which concerns are raised that a child or young person may have a learning disability, there is an action plan in place to determine the nature and impact of the learning disability.

Service User Perspective:

Parents will have an action plan that clearly sets out the steps to be taken for discovering the nature and impact of learning disability their son or daughter may have.

Rationale:
Parents report dissatisfaction with the manner in which supports are organised when concerns begin to emerge that their son or daughter may have a learning disability. Professional efforts are often not well co-ordinated resulting in parents having to manage multiple appointments and, at times, conflicting advice.

Long delays are reported for appointments to specialists and parents can experience great difficulties in accessing the information they need and in understanding the roles that various professionals and organisations play.

Assessment needs to be timely, comprehensive and conducted in a co-ordinated manner.

Evidence:
Power, A (2008) 'It's the system working for the system': carers' experiences of learning disability services in Ireland: *Health and Social Care in the Community* (2008) http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2524.2008.00807.x/abstract

SCIE (2008) Guide 24: Learning together to safeguard children: developing a multi-agency systems approach for case reviews. www.scie.org.uk/publications/guides/guide24/index.asp

SCIE (2007) Knowledge Review 18: 'Necessary Stuff' – The social care needs of children with complex healthcare needs and their families. www.scie.org.uk/publications/knowledgereviews/kr18.asp

DHSSPS (2007) Complex Needs – The Nursing Response to Children & Young People with Complex Physical Healthcare needs. www.dhsspsni.gov.uk/complex_needs_report.pdf

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability http://www.dhsspsni.gov.uk/equallivesreport.pdf

Responsibility for delivery/implementation	Delivery and Implementation Partners
• HSC Board • Public Health Agency (PHA) • HSC Trusts • Primary Care	• Families • DHSSPS, DE • Early Years providers

Quality Dimension

Social Inclusion
Assessment takes account of the need for the child or young person to have as normal a life as possible and be socially included within the communities in which they live.

Empowerment
Children, young people and their families receive co-ordinated essential information about the services they can expect to receive and the roles that professionals will have in delivering these services and have an identified link person to whom they can refer any problems and with whom they can develop effective relationships.

Working Together
Professionals work together with families to determine a child/young person's condition within a required timeframe and systems are put in place for effective ongoing communication and delivery of supports.

Individual Support
Assessments are co-ordinated effectively between professionals and families and parents are clear as to actions planned by HSC professionals.

Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
1 Percentage of parents who express satisfaction with the assessment process and how the outcomes were conveyed.	Audit of sample family carers	Establish baseline of information provided Performance levels to be determined once baseline established	Year 2 Year 3

Standard 11:
Children and young people should receive child-centred and coordinated services through assessment to ongoing care and support from the point at which a determination has been made that they have a learning disability.

Service user perspective:

"My son or daughter receives services that are child-centred, appropriate and co-ordinated."

Rationale:
The Children Order (NI) 1995 outlines that a child is a 'child in need' by virtue of the fact that he/she is disabled (Art17(C)). Trusts and statutory bodies are required to comply with their statutory duties in respect of children in need, including those in relation to carers needs under this legislation.

Getting the right care and support for children, young people and their families makes a significant impact on positive outcomes in adulthood. A child's needs cover the whole range of public services and resources including play, leisure, housing and education. The involvement of all these interests is essential if we are to avoid confining the lives of children with a learning disability within the health and social care system.

Evidence:
DHSSPS (2009) NI Single Assessment Tool
http://www.dhsspsni.gov.uk/index/hss/ec-community-care/ec-northern-ireland-single-assessment-tool.htm

DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011)
http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

DHSSPS (2009) Integrated Care Pathway for Children & Young People with Complex Physical Healthcare Needs
http://www.dhsspsni.gov.uk/integrated_care_pathway-july09.pdf

DHSSPS (2008) UNOCINI Guidance
http://www.dhsspsni.gov.uk/microsoft_word_-_unocini_guidance_revised_june_2011_inc_mh_domain_elements.pdf

Black, LA *et al* (2008) Lifelines Report An Evaluation Report of the Impact of the Families Services delivered by Positive Futures in Rural and Urban Areas of Northern Ireland. http://www.positive-futures.net/sites/default/files/LIFELINES%20Full%20Report.pdf

Kenny, K and McGilloway, S. (2007) Caring for children with learning disabilities: an exploratory study of parental strain and coping, British Journal

of Learning Disabilities, p221-8.
http://onlinelibrary.wiley.com/doi/10.1111/j.1468-3156.2007.00445.x/abstract

SCIE (2007) Knowledge Review 18: 'Necessary Stuff' – The social care needs of children with complex healthcare needs and their families
www.scie.org.uk/publications/knowledgereviews/kr18.asp

DHSSPS (2007) Complex Needs – The Nursing Response to Children & Young People with Complex Physical Healthcare needs.
www.dhsspsni.gov.uk/complex_needs_report.pdf

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability
http://www.dhsspsni.gov.uk/equallivesreport.pdf

Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• HSC Board • HSC Trusts/Children's Services	• Families • DHSSPS, DE, DCAL • Voluntary and community sector providers

Quality Dimension

Social Inclusion
Assessment and supports take account of the need for the child or young person to have as normal a life as possible and be socially included within the communities in which they live.

Empowerment
Children, young people and their families receive co-ordinated essential information about the services they can expect to receive and the roles that professionals will have in delivering these services and have an identified link person to whom they can refer any problems and with whom they can develop effective relationships.

Working Together
Professionals work together with parents as partners in developing family centred plans to meet the care and support needs of the child and his/her family. Plans must take account that the needs of children and young people with a learning disability cannot be met by health and social care alone and will involve close working with other interests including housing, leisure and education.

Individual Support
Supports are co-ordinated effectively between professionals and the family and the child/young person has a plan in place that is regularly reviewed to ensure that supports remain appropriate.

Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
1 Percentage of children and young people with a learning disability and carers who have been offered an assessment either under the Family Health Needs Assessment or UNOCINI assessments.	Audit/Sampling	Establish baseline Performance levels to be determined once baseline established	Year 2 Year 3
2 Percentage of children and young people who have an agreed support plan detailing a pathway to receiving appropriate care and support.	Audit to include UNOCINI referrals and completed family support and Looked After Children (LAC) pathway assessments following initial referral	Establish baseline Performance levels to be determined once baseline established	Year 2 Year 3

Standard 12:
HSC services should respond to the needs of children and young people who have a learning disability and complex physical health needs in a manner that is personalised, developmentally appropriate and which support access to appropriate care.

Service User Perspective:

"If my son or daughter has complex physical health needs we will receive care and support in a flexible way through services that are age appropriate."

Rationale:
Current services often lack the responsiveness and flexibility required to ensure that children and young people with a learning disability enjoy equal access to the full range of supports that are required to effectively address the needs arising from additional health problems they have. This can result in them receiving care and treatment that is less than optimum, is poorly coordinated, and sometimes delivered in settings, which are not developmentally appropriate.

Children and young people with a learning disability benefit greatly from effective transitions between hospital and community services and sensitive, detailed assessment and care planning across the range of HSC professionals involved with the family.

Evidence:
DHSSPS (2009) Integrated Care Pathway for Children & Young People with Complex Physical Healthcare Needs
http://www.dhsspsni.gov.uk/integrated_care_pathway-july09.pdf

DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011)
http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

DHSSPS (2009) Families Matter: Supporting Families in Northern Ireland
http://www.dhsspsni.gov.uk/families_matter_strategy.pdf

The Council for Disabled Children (CDC) (August 2009) The use of eligibility criteria in social care services for disabled children
http://www.ncb.org.uk/cdc/home.aspx

DHSSPS (2008) UNOCINI Guidance
http://www.dhsspsni.gov.uk/microsoft_word_-_unocini_guidance_revised_june_2011_inc_mh_domain_elements.pdf

DHSSPS (2007) Complex Needs – The Nursing Response to Children & Young People with Complex Physical Healthcare needs.
www.dhsspsni.gov.uk/complex_needs_report.pdf

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability http://www.dhsspsni.gov.uk/equallivesreport.pdf

Beecham,J. et al. (2002) Children with Severe Learning Disabilities: Needs, Services and Costs *Children & Society* pp. 168–181 www.lse.ac.uk/collections/PSSRU/staff/beecham.htm

Sloper, P. (1999) Models of service support for parents of disabled children. What do we know? What do we need to know? *Child: Care, Health and Development*, 25 (2), 85-99. www.ncbi.nlm.nih.gov/pubmed/10188064

Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• HSC Board • Public Health Agency (PHA) • HSC Trusts / Children's Services • Primary and Acute Services	• DHSSPS • Voluntary & Community Sector Providers • Families & carers

Quality Dimension

Citizenship
The rights of the child/young person/family are respected when assessing their needs and practical approaches are taken to meeting these needs that are equitable to the rest of the population.

Working Together
There is a coordinated approach to addressing health and social care needs where parents are clearly signposted to sources of care and support, particularly when the child/ young person moves between hospital and home.

Individual Support
Multi-disciplinary input is effective in providing assessment and supports that the child and family requires using person-centred and family centred approaches that are effective in maintaining, where possible, ordinary family life and are reviewed regularly or at least annually.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1 Percentage of parents whose child has a learning disability and complex physical health needs who have an identified key worker with co-ordinating responsibility	Annual Audit	Scope requirements and produce audit plan. Audit 50% of information available 100%	Year 1 Year 2 Year 3

2 Percentage of children and young people with complex physical health needs who have effective transition arrangements in place between hospital and community.	SAAT	Develop and implement SAAT Performance levels to be determined based on SAAT outcomes. Fast track arrangements for access to hospital /community services to be audited following establishment of baseline	Year 1 Year 2
3 Percentage of children with a learning disability and complex physical health needs who have received a multi-professional assessment using the UNOCINI frameworks.	Trust Reports	90% 95% 98%	Year 1 Year 2 Year 3
4 Percentage of children and young people with a learning disability and complex physical health needs who are receiving care under the integrated care pathway.	SAAT	Develop and implement SAAT Performance levels to be determined based on SAAT outcomes.	Year 1 Year 2

Standard 13:
Any child or young person who cannot live at home permanently should have their placement/ accommodation needs addressed in a way that takes full account of their learning disability.

Service User Perspective:

"If I cannot live at home permanently, my needs will be addressed in a way that takes full account of my learning disability."

Rationale:
A small number of children and young people who have a learning disability cannot live with their natural families. Many have severely challenging behaviours, specific health needs and/or Autistic Spectrum Disorders (ASD). They require support and living arrangements that are sufficiently expert to address their complex individual needs. Decisions about future care and support arrangements need to be taken in a timely manner and in a way that supports permanency.

Evidence:
DHSSPS (2009) Autism Spectrum Disorder (ASD) Strategic Action Plan 2008/09 – 2010/11
http://www.dhsspsni.gov.uk/asd_strategic_action_plan.pdf

DoH (2005) Valuing People: The story so far (p44)
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4107059.pdf

McConkey *et al* (2004). The characteristics of children with a disability looked after away from home and their future service needs. British Journal of Social Work, 34 (4), 561-576. http://bjsw.oxfordjournals.org/content/34/4/561.abstract

Chadwick *et al* (2002) Respite Care for Children with Severe Intellectual Disability and their Families: Who Needs It? Who Receives It? Child and Adolescent Mental Health vol7 (2): 66-72.
http://onlinelibrary.wiley.com/doi/10.1111/1475-3588.00013/full

Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• HSC Board • HSC Trusts	• DHSSPS • Other Service Delivery Partners

Quality Dimension

Citizenship/Social Inclusion
Children & young people with a learning disability have their needs met within environments that promote social inclusion and full citizenship

Empowerment
Children, young people and their family members are supported to express their views on the care and support services that they require and are supported to maintain links with each other when a child/young person lives away from home.

Working Together
Professionals collaborate to provide responsive services through developing a person-centred Permanency Plan to meet the needs of the individual child/young person.

Individual Support
The Permanency Plan includes arrangements for specialist placements based on the short, medium and long term needs of the individual.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1 Percentage of looked after children or young people with a learning disability who cannot live with their families who have a Permanency Plan.	SOSCARE	Establish baseline Performance level to be determined once baseline established	Year 1 Year 2
2 Percentage of looked after children or young people with a learning disability who cannot live at home, who have access to specialised placements where the need for this is indicated in the Permanency Plan.	SOSCARE	Establish baseline Performance level to be determined once baseline established	Year 1 Year 2

CHAPTER 6: ENTERING ADULTHOOD

The manner in which young people are supported at the time of transition from adolescence to adulthood is a crucial component in determining the degree to which they are enabled to live full and valued lives in their communities.

Supporting effective transition is the responsibility, not only of HSC organisations, but also requires the effective engagement of other government departments, notably DEL and DE, and other agencies. There is scope for improvement in the quality of the transition experience. Many young people have unsatisfactory experiences during the move from school towards adulthood.

