Department of
Health, Social Services
and Public Safety

An Roinn
Sláinte, Seirbhísí Sóisialta
agus Sábháilteachta Poiblí

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a healthier future

A Twenty Year Vision for Health and Wellbeing in Northern Ireland

2005 - 2025

CONTENTS

MINISTERIAL PREFACE

At some point in our lives every one of us will use health and social services when we are ill or when we need extra help and support, coping with day to day life.

Health and social services are our largest single employer and historically have played a vital role in promoting our health and wellbeing regardless of religion, gender, age or any other factor that distinguishes people from each other.

Improving the health and wellbeing of the population and protecting the vulnerable is a long-term challenge, as is the education and training of new staff, the development of new partnerships and the building of new facilities. We must make plans and decisions now which will not only impact on this generation but on future generations.

Of course we cannot take every decision for the coming decades now or even anticipate all of the challenges that we will face. What we can and must do is establish a common and agreed direction and purpose. This must include working more closely with partners who can impact on all the determinants of health and wellbeing such as housing and education. And it must lead us to tackle the inequalities in society which cause poor health and social harm.

All of us, as individuals, families, communities and society have a responsibility for our health and social wellbeing and for protecting the most vulnerable.

There are challenges to be faced, and we must face them honestly, but the rewards for all of us mean that we must make every effort to make our twenty year vision a reality.

Angela Smith

PREFACE BY PERMANENT SECRETARY

Health and social services are important to all of us. When we need them they must be accessible, safe, effective and appropriate. Over the next twenty years our need for health and social services will change as our society changes. The range and nature of services that can be provided will also change as new ways of working, new technologies and new treatments are developed. If we are to respond effectively to these new demands and opportunities we must plan now for the future.

This new Regional Strategy, *A Healthier Future*, aims to address these issues and provide a vision of how our health and social services will develop and function over the next 20 years. In order to succeed, it must embrace the measures needed to promote health and wellbeing, support, protect and care for the most vulnerable and facilitate the delivery of services.

It must contribute to effective working across organisations and tackle the inequalities that so often give rise to poor health. In doing so, *A Healthier Future* places a special emphasis on promoting equality of access for all groups in our society.

A Healthier Future must also take due account of the changes which are likely to occur in terms of the composition of our population, its health and wellbeing status, the nature of our society and advances in medicine, science and technology. It must have due regard for the changing attitudes and expectations of those who will use the services and acknowledge the wider legal, moral and ethical framework within which services must be delivered.

One message is clear from our analysis of these trends so far. Needs and demands will grow over the next twenty years, whereas resources will always be finite. As we look towards our future we must be both visionary *and* realistic. We must plan to achieve real improvements with the resources we have without falsely raising expectations or creating more pressures on staff who in some cases are finding it difficult to cope with existing demands on them.

The timeframe for delivery of this vision will be affected by a range of factors, including the future availability of resources. In keeping with any long term plan, the *A Healthier Future* is an aspirational document. However, through the Strategy we will be able to make an effective case for future investment in health and social care and ensure that existing resources are used to greatest effect.

A Healthier Future is an overall framework for the development of health and social services across Northern Ireland. It takes account of strategies and policies, both emerging and established, across a range of specific areas of activity and seeks to place them within a broad and inclusive framework.

A Healthier Future does not amend or alter those specific strategies but builds on them by seeking to ensure that they are part of our overall vision for health and social care here over the next 20 years. It also seeks to ensure that these strategies are prioritised and implemented coherently in support of that vision.

The future beckons.

Clive Gowdy

STRATEGIC THEMES

In developing this strategy we have undertaken one of the most extensive consultations ever carried out in relation to the health and social services in Northern Ireland. Based on this engagement we have identified five cross-cutting themes around which we have designed the new strategy. These are:

- **Investing for health and wellbeing**
- **Involving people**
- **Teams which deliver**
- **Responsive and integrated services**
- **Improving quality**

We have also identified, within these themes, 16 Policy Directions, which set out the key messages in *A Healthier Future*.