Parents and young people should be offered a transitions pathway that outlines their:

- individual interests;
- aspirations;
- strengths and needs including vocational training;
- education;
- employment;
- health profile;
- social supports;
- friendships (including meaningful relationships); and
- social development.

Standard 14:
Young people with a learning disability should have a transition plan in place before their 15th birthday and arrangements made for their transition to adulthood by their 18th birthday.

Service User Perspective:

"I will have a transition plan in place before my 15th birthday."

"I will know the arrangements that are in place for when I leave school before my 18th birthday."

Rationale:
Effective transition planning at an early stage is vital if young people are to move successfully from school towards fuller adult lives. This is a statutory requirement under special education legislation and a recommendation of the Bamford Review. These arrangements should be made in partnership with the young person, their family/carers and adult learning disability services for transition to appropriate adult services in accordance with agreed transition protocols. The objective of this transition planning is to support people into the same life chances as other non-disabled young people e.g. a job, relevant education, positive relationships and the start of living independently.

It is noted that increased numbers of children with statements of special education needs, including those with disabilities are accessing mainstream education. Under the Special Educational Needs and Disability (NI) Order 2005 (SENDO) Code of Practice, transition planning in schools commences for 'statemented' pupils at the first annual review following the child's 14th birthday. The Education and Library Board's (ELB) Transition Service will ensure, in the most complex of cases, that appropriate advice givers will be present as part of the annual review process. Transition planning and services should be available, with young people and carers made aware of them, and able to access transition supports following post primary education with sufficient forward planning to minimise apprehension and stress for those young people and their carers.

Evidence:
DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011)
http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

DoH (2008) Getting a Life 2008-11 http://www.gettingalife.org.uk

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability
http://www.dhsspsni.gov.uk/equallivesreport.pdf

Special Educational Needs and Disability (NI) Order 2005 (SENDO)

Education (NI) Order 1996 and Code of Practice
http://www.deni.gov.uk/index/7-special_educational_needs_pg/special_needs-codes_of_practice_pg.htm

Responsibility for delivery/implementation	Delivery and Implementation Partners
• HSC Board • Public Health Agency (PHA) • HSC Trusts	• DHSSPS, DE (ELBs, schools and FE colleges), DEL • Education Transitions Co-ordinators • Voluntary agencies • Youth services • Councils • Independent providers • RQIA • Young people and their families • Advocacy organisations

Quality Dimension

Citizenship
A common assessment pathway will help to ensure equity of services for all.

Social Inclusion
Accessible information will be provided to allow young people, their carers and relevant others to participate fully in the development of a transition plan. Such information is available in a range of media and from a wide range of sources. Young people's involvement will create a move away from a narrow focus on services to a broader expression of aspirations for the future.

Empowerment
The process of preparing the Transitions Plan will place the young person and his/her family at the centre of planning for the future

Working Together
Decisions about eligibility for services will be the outcome of a multi-disciplinary assessment, and will be open and transparent for parents. The plan will be developed on a multi-disciplinary/multi agency basis with clear accountability lines for delivery by all the contributors.

Individual Support
A preliminary assessment will feed into an individualised transitions plan. Each plan will reflect the young person's aims and objectives in life including specific individual needs and interests, continuing education and training, employment, social and leisure activities and day opportunities.

Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
1 Percentage of young people who express satisfaction that their transition plan has been implemented within 2 years of leaving school.	SAAT	Develop and implement SAAT Performance levels to be determined based on SAAT outcomes	Year 2 Year 3
2 Evidence of transfer to DES, where appropriate, for health checks for children on transition to adult services	DES	90% 95% 98%	Year 1 Year 2 Year 3

Standard 15:
People with a learning disability should be supported to have meaningful relationships, which may include marriage and individual, unique, sexual expression within the law, balancing their rights with responsibilities.

Service User Perspective*:*

"I will be supported to enjoy meaningful relationships."

Rationale:
The Bamford Review promotes the importance of people with a learning disability benefiting from meaningful relationships and the need to offer support, guidance, training and related services to ensure that this happens.

The Human Rights Act 1998 includes the right to respect for privacy and family life, freedom of expression, the right to marry and to found a family and the right not to be discriminated against in respect of these rights and freedoms. This has to be balanced with positive risk taking strategies. Safeguards need to be put in place, where necessary and appropriate, but within a framework that ensures the objective is to support people who are having positive relationships whenever possible.

People with a learning disability have a right to learn about sexuality and the responsibilities that go along with exploring and experiencing one's own sexuality. They have to know how to protect themselves from unplanned pregnancy, HIV and other sexually transmitted infections, and sexual and gender-based violence. Education programmes for people with a learning disability should begin during adolescence as part of their general education. The implementation of this standard will need to be supported by the provisions detailed in Standard 3 (Consent and Capacity).

Evidence:
DHSSPS (2010) Adult Safeguarding: Regional & Local Partnership Arrangements http://www.dhsspsni.gov.uk/asva- march 2010.pdf

DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011)
http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

DHSSPS (2008) Sexual Health Promotion Strategy & Action Plan 2008-2013
http://www.dhsspsni.gov.uk/dhssps_sexual_health_plan_front_cvr.pdf

Simpson, A et al (2006) Out of the shadows: A report of the sexual health and well being of people with learning disabilities in Northern Ireland. Newnorth Print Ltd.

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability
http://www.dhsspsni.gov.uk/equallivesreport.pdf

SCIE (2004) The Road Ahead: Information for Young people with Learning Difficulties, their Families and Supporters at Transition
http://www.scie.org.uk/publications/tra/index.asp

The Human Rights Act, 1998
http://www.direct.gov.uk/en/Governmentcitizensandrights/Yourrightsandresponsibilities/DG_4002951

Responsibility for delivery/implementation	**Deliver and Implementation Partners**
• HSC Board • Public Health Agency (PHA) • HSC Trusts	• DHSSPS, DE (Education and Library Boards and Schools) • Voluntary sector • Service Users • Families

Quality Dimension

Citizenship
The right to personal relationships is enshrined in Human Rights legislation. Meaningful relationships are a fundamental component of health and social wellbeing.

Social Inclusion
People will be supported to access social and leisure opportunities where friendships may be developed.

Empowerment
People will be supported to appreciate the rights, risks and responsibilities involved in personal relationships

Working Together
Staff and family carers will contribute to the development of policies and best practice guidelines in this area.

HSC Trusts will implement the Adult Safeguarding arrangements and staff will be trained appropriately to discharge it.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1 Regional guidelines on sexuality and personal relationships are developed to ensure a consistent approach	HSC Board Report	HSC Board policy developed and agreed	Year 1

2 Trusts to facilitate appropriate training for staff.	Trust Reports	40% 80%	Year 2 Year 3
3 Trusts to facilitate appropriate training for service users and family carers.	Trust Reports	Level to be established pending development of regional policy	Year 3
4 Increase in the number of people with a learning disability accessing sexual health & reproductive healthcare services.	SAAT	Establish baseline Performance levels to be determined once baseline established	Year 1 Year 2

CHAPTER 7: INCLUSION IN COMMUNITY LIFE

Emotional and social wellbeing are directly related to the degree to which people are able to live valued lives and participate in community opportunities.

For people with a learning disability barriers can exist which prevent them from accessing the opportunities that are open to the rest of society. Many of these barriers do not relate directly to the disability, but rather are the result of discrimination and approaches based on a belief that social education and leisure opportunities need to be provided within the context of HSC provision. This has resulted in the social exclusion of people with a learning disability and the development of services that group people together on the basis of a shared learning disability, rather than addressing individual needs and aspirations.

The HSC has a role in working with others in employment, housing, leisure and education to maximise opportunities that enable people with a learning disability to actively participate in their communities and engage in meaningful daytime activities, friendships, employment and leisure.

The majority of men and women with a learning disability live at home with their families. Appropriate short breaks are often an important component in supporting these arrangements.

Increasingly people with a learning disability express an aspiration to have children. HSC services must work together to ensure that people who have a learning disability are appropriately supported in their parenting role.

Standard 16:
Adults with a learning disability should be able to access support in order that they can achieve and maintain employment opportunities in productive work.

Service User Perspective:

"I will be able to get support to help me find and keep a job."

Rationale:
The Lisbon Agenda (2000) promotes the integration of people traditionally excluded from the labour market. The Bamford Review recommends that agencies should work in partnership to promote and deliver supported employment services. HSC Trust day opportunities strategies promote the development of supported employment as an integral part of service development.

A cultural shift away from a reliance on day centres should be encouraged, towards alternative options which enable individuals with a learning disability to participate in society through day opportunities and work placements that will improve their skills and allow them the opportunity to integrate with others. Those involved in person centred planning should actively consider employment as one of these options.

Evidence:
Beyer S, (2010) Using a Cost Benefit Framework for Supported Employment Policy and Practice: an analysis of 2 UK agencies Journal Appl Res Intellect, Volume 23, 5 (September 2010) pp.447-447
http://onlinelibrary.wiley.com/doi/10.1111/j.1468-3148.2010.00584.x/pdf

DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011)
http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

DoH (2009) Valuing Employment Now – Real Jobs for People with Learning Disabilities
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_101401

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability
http://www.dhsspsni.gov.uk/equallivesreport.pdf

DELNI (2008) Pathways to Work (New Deal)
http://www.delni.gov.uk/index/finding-employment-finding-staff/fe-fs-help-to-find-employment/stepstowork.htm (Accessed 15 April 2011)

OFMDFM Promoting Social Inclusion (PSI) Disability
http://www.ofmdfmni.gov.uk/index/equality/disability/disability-promoting-

social-inclusion.htm

Lisbon Agenda (2000) http://www.euractiv.com/en/future-eu/lisbon-agenda/article-117510

Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• HSC Board • HSC Trusts	• DEL, OFMDFM • Supported employment providers • Northern Ireland Union of Supported Employment (NIUSE)

Quality Dimension

Working Together
HSC staff, in partnership with DEL and others, will enable people with a learning disability to achieve and maintain employment opportunities with ongoing professional support.

Social Inclusion
Historically there have been barriers to opportunities for meaningful employment for men and women with a learning disability. Increasing such opportunities will be a key contributor to improving social inclusion.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1 Percentage of school leavers with a learning disability who access work placements or employment within one year of leaving school (as percentage of total learning disabled school leaving population).	ELB Transition Service	Establish baseline Performance levels to be determined once baseline established	Year 1 Year 2
2 Percentage of adults with a learning disability who receive HSC support to help them secure employment (as a measure of those who request support).	Audit	Establish baseline Performance levels to be determined once baseline established	Year 1 Year 2

Standard 17:
All adults with a severe or profound learning disability should be able to access a range of meaningful day opportunities appropriate to their needs.

Service User Perspective:

"I will be supported to take part in a range of activities during the day"

Rationale:
There is a need for a radical reconfiguration of existing day service provision based on a progressive shift towards a resource model. As alternative provision develops there should be a reduction in the number of people who attend Adult Centres on a full-time basis. It is anticipated that these centres will, in the future, be providing a service to men and women with increasingly complex needs who should also be enabled to access opportunities for community integration. Adult Centres will need to explore the potential to develop sites for meeting the particular needs of people with more complex needs. The potential for Adult Centres to be used as a community resource is particularly under-utilised at present. Partnerships with community and voluntary groups should involve promoting the inclusion of people with a learning disability.

Evidence:
DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011)
http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

SCIE (2007) Knowledge Review 14: Having A Good Day? A study of community-based day activities for people with learning disabilities
www.scie.org.uk/publications/knowledgereviews/kr14.asp

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability
http://www.dhsspsni.gov.uk/equallivesreport.pdf

PCC (2011) My Day, My Way The Bamford Monitoring Group's Report on Day Opportunities
http://www.patientclientcouncil.hscni.net/uploads/research/My_Day_My_Way_FINAL.pdf

Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• HSC Board • HSC Trusts	• Local community organisations • DHSSPS, DEL • FE providers • Local economy

Quality Dimension

Social Inclusion
Reconfiguration of day centres may reduce the number of days attended and an

expansion of wider community options for individuals.

Working Together
Each person will have a person-centred plan which will identify the multi-disciplinary and community inputs required to deliver on that plan. A lead person will be accountable for the delivery of the plan, which must be reviewed 6 monthly.

Individual Support
Admission criteria and processes in day centres will be in line with the standard and clear processes will be in place to consider intake and development of opportunities in local communities.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1 Percentage of adults with a severe or profound learning disability who have meaningful day opportunities in mainstream community settings.	SAAT	Develop and implement SAAT Performance levels to be determined based on SAAT outcomes	Year 1 Year 2
2 Percentage of adults with a learning disability supported by HSC who express satisfaction with the choice of day opportunities they can access.	SAAT	Develop and implement SAAT Performance levels to be determined based on SAAT outcomes	Year 1 Year 2

Standard 18:
All parents with a learning disability should be supported to carry out their parenting role effectively.

Service User Perspective:

"If I have children I will get support to be a good parent."

Rationale:
An increasing number of adults with a learning disability are becoming parents. In about 50% of cases their children are removed from them largely because of concerns about the children's wellbeing or the lack of appropriate support.