INVESTING FOR
HEALTH AND WELLBEING

1. INVESTING FOR HEALTH AND WELLBEING

1.1 **Policy Direction 1: Our overall aim is to improve the physical and mental health and social wellbeing of the people of Northern Ireland.**

1.2 This section represents the first of the five strategic themes: Investing for Health. It focuses on measures to prevent illness and promote health and wellbeing by tackling the root causes of ill health and social harm. So, how good is our health?

1(i) A Healthier Society

1.3 The mental and physical health and wellbeing of our population is not as good as it should be. The number of people dying from heart disease in Northern Ireland is amongst the highest in Europe and significantly higher than in England. Our survival rate from cancer is only in the middle range for European countries and is particularly poor for some cancers. The number of accidental deaths here is the highest in the UK and our record on child pedestrian fatalities is particularly bad when compared to the European average.[1] Breast feeding rates are the lowest in the UK while the rate of teenage pregnancy is one of the highest in Europe.[2]

1.4 Improving health and wellbeing status will be one of the most fundamental ways of improving people's quality of life here and to achieve that we will need to maintain a strong system of health and social care. Two-thirds of the reduction in mortality in the first half of the 20th century was due to a decrease in deaths from infectious diseases like measles and diphtheria. By the end of the century the main killers here were the chronic non-communicable diseases.

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1. Department for the Environment and local Government. *The Road to Safety: Government Strategy for Road Safety 1998-2002.* Dublin
2. Department of Health, Social Services and Public Safety, 2003. *Needs and Effectiveness Evaluation: Health and Social Care Report.* Belfast.

A Journey through a Lifetime

Health and Wellbeing Promotion

Clean Air, Water   Promoting Physical Activity and Healthy Eating   Promoting Active Old Age
Parenting Skills   Nutrition   Alcohol, Drug, Sexual Health Awareness   Good Housing
Accident Prevention/Safe Communities   Building Caring Communities

Our Role is to Make Lives Longer...

Conception
Before we are born, our health and wellbeing is influenced by our parents and the pre-natal care available. Are they wealthy or deprived? Do they drink alcohol, smoke? Are they supported in getting ready to be parents?

Birth
We are born. Modern maternity services mean that if there are complications we are more likely to live.

Infancy
Our lives begin. If we are breast-fed we can expect better health. Are we living in smoke, or damp? Are we immunised to protect us from diseases? Are we wanted? Do our parents interact with us well?

Childhood
We explore the world. There are many new dangers. We develop a sense of self. Are we valued/confident? Can our families cope? Do we need extra care or support? We develop habits (e.g. diet, physical activity) which will impact on our whole lives. Oral care now protects our teeth from future decay.

Adolescence / Young Adult
Where we live and go to school has a huge impact. We need self esteem to protect us from suicide, depression, bullying. Do we engage in physical activity? Do we eat fast food? Have we begun to smoke, or drink? Do we take drugs? Have we received a sexually transmitted disease or become pregnant? Are we vulnerable to homelessness?

Adult/Middle Age
Are we working? Have we an income? Now is a critical time in our lives. Women can be subject to breast or cervical cancers. Men can be subject to testicular cancers. Our health and wellbeing begin to reflect our life so far. Are we developing coronary heart disease, lung cancer, diabetes, colo-rectal cancer? Has our drinking developed into dependency. Are we obese? All of life's pressures can build on us. Stress, mid-life changes, death of parents can all contribute to depression and poor mental health. Are we at risk of domestic violence?

Older Ages
The good news is that we have survived all life's challenges. We can look forward to years more active life than earlier generations.
However, depending on our earlier lives and a variety of other factors, we may be subject to social isolation, stroke or cancer. We may find ourselves managing a chronic disease or caring for an ill or infirm partner

...and to Promote Quality of Life

Care, Treatment and Protection

Ante Natal Care   Advised self-care   Chronic Disease Management   Genetic Screening
Emergency Medical Services/Acute Care   Screening   Family Support   Community Involvement
Care Packages   Immunisation   Elective Procedures   Palliative Care   Protection Services

1.5 Some of these improvements have been achieved through improved social or environmental conditions but population-based health interventions have been crucial. Immunisation has been one of the great public health success stories. With high childhood immunisation uptake rates, deaths from a number of infectious diseases are at very low levels.