Barriers to the provision of appropriate supports include negative and stereotypical attitudes. Men and women with a learning disability have a right to be parents and where they choose to exercise this right, effective support should be in place to avoid adverse outcomes for them and their children.

If support is provided early it is more likely that the family unit will be successfully supported to stay together.

Evidence:

DoH (2009) New Horizons: A Shared Vision for Mental Health
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_109708.pdf

Aunos, M *et al* (2008) Mothering with Intellectual Disabilities: Relationship Between Social Support, Health and Wellbeing, Parenting and Child Behaviour Outcomes. http://onlinelibrary.wiley.com/doi/10.1111/j.1468-3148.2008.00447.x/abstract

Tarleton, B *et al* (2006) Finding the right support? A Review of Issues and Positive Practice in Supporting Parents with Learning Difficulties and Their Children. The Baring Foundation
www.bristol.ac.uk/norahfry/research/completed-projects/rightsupport.pdf

IASSID Special Interest Research Group on Parents and Parenting with Intellectual Disabilities (2008) Parents labelled with Intellectual Disability. Position of the IASSID SIRG on Parents and Parenting with Intellectual Disabilities. Journal of Applied Research in Intellectual Disabilities, 21: 296–307. http://onlinelibrary.wiley.com/doi/10.1111/j.1468-3148.2008.00435.x/abstract

Booth T *et al* (2006) Temporal discrimination and parents with learning difficulties in the child protection system. *British Journal of Social Work* 36(6), 997–1015. http://bjsw.oxfordjournals.org/content/36/6/997.abstract

SCIE (2006) Knowledge Review 11: Supporting disabled parents and parents with additional support needs.
http://www.scie.org.uk/publications/knowledgereviews/kr11.asp

CSCI (2006) Supporting Parents, Safeguarding Children: Meeting the needs of parents with children on the child protection register http://www.pmhcwn.org.uk/files/supporting_safeguarding.pdf (Accessed 15 April 2011)

Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• HSC Board • Public Health Agency (PHA) • HSC Trusts	• DHSSPS • Community and voluntary sector providers • Advocacy services

Quality Dimension

Citizenship
Independent advocacy support is provided to enable parents with a learning disability to be involved in the decision making process within multi-disciplinary meetings and other decision making fora.

Social Inclusion
Supports provided promote and encourage the parents to become less isolated from the community in which they live.

Empowerment
More parents and their children will be receiving appropriate care and support resulting in a smaller percentage of children of parents with learning disabilities being subject to Care Orders.

Working Together
Professionals work collaboratively across children's and adult's services to provide effective support to the parent and work will continue to develop policy on positively supporting parents with a learning disability to continue caring for their children.

Individual Support
Parents will be better enabled to care for themselves and their children through having their needs properly assessed and being appropriately supported in their parenting role.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1 Develop and agree a regional protocol between children's and adult services for joint working and care pathways.	HSC Board Report	HSC Board in collaboration with all HSC Trusts	Year 1

2 Percentage of parents with a learning disability who have a multi-professional/agency competence based assessment and subsequently receive appropriate support services	Trust Report	Establish baseline Performance level to be determined once baseline established	Year 2 Year 3
3 Percentage of parents with a learning disability involved in child protection or judicial processes who have received locally based skills training.	Trust Reports	85% 90% 95%	Year 1 Year 2 Year 3
4 Percentage of parents with a learning disability involved in child protection or judicial processes who have access to the services of an independent advocate.	Trust Reports	Establish baseline Performance level to be determined once baseline established	Year 1 Year 2

CHAPTER 8: MEETING GENERAL PHYSICAL AND MENTAL HEALTH NEEDS

Physical and mental health are inextricably linked with each impacting upon the other. The World Health Organisation (WHO) gives equal value to physical and mental health in the definition of health as “a complete state of physical, mental and social wellbeing, not just the absence of disease and infirmity”. People with poor physical health are at higher risk of experiencing common mental health problems and people with mental health problems are more likely to have poor physical health. Many factors influence the health of individuals and communities. Whether people are healthy or not depends a great deal on their circumstances and the environment in which they live. The determinants of health and wellbeing include:

- social environment
- the physical environment
- the person’s individual characteristics and behaviour

Many of these factors of health are not under the direct control of the individual and therefore one person’s health may differ from another’s depending on their circumstances.

Evidence demonstrates that there are significant disparities in health outcomes for people with a learning disability. They experience higher levels of physical and mental ill health, yet have lower access to primary care services, health screening and health promotion activities.

People with a learning disability can experience difficulties when using general health services, hospitals and primary care services. There is a need to proactively ensure that there is equity of access to the full range of health care services enjoyed by the general population. This is enshrined in disability discrimination and human rights legislation.

Standard 19:
All people with a learning disability should have equal access to the full range of health services, including services designed to promote positive health and wellbeing.

Service User Perspective:

"I have equal access to the full range of health services as other people in the community."

Rationale:
It is known that people with a learning disability often experience difficulties when using health services and this can result in their health needs not being effectively assessed or met.

Most people with a learning disability do not require specialist services to address their health needs but many will require a range of reasonable adjustments to help them make use of generic health services such as primary care, acute hospitals and dentistry. Specialist learning disability services are a key resource to support mainstream health services develop the knowledge and skills to do this effectively.

Reasonable adjustments can be many and are wide ranging, but it is important to remember that they must be individualised to the person, and may include such things as:

- longer appointment times
- offering the first or last appointment
- the provision of easy read information to enhance understanding
- close involvement and support of family carers
- appropriate waiting facilities
- pre-admission visits
- fast tracking arrangements when appropriate (e.g. in A&E Departments)

The standard links closely to Standards 4 and 5 (Communication and Involvement in the Planning and Delivery of Services).

Evidence:
Learning Disabilities Observatory: Improving Health and Lives (2010) Health Inequalities Report
http://www.improvinghealthandlives.org.uk/projects/particularhealthproblems

GAIN (2010) Guidelines: Caring For People With A Learning Disability In General Hospital Settings
http://www.gain-ni.org/Library/Guidelines/Gain%20learning.pdf

DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and

Learning Disability Action Plan (2009-2011)
http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

Mencap (2007) Death by Indifference
www.mencap.org.uk/case.asp?id=52&menuId=53&pageno

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability
http://www.dhsspsni.gov.uk/equallivesreport.pdf

Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• HSC Board • Public Health Agency (PHA) • HSC Trusts • Primary Care (including pharmacy and dental)	• DHSSPS • Service users and carers

Quality Dimension

Citizenship
People with a learning disability are equal citizens and must be able to readily access the full range of services that support their health and social wellbeing as are available to the rest of the population.

Social Inclusion
Primary care services, acute hospital services and other specialist services, such as, palliative care should have knowledge of the specific issues for people with a learning disability accessing these services and make reasonable adjustments accordingly.

Working Together
All generic services should have knowledge of local learning disability specific services and how to access them when required. This includes access to advocacy services.

Individual Support
The provision of all services should be tailored to the individual needs of the person with a learning disability, and reasonable adjustments made accordingly. An individual with a learning disability should be able to make round the clock contact with services and receive the care needed to meet their needs.

Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
1 All acute hospitals should have an action plan for implementing the GAIN Guidelines for improving access to acute care for people with a learning disability and be able to demonstrate a clear commitment to the implementation of such a plan.	Trust report	All HSC trusts establish baseline Performance levels to be determined once baseline established	Year 1 Year 2
2 Percentage of GPs who have a system for identifying people with a learning disability on their register.	DES	Baseline as per learning disability DES Performance levels to be determined once baseline established	Year 1 Year 2
3 Each GP practice has a designated link professional within local learning disability services.	Trust report as per GAIN Guidelines	Establish baseline Performance levels to be determined once baseline established	Year 1 Year 2
4 Evidence of reasonable adjustments by health service providers.	Report from HSC Trust learning disability services	Establish baseline Performance levels to be determined once baseline established	Year 1 Year 2

Standard 20: (Generic)
All HSC staff, as appropriate, should advise people who smoke of the risks associated with smoking and signpost them to well developed specialist smoking cessation services.

Service user perspective:

"I will be advised on the dangers of smoking"

Rationale:
Smoking is a major risk factor for a number of chronic diseases including a range of cancers, coronary heart disease, strokes and other diseases of the circulatory system. Its effects are related to the amount of tobacco smoked daily and the duration of smoking.

A number of specialist smoking cessation services have been commissioned in a range of settings across Northern Ireland. These services offer counselling and support in addition to the use of pharmacotherapy by trained specialist advisors.

Evidence:
DHSSPS (2010) Tobacco Control Strategy for Northern Ireland
http://www.dhsspsni.gov.uk/tobacco-strategy-consultation.doc

NICE (2008) Smoking cessation services in primary care, pharmacies, local authorities and workplaces, particularly for manual working groups, pregnant women and hard to reach communities http://www.nice.org.uk/Guidance/PH10

NICE (2006) Brief Interventions and Referral for Smoking Cessation in Primary Care and Other Settings http://www.nice.org.uk/Guidance/PH1

Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• HSC Board • HSC Trusts • Public Health Agency (PHA) • Primary Care	• DHSSPS • Families & carers • Voluntary, education, youth and community organisations

Quality Dimension

Citizenship
People with a learning disability can exercise their rights as citizens if they have accessible information to inform decision-making.

Empowerment
All members of the public will benefit from access to public information and education campaigns that raise awareness of issues relating to tobacco use, such as, the health risks to smokers and non-smokers. People who are ready to

stop smoking are able to access specialist smoking cessation services in a choice of settings.

Working together
Brief Intervention Training for Health and Social Care Staff will ensure patients and clients receive consistent and timely advice on smoking cessation. Specialist smoking cessation services will be delivered to regional quality standards ensuring equitable service provision. Provision of information in an accessible format is a key step towards enabling effective partnership between those who work in services and those who use them. HSC professionals should take account of what is important to the person, their relationships and activities in working with them to address issues around smoking. Brief Intervention training for HSC staff will ensure that service users receive consistent and timely advice.

Individual Support
Effective person-centred support should take account of balancing what is important to people with what is important to them in regard to their health and wellbeing. Specialist smoking cessation services will be delivered to regional quality standards ensuring equitable service provision.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
Percentage of people accessing smoking cessation services who have heard about the service from an HSC professional.	ELITE (PHA Stop Smoking Services Report)	Establish baseline. Performance levels to be determined once baseline established	March 2013
Percentage of people accessing smoking cessation services offered by HSC providers who have quit.	ELITE	Establish baseline. Performance levels to be determined once baseline established	March 2013

Standard 21:
All people with a learning disability should be supported to achieve optimum physical and mental health.

Service User Perspective

I will be helped to stay as physically and mentally healthy as possible.

Rationale:
People with a learning disability are more likely to experience major illnesses, to develop them younger and die of them sooner than the population as a whole. They have higher rates of obesity, respiratory disease, some cancers, osteoporosis, sensory impairment, dementia and epilepsy. It is estimated that people with learning disability are 58 times more likely to die prematurely. However, even with such a dramatic health profile, the learning disabled population are less likely to get some of the evidence-based treatments and checks they need, and continue to face real barriers in accessing services. This contributes to preventable ill health, poor quality of life and potentially, premature death.

Effective screening and regular health checks help to identify unmet need and prevent health problems arising. People with a learning disability participate less in screening and regular health checks than the rest of the population. Information on, and activities in, health promotion can be difficult to access.

Evidence:

Learning Disabilities Observatory (2011) The Estimated Prevalence of Visual Impairment among People with Learning Disabilities in the UK
http://www.improvinghealthandlives.org.uk/publications/

DoH (2009) Improving the health and well being of people with learning disabilities: world class commissioning www.dh.gov.uk/commissioning

DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011)
http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

DoH (2009) Valuing People Now: A new three-year strategy for people with learning disability
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093377

DoH (2009) Health Action Planning and Health Facilitation for people with learning disabilities: good practice guidance
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_096505

DoH (2009) Delivering Better Oral Health: An evidence- based toolkit for

prevention – second edition

DoH (2008) High quality care for all: NHS Next Stage Review Final Report
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825

DHSSPS (2007) Guidance on Strengthening Personal and Public Involvement in Health and Social Care (HSC (SQSD) 29/07)
http://www.dhsspsni.gov.uk/hsc__sqsd__29-07.pdf

DHSSPS (2007) Oral Health Strategy for Northern Ireland
http://www.dhsspsni.gov.uk/2007_06_25_ohs_full_7.0.pdf

Disability Rights Commission (2007) Equal Treatment: Closing the Gap: A Formal Investigation into Physical Health Inequalities Experienced by People with Learning Disabilities and/or Mental Health Problems
http://onlinelibrary.wiley.com/doi/10.1111/j.1741-1130.2006.00100.x/abstract

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability
http://www.dhsspsni.gov.uk/equallivesreport.pdf

Foundation for People with Learning Disabilities (2005) Communication for person-centred planning
http://www.learningdisabilities.org.uk/publications/communication-person-centred-planning/

Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• HSC Board • Public Health Agency (PHA) • Primary Care • HSC Trust (Learning Disability Teams)	• Families • Voluntary and Community providers

Quality Dimension

Citizenship
People with a learning disability are supported to access the full range of screening and health checks as the rest of the population of NI.

Social Inclusion
Screening and health checks are made accessible to people with a learning disability and they are facilitated to participate in these activities.

Empowerment/Individual Support
Individuals will be supported to have regular screening and health checks on all the major illnesses and facilitated to make lifestyle choices that promote their good health and have in place a Health Action Plan as part of their person centred plan.

Working Together
There should be effective liaison and evidence of advance planning between

HSC staff and family carers to fully embrace people with learning disabilities into the system of regular screening and health checks and health promotion activities. This should incorporate the development of Health Action Plans which includes details of health interventions, oral health, fitness and mobility, emotional needs and records of screening tests and identification of those responsible for taking action.			
Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1 The PHA and each HSC Trust has a health improvement strategy for people with a learning disability (children and adults) to address all relevant physical and mental health promotion and improvement needs.	Public Health Agency/ Trust Reports (to include reports from voluntary and community organisations Trust has commissioned services from)	All Trusts have in place a health improvement strategy for people with a learning disability.	Year 1
2 Percentage of adults with a learning disability who have an annual health check.	GP Records Health Facilitator records	Establish baseline Performance levels to be determined once baseline established	Year 1 Year 2
3 Percentage of adults with a learning disability who have an up to date and active Health Action Plan (HAP) following the annual health check.	GP records Health Facilitator records Learning Disability Teams	Establish baseline Performance levels to be determined once baseline is established	Year 1 Year 2
4 Percentage of people with a learning disability who have been examined by a dentist in the past year.	Audit	Establish Baseline Performance Levels to be determined once baseline established	Year 1 Year 2
5 Percentage of females with a	GP records	Establish Baseline	Year 1

learning disability who access cervical and breast screening services.	Health facilitators	Performance levels to be determined once baseline established	Year 2
6. Percentage of people with a learning disability who have had a sight test with an optometrist in the past year.	Audit	Establish Baseline Performance levels to be determined once baseline established	Year 1 Year 2

Standard 22:
All people with a learning disability who experience mental ill health should be able to access appropriate support.

Service User Perspective

"If I have mental illness I can get appropriate support."

Rationale:
People with a learning disability and mental health needs require a co-ordinated multi-disciplinary approach to having their needs met through integrated services responding flexibly to the demands of their conditions with clear pathways of care identified so that the most appropriate supports are immediately available to the person and their family carers when required.

Refer also to standard 56 in Service Framework for Mental Health and Wellbeing

Evidence:

DHSSPS (2011) Service Framework for Mental Health and Wellbeing Consultation Document
http://www.dhsspsni.gov.uk/service_framework_for_mental_health_and_wellbeing_-_consultation_version.pdf

DoH (2010) Raising our sights: services for adults with profound intellectual and multiple disabilities A report by Professor Jim Mansell
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114346

DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011)
http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

Emerson, E. and Hatton, C. (2007) The Mental Health of Children and Adolescents with Intellectual Disabilities in Britain. *British Journal of Psychiatry* 191, 493-499.
http://bjp.rcpsych.org/cgi/content/abstract/191/6/493

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability
http://www.dhsspsni.gov.uk/equallivesreport.pdf

NHS QIS (2004) Learning Disability Quality Indicators
http://www.healthcareimprovementscotland.org/previous_resources/indicators/learning_disability_quality_in.aspx

Carpenter, B. (2002) Count Us In: report of the inquiry into meeting the mental health needs of young people with learning disabilities. London: Foundation for People with Learning Disabilities London:
http://www.learningdisabilities.org.uk/publications/count-us-in/

Responsibility for delivery/implementation	Delivery and implementation partners
• HSC Board • Public Health Agency (PHA) • HSC Trusts • RQIA	• DHSSPS • Other service providers

Quality Dimension

Citizenship
Addressing the mental health needs of people with a learning disability requires a combination of services that are consistently available to enable their full participation within the structures of society

Social Inclusion
The mental health needs of people with a learning disability are met in the most appropriate setting.

Empowerment/Individual Support
People with a learning disability and mental illness have person-centred plans in place with clear pathways of care identified and planned to enable them to lead as normal a life as is possible given the conditions of their illness. To involve the person, their parents or family carer in this process empowers the family and the person with a learning disability to make informed choices

Working Together
Services surrounding the person with a mental illness should be co-ordinated and resourced appropriately with a lead person identified to effectively manage and promote the mental health and wellbeing of the person requiring services.

Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
1. A regional protocol is developed to ensure that people with a learning disability can access mainstream mental health services.	HSC Board	Protocol in place	Year 1
2. Percentage of people with a learning disability and mental health needs who access mainstream mental health services e.g. psychological and talking therapies	Audit	Establish baseline Performance levels to be determined once baseline established	Year 2 Year 3

where indicated in their treatment plan.			
3. Percentage of Health Action Plans and health checks which include mental health assessment and mental health promotion	GP Records	Establish baseline Performance levels to be determined once baseline established	Year 1 Year 2

Standard 23: (Generic)
All HSC staff, as appropriate, should provide people with healthy eating support and guidance according to their needs.

Service user perspective:

"I will be provided with healthy eating support and guidance"

Rationale:
Reducing fat and salt in the diet and increasing fruit and vegetable consumption is associated with a reduction in the risk of cardiovascular disease and hypertension.

Having a well balanced and nutritious diet will also help prevent many diseases which are linked to being overweight and obese such as high blood pressure, heart problems, risk of stroke, some cancers and Type 2 Diabetes. In addition, an improved diet can also contribute to an improvement in an individual's mental health and wellbeing.

Evidence:
DHSSPS Draft Framework for Preventing and Addressing Overweight and Obesity in Northern Ireland (2011-2021)
http://www.dhsspsni.gov.uk/showconsultations?txtid=44910

DHSSPS (2005) Fit Futures http://www.dhsspsni.gov.uk/ifh-fitfutures.pdf

WHO (2004) Global Strategy on Diet, Physical Activity and Health
http://www.who.int/dietphysicalactivity/strategy/eb11344/strategy_english_web.pdf

SCAN (2008) Scientific Advisory Committee on Nutrition. The Nutritional Wellbeing of the British population
http://www.sacn.gov.uk/pdfs/nutritional_health_of_the_population_final_oct_08.pdf

Responsibility for delivery/implementation	**Delivery and implementation partners**
• HSC Board • Public Health Agency (PHA) • HSC Trusts	• Primary care team, inclusive of social care

Quality Dimension

Citizenship
People with a learning disability are provided with healthy eating support and advice as are the rest of the population.

Empowerment/ Individual support
Individuals will receive support and advice, appropriate to their needs, in a range of settings to develop skills for healthy eating and be facilitated to make lifestyle choices that promote their good health and wellbeing as part of person-centred

planning.

Lifestyle issues including eating and physical activity choices should be explored through knowledge of what is important to the person. This should take account of what has worked and what has not worked in the past.

Working Together
There should be effective liaison and evidence of advance planning between staff and family carers to fully embrace people with a learning disability into the system of health promotion activities. All stakeholders should promote a consistent nutrition message by using the Eat Well – getting the balance right model.Training and education should be available for child carers / group care workers.

Schools / hospitals / residential care and nursing homes should be supported in the implementation of nutrition standards. Support and advice to develop skills for healthy eating in a range of settings should be available.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1. Percentage of people eating the recommended 5 portions of fruit or vegetables each day.	Northern Ireland Health Survey	Establish baseline Performance level to be agreed thereafter	March 2013

Standard 24: (Generic)
All HSC staff, as appropriate, should provide support and advice on recommended levels of physical activity.

Service user perspective:

"I will be provided with support and advice on physical activity"

Rationale:
The National Institute for Health and Clinical Excellence (NICE) has fully endorsed the importance of physical activity as a means of promoting good health and preventing disease. Lack of physical activity is associated with an increase in the risk of coronary heart disease.

The recently reviewed and updated UK Physical Activity Guidelines, supported by all four CMO's, provide advice and guidance on the recommended levels of physical activity throughout the life course. The report also presents the first time guidelines have been produced in the UK for early years (under fives) as well as sedentary behaviour, for which there is now evidence that this is an independent risk factor for ill health.

Evidence:
DHSSPS Draft Framework for Preventing and Addressing Overweight and Obesity in Northern Ireland (2011-2021)
http://www.dhsspsni.gov.uk/showconsultations?txtid=44910

DoH (2011) New UK Physical Activity Guidelines
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_127931

NICE (2006) Public Health Intervention Guidance No.2 Four commonly used methods to increase physical activity: Brief intervention in primary care, exercise referral schemes, pedometers and community-based exercise programmes for walking and cycling http://www.nice.org.uk/nicemedia/pdf/word/PH002_physical_activity.doc

DHSSPS (2005) Fit Futures http://www.dhsspsni.gov.uk/ifh-fitfutures.pdf

WHO (2004) Global Strategy on Diet, Physical Activity and Health
http://www.who.int/dietphysicalactivity/strategy/eb11344/strategy_english_web.pdf

Responsibility for delivery/implementation	**Delivery and implementation partners**
• HSC Board • Public Health Agency (PHA) • HSC Trusts	• Primary care team, inclusive of social care

Quality Dimension			
Empowerment People with a learning disability will benefit from access to appropriate information and advice on physical activity. **Working Together** HSC staff recognise their responsibility to ensure service users receive consistent and timely health promotion messages. Appropriate physical activity brief intervention training should be provided for HSC staff to ensure patients and clients receive consistent and timely advice. **Individual Support** Lifestyle issues including physical activity choices should be explored through knowledge of what is important to the person. Paying attention to what works best for the person in undertaking physical activity, working with their interests. This should take account of what has worked in the past and what does not work**.**			
Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1. Percentage of people meeting the recommended level of physical activity per week.	Northern Ireland Health Survey	Establish baseline. Performance level to be agreed thereafter.	Year 1 Year 2

Standard 25: (Generic)
All HSC staff, as appropriate, should provide support and advice on recommended levels of alcohol consumption.

Service user perspective:

"I will receive support and advice on the use of alcohol"

Rationale:
Excessive alcohol consumption is associated with many diseases such as cancers (oesophagus, liver etc), cirrhosis of the liver and pancreatitis. There are also direct effects of alcohol and an increased association with injuries and violence.

Excessive alcohol consumption can affect the cardiovascular system, and is associated with high blood pressure, abnormal heart rhythms, cardiomyopathy and haemorrhagic stroke.

Evidence:
DHSSPS (2006) New Strategic Direction for Alcohol and Drugs (2006-2011)
http://www.dhsspsni.gov.uk/nsdad-finalversion-may06.pdf

SIGN (2003) Scottish Intercollegiate Guidelines Network The Management of harmful drinking and alcohol dependence in Primary Care No 74
http://www.sign.ac.uk/pdf/sign74.pdf

Responsibility for delivery/implementation	**Delivery and implementation partners**
• HSC Board • Public Health Agency (PHA) • HSC Trusts	• Primary care team, inclusive of social care

Quality Dimension

Citizenship
People with a learning disability and alcohol related issues should be able to access mainstream services. They are likely to require the support of learning disability personnel to utilise the services offered by the mainstream addiction teams.

Working Together
Appropriate alcohol brief intervention training should be provided for HSC staff to ensure patients and clients receive consistent and timely advice.

Individual Support
HSC staff should take account of what and who is important to the person now and in the future in relation to lifestyle and where alcohol fits in. Explore how alcohol can be managed in the person's life by taking account of what has worked and what has not worked in the past for this person.

Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
1 Percentage of people who receive screening in relation to their alcohol consumption.	Northern Ireland Local Enhanced Service	Establish baseline Performance level to be determined once baseline established	Year 1 Year 2

CHAPTER 9: MEETING COMPLEX PHYSICAL AND MENTAL HEALTH NEEDS

Children and adults with a learning disability may experience significant additional, complex health needs. Complex physical and mental health needs may be defined as those requiring a range of additional support services beyond the type and amount required by people generally and those usually experienced by people with impairments and long-term illnesses. These needs require a high level of effective integration between specialised and general services.

Supports to children, young people and adults who have complex physical and mental health needs will be most effective if they are based on person-centred planning approaches and within an ethos of ensuring bridging between learning disability expertise and other service settings. (Standard 10 sets out the specific standard for children and young people with complex physical health needs).

Standard 26:
All people with a learning disability whose behaviour challenges should be able to get support locally from specialist learning disability services and other mainstream services, as appropriate, based on assessed need.

Service User Perspective:

I can get support locally from specialist learning disability services if my behaviour challenges services and/or my carers

Rationale:
Emerson (1995) defines 'challenging behaviour' as behaviour of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to the use of ordinary community facilities.

People who present behaviours that challenge services are generally well known to staff working within specialist learning disability services and they are therefore in a position to provide relevant information to other services and support the person and family carers to enable him/her to continue to access these services.