1.6 Screening plays a vital role in preventing illness before symptoms appear. For many people the early identification of disease and subsequent early intervention will result in an improved outcome. Since the late 1980s two screening programmes, for breast and cervical cancer, have been in place here.

1.7 A very considerable burden of injury and ill-health is, however, created through inappropriate or unsafe behaviour. Our public health system is increasingly addressing this by tackling issues such as smoking, alcohol related harm, drug misuse, obesity and lack of exercise.

Smoking Kills and Injures

Smoking claims over 2,800 lives here each year. It is the single greatest cause of premature death and avoidable illness. Some 1.5million working days are lost each year due to smoking-related illness. And there is a huge economic cost associated with this.[3] The Chief Medical Officer in her Annual Report 2001 estimated that the annual in-patient care costs to the health service are over £22million. We spend a greater proportion of our weekly outgoings on cigarettes than any region in the UK.[4]

We must continue to make every effort to:
- prevent people starting to smoke;
- help smokers to quit; and
- protect non-smokers from the harmful effects of tobacco smoke.

Smoke-free Public Places and Workplaces

It is clear from the available evidence that the public needs to be protected from exposure to tobacco smoke. While some progress has been made in the area of smoke-free provision, we are consulting on strengthening existing controls on tobacco use.

While we will continue to encourage and support people who want to stop smoking, there are three options for strengthening the current approach, on which we would wish to take public opinion:

i. One is to build on the existing policy of exhorting and supporting smoking cessation. Some have argued that this is a matter of personal choice and that the role of Government should be to educate the public on the dangers of smoking and to encourage greater adoption of smoke-free provision in public places and in workplaces through self-regulation.

ii.The second option is that we might, as proposed for England, prohibit smoking in most enclosed public places and workplaces, while still allowing smoking in some pubs and bars, other than those preparing and serving food. Private clubs would have the discretion to take their own decision on smoking based on the views of their members.

iii.The third option is to adopt the approach taken in the South of Ireland and to be introduced in Scotland and ban smoking in all enclosed public places and workplaces in Northern Ireland.

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3. Department of Health, Social Services and Public Safety, 2002. *Investing for Health*. Belfast.
4. Office for National Statistics, 2002-2003

1.8 Alcohol misuse, and in particular binge drinking, is also damaging the physical and mental wellbeing of individuals, families and communities. Around 750 people die prematurely in Northern Ireland each year as a direct result of alcohol related harm. Some £34 million per year is incurred here in costs which directly impact on Government spending (e.g. hospital costs, general practice costs, prisoner costs associated with alcohol related crime).

1.9 A further £740 million per year is incurred in alcohol related costs which impact on Government spending less directly (e.g. premature death, costs to industry due to sickness absence and road traffic accidents). A 1999 review of children who were the subject of Care Orders found that 85% of children whose case files were examined had one or both parents who had longstanding problems relating to their use of alcohol and/or drugs.[5]

1.10 Rising levels of obesity and lower levels of physical activity will increasingly contribute to the burden of disease. Obesity is a contributory factor to a number of conditions such as stroke and cardiovascular disease. Obese men are more than 33% more likely to die from cancer and obese women are more than 50% more likely to die from breast cancer.[6]

1.11 The 1997/98 Health Behaviour in School Children survey showed that we topped the table for the UK in all three age groups in terms of the percentage of young people who reported eating sweets or chocolates every day. Some 25% of all people in Northern Ireland can be classed as sedentary and the costs attributable to lack of physical activity include[7] over 2,100 deaths per annum, equivalent to over 18,000 life years lost, and 1.2 million working days lost each year.