The specialist supports available should include social work, psychiatry, psychology, speech and language therapy, physiotherapy, nursing and any other relevant disciplines and these should be available 24 hours a day, 7 days a week. Should crises occur there needs to be the capacity to respond with appropriate interventions that maintain the person in the community/home in which he/she resides and/or short breaks that provides time out from the situation.

Whilst significant evidence exists as to the need for timely, flexible, home-based support to address challenging behaviours and to prevent unnecessary inpatient admission, work is not complete on the optimum service configuration and models required in Northern Ireland. To develop community based supports and move away from a traditional model of hospital admission will require resource investment and future detailed service planning.

Evidence:
NDTi (2010) Guide for Commissioners of Services for People With Learning Disabilities Who Challenge Services
http://www.ndti.org.uk/uploads/files/Challenging_behaviour_report_v7.pdf

DoH (2010) Raising our sights: services for adults with profound intellectual and multiple disabilities A report by Professor Jim Mansell
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114346

DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011)
http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability

http://www.dhsspsni.gov.uk/equallivesreport.pdf

NHS QIS (2004) Learning Disability Quality Indicators
http://www.healthcareimprovementscotland.org/previous_resources/indicators/learning_disability_quality_in.aspx

Emerson, E (1995) Challenging behaviour - analysis and intervention in people with a learning disability Cambridge University Press

Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• Commissioning organisations • HSC Trusts • RQIA	• DHSSPS • Family carers • Advocacy providers • Other service providers

Quality Dimension

Citizenship
Providing support to an individual who presents behaviours that are challenging to access mainstream health and social care services maintains their equity with the rest of the population of NI.

Social Inclusion
There are community-based services to meet the needs of people with challenging behaviour.

Empowerment
Incidents of challenging behaviours are reduced when appropriate support mechanisms are available so that they can continue to receive the community - based services they require.

Working Together
Mainstream and specialist services should be collaborating on the needs of people with a learning disability who present behaviours that challenge mainstream services so that the person can access the healthcare services they require and services comply with regional guidelines on the management of challenging behaviours.

Individual Support
Management and intervention for challenging behaviour is practised and the approaches used have proven evidence-based effectiveness and social validity.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1 Percentage of individuals with significant challenging behaviours who have a Behaviour Support Plan including advance directives in	SAAT	Develop and implement SAAT Performance levels to be determined based on SAAT outcomes	Year 1 Year 2

place that detail actions to be undertaken in the event of their challenging behaviours escalating.			
2 Where challenging behaviours present a significant risk to the individual or others or a risk of breakdown in accommodation arrangements, a specialist assessment has been completed within 24 hours.	SAAT	Develop and implement SAAT Performance levels to be determined based on SAAT outcomes	Year 1 Year 2
3 Where challenging behaviours present a significant risk to the individual, a Management Plan has been developed and implemented within 48 hours.	SAAT	Develop and implement SAAT Performance levels to be determined based on SAAT outcomes	Year 1 Year 2
4 Evidence that HSC has engaged with other relevant delivery partners in developing and implementing consistent approaches in individual cases.	Trust report Audit of voluntary/ community sector	All HSC Trusts	Year 2
5 Percentage of people labelled as challenging who are not living in a congregate setting described as a challenging behaviour or specialist assessment/ treatment service	SAAT	Develop and implement SAAT Performance levels to be determined based on SAAT outcomes	Year 3

Standard 27:
All people with a learning disability who come into contact with the Criminal Justice System should be able to access appropriate support.

Service User Perspective:

I will get support If I come in contact with the police, courts or prisons

Rationale:
Men and women with a learning disability can come into contact with the Criminal Justice System in a range of different ways. They can be suspects, remandees, prisoners or indeed witnesses. However, people with a learning disability can be particularly vulnerable as they may not understand the processes involved, the information given to them, or their rights. The Reed Report (1992) highlighted the needs of mentally disordered offenders and recommended that, where appropriate, people with a learning disability who offend should be directed to HSC services, while emphasizing the need for services to be based on a multi-agency needs assessment.

It is vital that an offender with a learning disability does not go unrecognised and unsupported whilst in the prison system and that care pathways are established between primary care, learning disability services and Criminal Justice Services.

Evidence:
DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011)
http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

DoH (2009) The Bradley Report: Lord Bradley's review of people with mental health problems or learning disabilities in the criminal justice system
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_098698.pdf

RCSLT (2009) Locked Up and Locked Out: Communication Is The Key
http://www.rcslt.org/news/events/Locked_Up_NI_post_event_report

Prison Reform Trust (2008) No-One Knows. Police Responses to Suspects Learning Disabilities and Learning Difficulties: A Review of Policy and Practice
www.prisonreformtrust.org.uk

DHSSPS (2006) The Bamford Review of Mental Health and Learning Disability (NI): Forensic Services
http://www.dhsspsni.gov.uk/forensic_services_report.pdf

Reed Report (1992) Review of mental health and social services for mentally disordered offenders and others requiring similar services: Vol. 1: Final summary report. (Cm. 2088) London: HMSO ISBN 0101208820

Responsibility for delivery/implementation	Delivery and implementation partners
• HSC Board • HSC Trusts • General Practitioners	• DHSSPS, DoJ • Police Service of Northern Ireland (PSNI) • Probation Board for Northern Ireland (PBNI) • NI Prison Service • NI Courts Service • Youth Justice Agencies • Voluntary and community providers

Quality Dimension

Citizenship
People with a learning disability going through the Criminal Justice System have the same rights as other members of society and there is evidence of good practice available to ensure that this is the case.

Social Inclusion
Offending behaviours have the potential to increase the person's social exclusion and measures must be evidenced within their person-centred plan (PCP) that promotes their social inclusion in mainstream activities upon discharge from any institutional setting.

Empowerment
Measures are in place to minimise the person's vulnerability when they are in contact with the Criminal Justice System

Working Together
There is evidence of multi-disciplinary working practices to ensure that people with a learning disability are supported within the Criminal Justice System.

Individual Support
Community based services are in place which support people, prevent admissions where possible, and facilitate discharge from inpatient and other secure settings. The least restrictive options for individuals should be available.

Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
1 Evidence that HSC has engaged and developed local protocols with relevant delivery partners to achieve consistent and	HSC Board Report	Protocols in place	Year 1

coordinated approaches to working with people with a learning disability who have offended or are at risk of offending.			

CHAPTER 10: AT HOME IN THE COMMUNITY

To maximise their health and social wellbeing, people with a learning disability should be supported to live in the community close to family, friends and community resources. Where they currently live with family they (the family) should be supported to provide the necessary care and support.

A greater focus on 'purposeful lives' will support people with a learning disability to live as independently as possible. It is vital that people are supported to live in the community and that inappropriate admission to hospital is avoided. People with a learning disability who require hospital treatment should be speedily discharged when the treatment ends to community homes with appropriate care and support. Resettlement of long stay populations, the development of innovative approaches to prevent delayed discharges and the promotion of 'purposeful respite' will enhance outcomes for people with a learning disability, their families and carers.

Standard 28:
HSC professionals should work in partnership with a variety of agencies in order to ensure that the accommodation needs of people with a learning disability are addressed.

Service User Perspective:

"My accommodation needs will be met by staff from different agencies who work well together"

Rationale:
People with a learning disability aspire to have the same standard in living options that are available to their non-disabled peers.

In NI the majority of adult persons with a learning disability continue to live with family carers. As carers age, they may require extra support to maintain their caring role. In addition, people with a learning disability may need support to participate in community activities with their peers.

Person-centred support plans should identify the person's preferred living arrangements and these should be regularly reviewed. It is important that as family carers age they are supported to plan for the future to allow for a smooth transition to new care arrangements either within the family or in supported accommodation (refer to Chapter 12: Ageing Well).

Small-scale, supported living arrangements (5 persons or less) have been shown to offer a better quality of life for people with a learning disability as compared to congregated living arrangements.

People living outside of family care should have a tenancy or occupancy agreement to offer them security of tenure along with an agreement to the number of support hours available to them individually.

People should be involved in decisions about sharing their homes with others. As far as possible they should be offered a choice of accommodation in a locality of their choosing.

Evidence:
DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011)
http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

SCIE (2009) At a glance 8: Personalisation Briefing: Implications for housing providers www.scie.org.uk/publications/ataglance/ataglance08.asp

DHSSPS (2008) Residential Care Homes: Minimum Standards
http://www.dhsspsni.gov.uk/care_standards_-_residential_care_homes.pdf

NDA (2007) Supported Accommodation Services for People with Intellectual Disabilities: A review of models and instruments used to measure quality of life in different various settings (Walsh, PN *et al*, 2007)
http://www.nda.ie/website/nda/cntmgmtnew.nsf/0/929ECD4441474CA280257872004B8619/$File/SupportedAccommodation.pdf

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability
http://www.dhsspsni.gov.uk/equallivesreport.pdf

McConkey, R (2005) Fair shares? Supporting families caring for adult persons with intellectual disabilities. Journal of Intellectual Disability Research, vol 49, Issue 8, 600 – 612
http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2788.2005.00697.x/full

NIHE (2003) Supporting People
http://www.nihe.gov.uk/index/sp_home/strategies/independent_living-2/supporting_people_strategy.htm

Responsibility for delivery/implementation	**Delivery and implementation partners**
• HSC Board • HSC Trusts	• DSD • NIHE • Other service and housing providers

Quality Dimension

Citizenship
People with a learning disability have equity of access to housing options similar to the general adult population.

Social Inclusion
People with a learning disability are living in communities.

Empowerment
People with a learning disability are supported to access information and advice to exercise their preference of where they live and who they wish to live with, through the help of independent advocates where necessary and, tailoring support to people's individual needs to enable them to live full, independent lives.

Working Together
HSC professionals are involved in developing strategies, information and advice to housing providers on identified housing needs of people with a learning disability. Joint planning and partnership working is promoted towards meeting a person's housing need.

Individual Support
Support Plans are in place that support the person with a learning disability and their carers' independence. Funding sources are maximised that support this position and planning for the future is incorporated into this process.

Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
1 Percentage of support plans that take account of people's aspirations in relation to future accommodation needs, including independent living	SAAT	Develop and implement SAAT Performance level to be determined based on SAAT outcomes	Year 1 Year 2
2 Percentage of adults who are living with a single carer or where there are 2 carers and the primary carer is aged over 65 who have a futures plan in place	SAAT	Develop and implement SAAT Performance level to be determined based on SAAT outcomes	Year 1 Year 2
3 Percentage of people in receipt of public funding living in households of 5 people or less with a learning disability	SAAT	Develop and implement SAAT Performance level to be determined based on SAAT outcomes	Year 1 Year 2
4 Percentage of people leaving learning disability hospital within one week after treatment has been completed	PfA monitoring	95% 97% 100%	Year 1 Year 2 Year 3

Standard 29: (Generic)
All HSC staff should identify carers (whether they are parents, family members, siblings or friends) at the earliest opportunity to work in partnership with them and to ensure that they have effective support as needed.

Service user perspective:

" My carer's needs will be considered and supported"

Rationale:
Carers are central to providing health and social care. People want to live in their own homes as independently as possible and family caring is critical in achieving this goal. Breakdown in caring has a major impact on readmission rates to hospital and unnecessary admissions to residential and nursing home care placements.

Caring is both a demanding and rewarding activity. Evidence shows that unsupported caring can have a negative impact on the physical, social and emotional well being of an adult carer. It is in everyone's interest to ensure that carers can continue to care for as long as they wish and are able to, without jeopardising their own health and wellbeing or financial security, or reducing their expectations of a reasonable quality of life.

Young carers (children and young people up to the age of 18 years who have a substantive caring role for a member of their family) often do not have an alternative but to be a carer. These children can be lonely, isolated, lose friendships and miss out on education and social activities. Young carers are frequently involved in activities that are developmentally inappropriate and the impact on their lives is unknown. Many young carers go unidentified. This highlights the need to identify young carers and provide support and assistance which will promote their health, development and inclusion in educational and social activities.

Early intervention, individually tailored to the needs of the carer and the cared for person, can be crucial in avoiding breakdown in the caring role. Forming meaningful partnerships with carers and making agreements with them about support to be provided is essential. Carers identify their requirements as respite care, information, personal care for the cared for person and practical and emotional support to continue in their role. This highlights the need for service planning and commissioning based on partnership working between statutory and independent sector and involvement of carers or their representatives to shape future services.

To enable carers to access the right information, support and services, current methods for identifying carers and encouraging them to acknowledge their caring role need to be enhanced. Under the Carers and Direct payments Act, all staff have a duty to inform carers. Staff should be particularly proactive in identifying the presence of younger and older carers.

One of the most important and far-reaching improvements in the lives of carers will be brought about by how health and social care staff view and treat them. Changes in staff knowledge of carers' issues could promote a more positive attitude to carers and this would make a significant difference to the lives of carers. Services should recognise carers both as individuals in their own right and as key partners in the provision of care and support.

Evidence:

PCC(2011) Young Carers in Northern Ireland: A report of the experiences and circumstances of 16 year old carers
http://www.patientclientcouncil.hscni.net/uploads/research/Young_carers_in_Northern_Ireland.pdf

Schubotz & McMullan (2010) The Mental and Emotional Health of 16-Year Olds in Northern Ireland: Evidence from the Young Life and Times Survey. Belfast: Patient and Client Council Report

DSD/ DHSSPS (2009) Review of Support Provision for Carers
http://www.dsdni.gov.uk/ssani-review-support-provision-carers.pdf

DHSSPS (2009) Regional Carer's Support and Needs Assessment Tool
http://www.dhsspsni.gov.uk/eccu2-09.pdf

DHSSPS (2008) Implementation of the Carers Strategy (Training for Carers)
http://www.dhsspsni.gov.uk/microsoft_word_-_circular_hss__eccu__3_2008_-_implementation_of_carers__strategy.pdf

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Evason, E. (2007) Who Cares Now? Changes in Informal Caring 1994 and 2006. Research Update 51. Belfast: ARK Publications www.ark.ac.uk

DHSSPS (2006) Caring for Carers Recognising, Valuing and Supporting the Caring Role http://www.dhsspsni.gov.uk/ec-dhssps-caring-for-carers.pdf

DHSSPS (2006) Implementation of the Carers Strategy (Identification of Carers) http://www.dhsspsni.gov.uk/hss__eccu__4-2006_carers_circular_-_signed.doc.pdf

SPRU (2004) Hearts and Minds: The health effects of caring
http://www.york.ac.uk/inst/spru/pubs/pdf/Hearts&Minds.pdf

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Responsibility for delivery/implementation	**Delivery and Implementation Partners**
• HSC Board • Public Health Agency • HSC Trusts	• Primary Care – GPs, LCGs • Independent Sector • DSD, DENI

Quality Dimension

Citizenship
Carers will feel valued and able to access the support they need. Staff will be facilitated to understand and value the role of carers.

Social Inclusion
Carers will be recognised as real and equal partners in the delivery of care. All carers, irrespective of age, who they care for or where they live will be directed toward appropriate agencies that can offer advice and support.

Empowerment
Carers will be encouraged to identify themselves as carers and to access information and support to protect and promote their own health and well-being and minimise the negative impact of caring

Working Together
Involving carers in the planning, delivery and evaluation of services improves outcomes for the carer and cared for person. Carers will be identified and supported best through partnerships between the statutory and voluntary sector and by good referral processes

Individual Support
Carers will be identified and signposted to help and support as early as possible in their journey and at times of crisis/transition.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1. Number of HSC Trust front line staff in a range of settings participating in Carer Awareness Training Programmes	Trust Training Report (including Induction programmes)	20% 50%	By end of Year 2 By end of Year 3
2. The number of carers who are offered Carers Assessments 3. The percentage of carers who participate in Carers Assessments	Health & Social Care Board/ DHSSPSNI returns	Improvement targets set by H&SC Board in conjunction with Carers Strategy Implementation Group	Reviewed annually

Standard 30:
All family carers should be offered the opportunity to have their needs assessed and reviewed annually.

Service User Perspective:

"The needs of family members who care for and support me will be assessed and regularly reviewed"

Rationale:
The majority of people with a learning disability live with their families. Nearly one-third live with a single carer and over 25% live with carers aged over 65 years. The pressures of caring can cause stress and ill health. Family carers report difficulties in accessing breaks from their caring responsibilities. The types of short breaks valued by family carers and people with a learning disability are wide ranging and needs to be flexible and responsive to the individual circumstances. This should include adult placement, drop-in services for people with a learning disability and support for the disabled family member to access social and recreational opportunities. A move away from an over reliance on short breaks in residential facilities is therefore signalled. Short breaks should be a positive experience for the person with a learning disability, adding to their lives' experiences as well as giving the family member a break.

Evidence:
NDTi (2010) Short Breaks Pathfinder Evaluation Greig,R., Chapman P., Clayson A., Goodey C., and Marsland D. http://www.education.gov.uk/publications/eOrderingDownload/DCSF-RR223.pdf

DHSSPS (2010) Care Management, Provision of Services and Charging Guidance http://www.dhsspsni.gov.uk/hsc-eccu-1-2010.pdf

DHSSPS (2009) Delivering the Bamford Vision. The Response of the Northern Ireland Executive to the Bamford Review of Mental Health and Learning Disability Action Plan (2009-2011) http://www.dhsspsni.gov.uk/bamford_consultation_document.pdf

DHSSPS (2009) Regional Carer's Support and Needs Assessment Tool http://www.dhsspsni.gov.uk/eccu2-09.pdf

Black, LA *et al* (2008) Lifelines Report: An Evaluation Report of the Impact of the Families Services delivered by Positive Futures in Rural and Urban Areas of Northern Ireland. http://www.positive-futures.net/sites/default/files/LIFELINES%20Full%20Report.pdf

Kenny, K and McGilloway, S. (2007) Caring for children with learning disabilities: an exploratory study of parental strain and coping, British Journal of Learning Disabilities, p221-8.

http://onlinelibrary.wiley.com/doi/10.1111/j.1468-3156.2007.00445.x/abstract

DHSSPS (2006) Caring for Carers: Recognising, Valuing and Supporting the Caring Role http://www.dhsspsni.gov.uk/ec-dhssps-caring-for-carers.pdf

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability http://www.dhsspsni.gov.uk/equallivesreport.pdf

Bamford (2004) University of Ulster Audit of Learning Disability Research in NI http://www.dhsspsni.gov.uk/learning-disability-consultation

Mencap (2003) Breaking point: A report on caring without a break for children and adults with profound learning disabilities. Mencap. London. http://www.mencap.org.uk/campaigns/take-action/our-other-campaigns/breaking-point

Responsibility for delivery/implementation	**Delivery Partners**
• HSC Board • HSC Trusts	• DHSSPS, DSD • Other Service Providers

Quality Dimension

Citizenship
Family carers have a voice in the development of strategies that impact on their role and ability to continue caring for their child, young person or adult

Social Inclusion
Carers are not left in isolation to cope with their role of caring for their child, young person or adult

Empowerment
Carers are better informed of their entitlements through the support and information they receive from professionals and /or independent advocates.

Working Together
Carers are involved in working as equal partners with statutory/other agencies in planning services that are flexible and responsive to meeting their needs and the needs of the person with a learning disability.

Individual Support
Carers of a person with a learning disability will have their support needs assessed and be provided with the services that support the family and / or the individual carer.

Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
1 Percentage of carers who express satisfaction at their annual review that their needs as identified in the carers' assessment have been met.	User and carer feedback	Establish baseline Performance levels to be determined once baseline established	Year 1 Year 2

CHAPTER 11: AGEING WELL

Life expectancy for men and women with a learning disability has increased markedly over recent years. Growing older is likely to present additional challenges for people with a learning disability owing to the impact of their disability.

People with Down's syndrome are at high risk of Alzheimer's disease as they grow older and virtually all people with Down's syndrome who live long enough will develop this type of dementia. In addition, it is estimated that between 20% – 40% of older people with a learning disability are liable to have a mental health problem.

The number of older family carers is also increasing which can create particular challenges, for example, older carers:

- are under greater physical and mental pressures because of their age;
- may be particularly anxious about the future;
- are more likely to be caring alone; and
- may have smaller social support networks.

There has been little emphasis on health and wellbeing for older people with a learning disability or indeed their ageing carers. Ageing well has not been proactively encouraged by service providers. This is reflected in the low number of older people with a learning disability who participate in leisure activities and in concerns about unhealthy life styles.

Standard 31:

All people with a learning disability should have the impact of ageing taken into account in having their future needs assessed and proactively managed.

Service User Perspective:

"As I get older HSC staff will support me to plan for the future taking account of my age"

Rationale:
To avoid unnecessary anxiety to the person with a learning disability and their ageing family carer they both need to think about and plan for the changes that are likely to happen in their lives. Where this is done, crisis intervention should be eliminated in all situations where a person is known to social services and their needs met when there is a requirement to do so. At the same time, plans should also be considered for the family carer, in line with the statutory entitlement to an assessment of carer's needs (as with Standard 29).

People with a learning disability should be enabled to remain in their own home with their family carer for as long as possible with appropriate care and support to do so.

People with a learning disability have the same needs for autonomy, continuity of support, relationships and leisure as other older people.

Evidence:
The Alzheimer's Society (2011) Adaptations, improvements and repairs to the home www.alzheimers.org.uk/factsheet/428

DHSSPS (2010) Improving Dementia Services in NI: A Regional Strategy Consultation Document http://www.dhsspsni.gov.uk/improving-dementia-services-in-northern-ireland-consultation-may-2010.pdf

DHSSPS (2009) Regional Carer's Support and Needs Assessment Tool http://www.dhsspsni.gov.uk/eccu2-09.pdf

DHSSPS (2008) Standards for Adult Social Care Support Services for Carers http://www.dhsspsni.gov.uk/standards_for_adult_social_carer_support_services_for_carers.pdf

DHSSPS (2007) Living Fuller Lives: Dementia and Mental Health Issues in Older Age Report (Bamford) http://www.dhsspsni.gov.uk/living_fuller_lives.pdf

Tinker, Prof (1999) Ageing in place: What can we learn from each other? Kings College London www.sisr.net/events/docs/obo6.pdf

McQuillan *et al* (2003) Adults with Down's Syndrome and Alzheimer's Disease.

Tizard Learning Disability Review 8(4): 4-13.
http://pierprofessional.metapress.com/content/41u62857klh37m32/

Responsibility for delivery/implementation	Delivery and implementation partners
• HSC Board • HSC Trusts	• DHSSPS, DSD • Other service providers

Quality Dimension

Citizenship
People with a learning disability have the same right of access to Allied Health Professionals and specialist services, including equitable access to equipment aids and adaptations that assist daily living. They should not be discriminated against because of their learning disability.

Empowerment
People with a learning disability are facilitated to ensure that they have support to express their views and wishes as they plan for their future. People with a learning disability are provided with accessible information and support to understand and make their decisions about the future including information about age-related benefits.

Working Together
People with a learning disability have the right to a seamless transition towards increasing involvement and co-operation with services for older people and this should include any changes between programmes of care/team/Directorates in a pro-active manner.

Individual Support
Plans are in place and reviewed for the time when the carer is unable to continue to care, and is considered as part of the ongoing assessment of client and carers needs.

Performance Indicator	Data source	Anticipated Performance Level	Date to be achieved by
1 Percentage of people whose care plan has been reviewed taking account of issues associated with ageing.	SAAT	Develop and implement SAAT Performance level to be determined based on SAAT outcomes	Year 1 Year 2

2 Percentage of carers aged 65 years and over receiving domiciliary or short break support services.	SAAT	Develop and implement SAAT Performance level to be determined based on SAAT outcomes	Year 1 Year 2

Standard 32:

All people with a learning disability should have access to dementia services at whatever age it becomes appropriate for the individual.

Service User Perspective:

"I can get care and support from dementia services when I need it"

Rationale:

The early stages of dementia in people with a learning disability are more likely to be missed or misinterpreted – particularly if several professionals are involved in the person's care. The person may find it hard to express how they feel their abilities have deteriorated, and problems with communication may make it more difficult for others to assess change. It is vital that people who understand the person's usual methods of communication are involved when a diagnosis is being explored – particularly where the person involved does not use words to communicate. It is important that any prescribed medicine is monitored closely and that other ways of dealing with the situation are thoroughly explored.

People who have Down's Syndrome develop signs of dementia at a much younger age than others resulting in their needs being planned for much earlier.

Carers should be provided with information that helps them identify the earlier onset of dementia symptoms and be provided with appropriate support to continue to care for their adult with a learning disability. Carer's assessments should seek to identify any psychological distress and the psychosocial impact on the carer, including after the person with dementia has been provided with alternative care options.

Understanding a person's past history is crucial to providing person-centred care for someone with a learning disability and dementia.

Evidence:

DHSSPS (2010) Improving Dementia Services in NI: A Regional Strategy Consultation Document http://www.dhsspsni.gov.uk/improving-dementia-services-in-northern-ireland-consultation-may-2010.pdf

DHSSPS (2010) Adult Safeguarding in NI: Regional & Local Partnership Arrangements http://www.dhsspsni.gov.uk/asva-_march_2010.pdf

Brooker, D (2007) Person-centred Dementia Care – Making Services Better. http://books.google.co.uk/books?id=FQ3CdTblObwC&pg=Brooker+2007

NICE (2006) Clinical Guideline 42: Dementia - Supporting people with dementia and their carers in health and social care (Revised 2011)

http://www.nice.org.uk/nicemedia/live/10998/30317/30317.pdf

Regional Adult Protection Forum (2006) Safeguarding Vulnerable Adults: Regional Adult Protection Policy & Procedural Guidance
http://www.shssb.org/filestore/documents/Safeguarding_Vulnerable_Adults_-_3_Nov_06.pdf

Bamford (2005) Equal Lives: Review of Mental Health and Learning Disability
http://www.dhsspsni.gov.uk/equallivesreport.pdf

Alzheimer's Society (2011) – Learning Disabilities and Dementia
http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=103

An Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing TILDA. Measures will address health, cognitive status, activities of daily living, living situations, social life and overall quality of life within which a descriptive statistical picture of the life experiences of adult persons of ID will be developed. Prof. Mc Carron's research. Commenced September 2008. Due to complete in October 2011. http://people.tcd.ie/mccarrm

Responsibility for delivery/implementation	**Delivery and implementation partner**
• HSC Board • HSC Trusts Dementia Services • Primary Care • RQIA	• DHSSPS • Other service providers • Family carers

Quality Dimension

Citizenship
People with a learning disability and dementia should have the same access to dementia services as everyone else. People with a learning disability and those supporting them should have access to specialist advice and support for dementia. People with a learning disability and dementia should feel equally valued and should not experience barriers to person-centred care.

Social Inclusion
Every effort should be made to ensure people with a learning disability and dementia are cared for at home. When a move is necessary a specific care plan should be drawn up to ensure continuity of care and support for the person and successful transfer of expertise to the new service. People with a learning disability and dementia should not be excluded from services because of their diagnosis, age (whether regarded as too young or too old) or any learning disability.

Empowerment
Treatment and care should take into account each person's individual needs and preferences. Individuals must be given all available support before it is concluded that they cannot make decisions for themselves. Advocacy services and voluntary support should be available to people with a learning disability and dementia and carers separately if required.

Working Together
There should be sharing of skills and expertise between dementia services and learning disability services with equity of access to the most appropriate service delivery area. Referral protocols and pathways need to be clearly defined to facilitate people receiving the right care and attention in the right place at the right time.

Individual Support
Carers (family, staff, statutory and independent residential and nursing care providers) should be provided with information including inter-agency working, support and training to enable them to continue to care for the person with a learning disability and dementia. Care plans should incorporate individual person centred planning principles and should reflect individually assessed dementia care related needs.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1 Percentage of people with a learning disability and dementia who can access appropriate dementia services as required.	Trust generic dementia service	Establish baseline Performance levels to be determined once baseline established	Year 1 Year 2
2 Percentage of people with a learning disability and dementia who have received additional supports following a dementia diagnosis.	SAAT	Develop and implement SAAT Performance level to be determined based on SAAT outcomes	Year 2 Year 3
3 Percentage of HSC professionals and other support providers who have received awareness training on the needs of people with a learning disability and dementia	HSC Trust report	Establish baseline Performance levels to be determined once baseline established	Year 1 Year 2

CHAPTER 12: PALLIATIVE AND END OF LIFE CARE

Palliative and end of life care focuses on all aspects of care needed by patients and their families, physical, emotional and spiritual. It involves relief of symptoms, making thoughtful decisions, supporting families and providing ongoing care in the appropriate setting. It is important that people in the last phase of life get the appropriate care, at the right time, in the right place, in a way that they can rely on. The following standards are designed to improve the patient and family experience of palliative and end of life care through *holistic assessment* of need, improved coordination of care and a greater focus on choice at end of life.

Standard 33: (Generic)
All people with advanced progressive incurable conditions, in conjunction with their carers, should be supported to have their end of life care needs expressed and to die in their preferred place of care.

Service User Perspective*:*

"I will be supported in my end of life care needs"

Rationale:
Most people would prefer to die at home (including residential and nursing home where this is the person's usual home) where this is possible.

In order to support this, identification of the possible last year/months/weeks of life should take place. Evidence shows that when end of life care needs are identified there is improved quality of life and even prolonged life, compared to when this stage of illness is not identified, particular in non-cancer conditions.

Advanced care planning allows more informed choice of care and enables people to be more supported to die in their preferred place of care.

Palliative care is the active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments. (WHO, 2002)

End of life care refers to the possible last year of life. It helps all those with advanced, progressive, incurable conditions to live as well as possible until they die. It enables the supportive and palliative care needs of both the patient and the family to be identified and met throughout the last phase of life and into bereavement. At this stage however it is often still appropriate to provide acute treatment in conjunction with palliative care, particularly in long term conditions. It includes physical care, management of pain and other symptoms and provision of psychological, social, spiritual and practical support. (National Council for Palliative Care, Focus on Commissioning, Feb 2007).

Evidence:
NCPC (2012) Palliative Care Explained
http://www.ncpc.org.uk/sites/default/files/PalliativeCareExplained.pdf (as accessed on 26 September 2012)

NICE (2011) Chronic Obstructive Pulmonary Disease (COPD): Quality Standard
http://guidance.nice.org.uk/QS10

DHSSPS (2010) Living Matters: Dying Matters – A Strategy for Palliative and End of Life Care for Adults in Northern Ireland.
http://www.dhsspsni.gov.uk/855_palliative_final.pdf

NICE (2010) Chronic Obstructive Pulmonary Disease; Management of Chronic Obstructive Pulmonary Disease in Adults in Primary and Secondary Care http://www.nice.org.uk/Guidance/CG12

Harrison , S et al, (2008), Identifying Alternatives to Hospital for People at the End of Life, The Balance of Care Group / National Audit Office http://www.balanceofcare.co.uk/previous_projects.html

Khan, SA; Tarver, K; Fisher S; Butler C (2007), Inappropriate Admissions of Palliative Care Patients to Hospital: A Prospective Audit, London, Pilgrims Hospices

Pleschberger, S, (2007), Dignity and the Challenge of Dying in Nursing Homes: The Residents' View http://ageing.oxfordjournals.org/content/36/2/197.short

DHSSPS (2006) Regional Cancer Framework: A Cancer Control Programme for Northern Ireland http://www.dhsspsni.gov.uk/eeu_cancer_control_programme_eqia.pdf

NHS (England) (2006) Gold Standards Prognostic Framework Programme, NHS End of Life Care Programme. Prognostic Indicator Papers vs 2.25 http://www.endoflifecare.nhs.uk/eolc/files/GSF-Guide-Prognostic_Indicators-Jul06.pdf

NICE (2004) Improving Supportive and Palliative Care for Adults with Cancer http://guidance.nice.org.uk/CSGSP

NICE (2004) Supportive and Palliative Care (CSGSP): Improving supportive and palliative care for adults with cancer http://www.nice.org.uk/Guidance/CSGSP

NHS Modernisation Agency (2004) Coronary Heart Disease Collaborative: Supportive and Palliative Care for Advanced Heart Failure http://www.improvement.nhs.uk/heart/Portals/0/documents/supportiveandpalliativecare.pdf

NICE (2003) Chronic Heart Failure; Management of Chronic Heart Failure in Adults in Primary and Secondary Care http://www.nice.org.uk/Guidance/CG5

Ellershaw & Wilkinson (2003), Care of the Dying: a Pathway to Excellence, Oxford University Press

Foote, C & Stanners, S, (2002), Integrating Care for Older People – New Care for Old – A Systems Approach, London, Jessica Kingsley

Responsibility for delivery/implementation	**Delivery and implementation partners**
• HSC Board • Public Health Agency (PHA) • HSC Trusts • Primary Care	• NICaN Supportive and Palliative Care Network • Primary care team, inclusive of social care • Voluntary palliative care

	organisations • Private nursing home and care providers

Quality Dimension

Citizenship
Earlier identification of palliative care needs and advance care planning will help improve quality of life and support a good death. Inappropriate admissions to hospital at the very end of life will be avoided.

Social Inclusion
People with non cancer conditions will have access to care and services traditionally available mainly to those with cancer conditions only

Empowerment
Involving service users, carers and families ensures that choices and preferences are taken into account in the planning and delivery of services

Working Together
HSC staff work in partnership with learning disability teams in order to ensure that appropriate reasonable adjustments are made to meet the specific needs of people with a learning disability.

Individual Support
Effective joint working between palliative care services and learning disability teams will ensure that the impact of learning disability is appropriately addressed in individual treatment plans.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1. Percentage of the population that is enabled to die in their preferred place of care.	NISRA survey for baseline of the population's preference Registrar General and PAS information for actual place of death	Establish baseline Performance indicator to be determined when baseline established	Year 1 Year 2
2. Percentage of the population with a understanding of advance care planning	NISRA survey for baseline levels	Establish baseline Performance indicator to be determined when baseline established	Year 1 Year 2

Standard 34:
All people with a learning disability being assessed for supportive and palliative care should have their learning disability taken into account in consultation with them, their carers and learning disability services when appropriate.

Service User Perspective*:*

If my health is getting worse and I need extra support towards the end of life staff will take into account my learning disability

Rationale:
Early identification of the supportive, palliative and end of life care needs of patients, their care-givers and family, through a holistic assessment, maximise quality of life for all in terms of physical, emotional, social, financial, and spiritual health and wellbeing.

People with a learning disability are entitled to the same services and respect throughout life as anyone else. Good palliative and end of life care is about enabling the individual to live out their potential when faced with an advanced progressive illness. By addressing the physical, emotional, spiritual and social issues which often make us fearful of death, it ensures that all individuals regardless of clinical diagnosis, get the appropriate care, at the right time, in the right place, in a way they can rely on.

Where necessary, reasonable adjustments should be made to take account of the impact of learning disability. Reasonable adjustments can be many and are wide ranging, but it is important to remember that they must be individualised to the person, and may include such things as:

- longer appointment times
- offering the first or last appointment
- the provision of easy read information to enhance understanding
- close involvement and support of family carers
- partnership working between learning disability services and other service providers.
- appropriate waiting facilities
- pre-admission visits
- fast tracking arrangements when appropriate (eg in A&E Departments)

Evidence:
Department of Health, Social Services and Public Safety (2010) *Living Matters: Dying Matters: A palliative and end of life care strategy for adults in Northern Ireland.* DHSSPS, Belfast.

Mencap (2008) Healthcare for All (The Michael Report) Report of the Independent Inquiry into access to healthcare for people with learning disabilities

National Institute for Clinical Excellence (2004) Improving Supportive and

Palliative Care for Adult with Cancer.
NHS (England) (2006) Gold Standards Prognostic Framework Programme, NHS End of Life Care Programme. Prognostic Indicator Papers vs. 2.25
http://www.endoflifecare.nhs.uk/eolc/files/GSF-Guide-Prognostic_Indicators-Jul06.pdf

NICE (2004) Improving Supportive and Palliative Care for Adult with Cancer. National Institute for Clinical Excellence: London
http://www.nice.org.uk/nicemedia/pdf/csgspmanual.pdf

NICE (2004) Management of Chronic Obstructive Pulmonary Disease in Adults in Primary and Secondary Care.
National Institute for Clinical Excellence: London
http://guidance.nice.org.uk/CG12

Responsibility for delivery/implementation	**Delivery and implementation partners**
• Primary Care • HSC Trusts • Public Health Agency	• Voluntary Palliative Care Organisations • Private nursing home and care providers

Quality Dimension

Empowerment
Involving service users, their carers and families ensures that their choices and preferences are taken into account in the design and delivery of services.

Working Together
Partnership with service users, their carers and families is only possible if they are proactively involved in decision-making processes. Effective partnerships will contribute to positive health and social care outcomes.

Individual Support
Effective person-centred support will ensure that individuals are appropriately assessed for supportive and palliative care.

Performance Indicator	**Data source**	**Anticipated Performance Level**	**Date to be achieved by**
1 Palliative care services have mechanisms to identify whether people have a learning disability.	SAAT	Develop and implement SAAT Performance levels to be determined based on SAAT outcomes.	Year 1 Year 2

2	Evidence of specific actions in service delivery that make reasonable adjustment for their learning disability.	SAAT	Develop and implement SAAT Performance levels to be determined based on SAAT outcomes.	Year 1 Year 2

ANNEX A

GLOSSARY OF TERMS

TERM	DEFINITION
Acute Care	Health care and treatment provided mainly in hospitals
Advocacy	A service that provides someone to represent your views or support you in expressing your own views
Allied Health Professionals	Allied health professionals (AHPs) work with all age groups and within all specialties. AHPs work in a range of surroundings including hospitals, people's homes, clinics, surgeries and schools.
Augmented forms of communication	Better more accessible communication
Autonomy	Freedom of will
Capacity (mental)	Being able to understand and use information to make a decision
Care order	Care order is a court order made on the application of a HSC Trust and granted where the court finds the child has suffered or is likely to suffer significant harm.
Care pathway	A plan for the care needed to help a person with a learning disability to move through the different services they may need.
Challenging behaviour	When someone is behaving in a way that might cause harm to themselves or other people. Services are challenged to find a way of managing the behaviour so the chance of harm is reduced.
Citizenship	People with a learning disability being treated equally with other people.
Commissioners	A term used to describe organisations or groups who have been given responsibility for purchasing of health and social services.

Community Care	Services provided outside the hospital setting by HSC professionals and other organisations in the community.
Competency – based	An ability to do something, especially measured against a standard
Crisis intervention	A situation or period in which things are very uncertain, difficult, or painful, especially a time when action must be taken to avoid things getting much worse.
Cross-sectoral	Links between organisations managed by Government and voluntary/ community organisations and private business
Direct Enhanced Services	A Directly Enhanced Service is a specialised service provided by all GPs in N Ireland for adults with severe learning disability
Direct Payments	Direct Payments have been available since 1996 and aim to promote independence by giving people flexibility, choice and control over the purchase and delivery of services that support them. Individuals can opt to purchase services tailored to suit them by means of a Direct Payment from the Trust. From 19 April 2004 Direct Payments were extended to a wider range of service users under the Carers and Direct Payments Act (Northern Ireland) 2002 to include carers, parents of disabled children and disabled parents.
Disparities	A lack of equality between people or things
Domiciliary care	Support or care provided to a person in their own home
Dual diagnosis	Two different illnesses
Eligibility	To meet requirements for a certain criteria
Empowerment	Supporting people to take a full part in making decisions about their life.
Evidence-based practice	Doing things that have been shown to work
Health Action Plan	Describes the care and support you need to look after yourself and stay healthy.

Holistic care	Comprehensive care that addresses the social, psychological, emotional, physical and spiritual needs of the individual.
Independent sector	Organisations that are not managed by Government – includes voluntary organisations, community organisations and private business
Informed consent	Agreement by you to undergo treatment or care after being informed of and having understood the risks involved.
Integrated care pathway (ICP)	A multi-disciplinary outline of anticipated care which identifies how a patient with a specific condition will be supported by a number of professionals or agencies.
Integration	Equal access for all
Inter-agency	Links between different organisations
Legislative	To do with law
Mainstream Services	Services that anyone can use.
Methodologies	Different way of doing research.
Multi-Agency	Staff from different agencies, for example health and social care, education and employment, working together.
Multi-disciplinary	Staff from different professions, for example, nurses, doctors, social workers, working together.
Optimum	Most suitable
Palliative care	The active, holistic care of patients with advanced progressive illness. The goal of palliative care is to achieve the best quality of life for patients and their families.
Partnership working	Different organisations working together to achieve something
Person-Centred	The person and their family and friends are central and fully involved in all aspects of their care. The service, the organisation and its systems are focused on the needs of (what is important to) the individual.

Preliminary reports	Reports done at the start.
Prevalence	How many people in the population have a particular problem
Primary Care	Health and social care services that are generally available to everyone, for example, GP, dentist.
Reasonable adjustments	Actions that service providers should take to make sure people with a learning disability can use their services.
Respite	Support which gives carers a break from their usual caring roles and duties.
SAAT	Self Assessment Audit Tool – a performance management tool designed to measure the delivery of key objectives
Secondary Care	Health and social care services that help people with more complicated needs than those that primary care deal with, but mostly in the community.
Self-determination	A right to decide for self
Self-directed support	Helping people be in control of the support they need to live their life as they chose.
Service Framework	A document that sets out what people can expect the service to provide.
Service User	Anyone who uses, requests, applies for, or benefits from health and social care services.
Social inclusion	Making people with a learning disability feel part of the community they live in.
Statutory sector	Those organisations that are managed by government
Stereotypical	To categorise individuals or groups according to an oversimplified standardised image or idea
Transition	A time in a person's life when big changes are happening, for example, leaving school
Universal	Meaning all

ANNEX B

MEMBERSHIP OF PROJECT BOARD

Dominic Burke	Western Health and Social Services Board (Chair to March 2009)
Fionnula McAndrews	Health and Social Care Board (Chair from April 2009)
Siobhan Bogues	Association for Real Change (Northern Ireland)
Dr Maura Briscoe	DHSSPS (to October 2009)
Peter Deazley	DHSSPS (from October 2009)
Paul Cavanagh	Western Health and Social Services Board (until March 2009 and from September 2009)
Jim Simpson	Western Health and Social Services Board (to August 2009)
Aidan Murray	Health and Social Care Board (from September 2009)

MEMBERSHIP OF PROJECT TEAM

Siobhan Bogues	Association for Real Change (Northern Ireland) (Chair of Project Team)
Charles Bamford	DHSSPS
Orlaigh Cassidy	Service User
Edna Dunbar	Association for Real Change (Northern Ireland) (to September 2009)
Paula McGeown	DHSSPS (from September 2009)
Veronica Gillen	DHSSPS (to September 2010)
Rosaleen Harkin	Western HSC Trust
Sandra Harris	Equal Lives Action Group
Roy McConkey	Expert Board on Mental Health and Learning Disability
Bryce McMurray	Southern HSC Trust
Bria Mongan	South-Eastern HSC Trust
John Mullan	Service User
Jim Simpson	Western Health and Social Services Board (to August 2009)
Miriam Somerville	Belfast HSC Trust
Tom Smith	Southern Health and Social Services Board (until August 2009)
Pat Swann	DHSSPS
Sam Vallelly	Northern HSC Trust
Adrian Walsh	Eastern Health and Social Services Board
Aidan Murray	Health and Social Care Board (from October 2009)
Molly Kane	Public Health Agency (from September 2009)

ANNEX C

MEMBERSHIP OF WORKING GROUPS

ACCOMMODATION

Bryce McMurray	Southern HSC Trust (Chair of Accommodation Working Group)
Richard Black	Southern HSC Trust
Dessie Cunningham	Southern HSC Trust
Tony Doran	Southern HSC Trust
Janet McConville	Southern HSC Trust
Sinead McGeeney	Disability Action
Paul Roberts	Positive Futures
Moira Scanlon	Southern HSC Trust
Tom Smith	Southern Health and Social Services Board
Chris Williamson	NI Federation of Housing Associations

AGEING

Rosaleen Harkin	Western HSC Trust (Chair of Ageing Working Group)
Tony Brady	Carer
Raymond Boyle	Western HSC Trust
Dr Michael Curran	Western HSC Trust
Brendan Duffy	Western HSC Trust
Dr Jennifer Galbraith	Western HSC Trust
Lee McDermott	Western HSC Trust
Mr Brian McGarvey	Mr Brian McGarvey
Pat McLaughlin	Western HSC Trust
Maureen Piggott	Mencap
Isobel Simpson	Western HSC Trust

CHILDREN AND YOUNG PEOPLE

Bria Mongan	South-Eastern HSC Trust (Chair of Children and Young People Working Group)
Sharon Bell	Parent
Dr Ann Black	South-Eastern HSC Trust
Gerry Campbell	NICCY
Heather Crawford	South-Eastern HSC Trust
Jennifer Creegan	South-Eastern HSC Trust
Maurice Devine	DHSSPS
Alice Lennon	South-Eastern Education and Library Board
Agnes Lunny	Positive Futures
Pauline McDonald	Belfast HSC Trust
Marian Robertson	South-Eastern HSC Trust
Colette Slevin	Mencap
Tracey Sloan	Parent

FULLER LIVES

Sam Vallelly	Northern HSC Trust (Chair of Fuller Lives Working Group)
Gareth Anderson	Northern HSC Trust
Ivan Bankhead	Northern HSC Trust
Mildred Bell	Northern HSC Trust
Pauline Cummings	Northern HSC Trust
Molly Kane	Northern Health and Social Services Board
Kate Kelly	Northern HSC Trust
Áine Lynch	North Regional College
Virgina Maxwell	Carer
Oonagh McCann	North-Eastern Education and Library Board
Oliver McCoy	Northern HSC Trust
Gerard McKendry	Service User (Compass Advocacy Group)
Donna Morgan	Northern HSC Trust
Judith Shaw	DEL
Bernie Doherty	DEL

Norman Sterrit	Triangle Housing Association

HEALTH

Miriam Somerville	Belfast HSC Trust (Chair of Health Working Group)
Kate Comiskey	Blair Lodge
Dr Petra Corr	Belfast HSC Trust
Maurice Devine	South-Eastern HSC Trust
Brian Irvine	Service User (Orchardville Training Centre)
Neil Kelly	Belfast HSC Trust
Rosalind Kyle	Belfast HSC Trust
Liz Leathem	Bryson Group
John McCart	Belfast HSC Trust
Dr Colin Milliken	Belfast HSC Trust
Mairead Mitchell	Belfast HSC Trust
Adian Murray	Eastern Health and Social Services Board
Fiona Rowan	Carer
Eilish Steele	Belfast HSC Trust

QUALITY IMPROVEMENT SUB-GROUP

Siobhan Bogues	Association for Real Change (ARC NI)
Edna Dunbar	Association for Real Change (ARC NI) (to September 2009)
Veronica Gillen	DHSSPS (to September 2010)
Seamus Logan	DHSSPS
Patrick Convery	Regulation & Quality Improvement Authority
Maureen Piggot	Mencap NI
Roy McConkey	University of Ulster
Jim Simpson	Western Health & Social Services Board (Until August 2009)
Stella Cunningham	Patient & Client Council
Molly Kane	Public Health Agency

COSTINGS SUB-GROUP

Adrian Walsh	Health & Social Care Board
Siobhan Bogues	Association for Real Change (ARC NI)

Veronica Gillen	DHSSPS (to September 2010)
Paula McGeown	DHSSPS (from September 2009)
Tracey McKeague	Health & Social Care Board
Bria Mongan	South-Eastern HSC Trust
Aideen O'Docherty	DHSSPS
Miriam Somerville	Belfast HSC Trust

ANNEX D

The five core values outlined in the Equal Lives Review (2005):

Citizenship	People with a learning disability are individuals first and foremost and each has a right to be treated as an equal citizen.
Social Inclusion	People with a learning disability are valued citizens and must be enabled to use mainstream services and be fully included in the live of the community.
Empowerment	People with a learning disability must be enabled to actively participate in decisions affecting their lives.
Working Together	Conditions must be created where people with a learning disability, families and organisations work well together in order to meet the needs and aspirations of people with a learning disability.
Individual Support	People with a learning disability will be supported in ways that take account of their individual needs and help them to be as independent as possible

ANNEX E

Bamford Review of Mental Health and Learning Disability Reports

• Mental Health Improvement and Wellbeing	May 2006
• Child and Adolescent Mental Health	July 2006
• Adult Mental Health	June 2005
• Dementia and Mental Health of Older People	June 2007
• Alcohol and Substance Misuse	Dec 2005
• Forensic Services	Oct 2006
• Learning Disability	Sept 2005
• Promoting Social Inclusion	Aug 2007
• A Comprehensive Legislative Framework	Aug 2007
• Human Rights and Equality	Oct 2006
• Delivering the Bamford Vision	2008

ANNEXE F

ABBREVIATIONS

A&E	Accident and Emergency
ASD	Autistic Spectrum Disorders
BMI	Body Mass Index
CSCI	Commission for Social Care Inspection (now Care Quality Commission)
CSR	Comprehensive Spending Review
DCAL	Department of Culture, Arts & Leisure
DE	Department of Education
DEL	Department of Employment & Learning
DES	Direct Enhanced Services
DfES	Department for Education and Skills (England)
DHSSPS	Department of Health, Social Services and Public Safety
DNAR	Do Not Attempt Resuscitation
DoH	Department of Health
DoJ	Department of Justice
DSCF	Department for Children Schools and Families (England)
DSD	Department of Social Development
ELB	Education and Library Board
FE	Further Education
GAIN	Guidelines and Audit Implementation Network
GMC	General Medical Council
GP	General Practitioner
HSC	Health and Social Care
IASSID	International Association for the Scientific Study of Intellectual Disabilities
LASPs	Local Adult Safeguarding Partnerships
LCG	Local Commissioning Group
NDA	National Disability Authority
NDTi	National Development Team for Inclusion

NHS	National Health Service
NIASP	Northern Ireland Adult Safeguarding Partnership
NICaN	Northern Ireland Cancer Network
NICE	National Institute for Health and Clinical Excellence
NIHE	Northern Ireland Housing Executive
NIUSE	Northern Ireland Union of Supported Employment
OFMDFM	Office of First Minister and Deputy First Minister
PBNI	Probation Board for Northern Ireland
PCC	Patient and Client Council
PCP	Patient-centred Plan
PfA	Priorities for Action
PHA	Public Health Agency
PPI	Personal & Public Involvement
PSNI	Police Service of Northern Ireland
QIS	Quality Improvement Scotland
RCSLT	Royal College of Speech and Language Therapists
RoI	Republic of Ireland
RQIA	Regulation & Quality Improvement Authority
PSSRU	Personal Social Services Research Unit
SAAT	Self Assessment Audit Tool
SACN	Scientific Advisory Committee on Nutrition
SBNI	Safeguarding Board for Northern Ireland
SCIE	Social Care Institute for Excellence
SENDO	Special Educational Needs and Disability Order
SIGN	Scottish Intercollegiate Guidelines Network
UNOCINI	Understanding the Needs of Children Northern Ireland
WHO	World Health Organisation

Produced by:
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Castle Buildings, Belfast, BT4 3SQ

Telephone (028) 9052 8321
www.dsspsni.gov.uk

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