1.12 One of the most significant diseases caused and exacerbated by current changes in lifestyle behaviours is diabetes. It is estimated that between 30,000 and 50,000 people in Northern Ireland have diabetes and that this will double over the next decade.[8] At least one third, and half, of the people diagnosed will have diabetes related complications before the point of diagnosis. Currently, diabetes care in Northern Ireland is costing 5% of HPSS expenditure and a total of 10% of hospital in-patient resources.[9]

A Global Burden

"…in the most industrialized countries of North America, Europe and the Asian Pacific, at least one-third of all disease burden is caused by tobacco, alcohol, blood pressure, cholesterol and obesity. Furthermore, more than three-quarters of cardiovascular disease - the world's leading cause of death - results from tobacco use, high blood pressure or cholesterol, or their combination. Overall, cholesterol causes more than 4 million premature deaths a year, tobacco causes almost 5 million, and blood pressure causes 7 million." (World Health Organisation, 2002).

1.13 Although the choices we make as individuals have a significant impact on health and wellbeing we also recognise that deprivation and health status are linked. At all ages the probability of premature death is significantly increased by adverse social conditions and the worst off in our society are more likely to have a disability or illness.

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5. Department of Health, Social Services and Public Safety, 1999. *SSI Inspection of Care Planning for Children the Subject of Care Orders.* Belfast.
6. Medical Research Council, July 2000.
7. Department of Health, Social Services and Public Safety, 2002. *Investing for Health.* Belfast.
8. Department of Health, Social Services and Public Safety, 2002. *The Health of the Public in Northern Ireland: Report of the Chief Medical Officer.* Belfast.
9. CREST, 2003. *Report of the Northern Ireland Taskforce on Diabetes.*

Deprivation and Health

Many of the most important factors in determining the health and social wellbeing of the population are determined by the circumstances in which we live and work, such as:

- disadvantage and social exclusion;
- poverty;
- unemployment;
- low educational achievement;
- social and community environment;
- housing and living conditions;
- working conditions;
- the wider environment.

1.14 People from less wealthy socio-economic groups tend to have less access to care facilities, present at a later stage of disease development and are less demanding of professionals.[10] People from poorer backgrounds are also more likely to smoke, become pregnant as teenagers and experience hopelessness, social exclusion and depression.[11]

Health and Wellbeing Inequalities in Northern Ireland[12]

- People from poorer socio-economic groupings tend to have higher incidence of cancer and poorer cancer survival rates.
- The highest levels of diabetes in Northern Ireland are among people in the ‘unskilled’ socio-economic grouping.
- There is a higher level of long standing illness among the poorer socio-economic groupings.
- Over half of households that contain one or more disabled people live in poverty.

1.15 Northern Ireland has suffered a series of economic and social problems associated with societal conflict. As a result many people here have experienced long term unemployment or economic inactivity, violence, social isolation and poverty.[13] Clearly these factors have contributed to a legacy of poor physical and mental health and a lack of social wellbeing in comparison to the rest of the UK and other EU countries.[14] This in turn has resulted in both a lower life expectancy and poorer quality of life for people here.

1(ii) Who is Responsible?

1.16 Whatever the causes of poor health, and of health inequalities, they are neither acceptable nor sustainable. Health and wellbeing is the responsibility of everyone and not only the health and social services. Individuals, families, communities, the business sector and Government all have a role to play. We must also be more aware of the needs of vulnerable people and accept collective responsibility for their protection and care while promoting their independence and inclusion in society.

1.17 We must work to tackle the social, economic and environmental inequalities that impact on our health and wellbeing. If we are to improve our health and wellbeing, each of us must take personal responsibility, within our individual circumstances, to make it happen. Everyone must be helped to make healthier choices and to take greater responsibility for maintaining their own health and wellbeing.

1.18 We will need a new emphasis on reducing smoking, reducing alcohol-related harm, tackling levels of obesity, increasing physical activity and promoting good mental health.

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[10] Hart, J.T, 1971. The Inverse Care Law. *The Lancet,* 405-412 referred to in Securing Our Future Health: Taking a Long Term View Final Report, Derek Wanless April 2002, pg21.
[11] Department of Health, Social Services and Public Safety, 2002. *Investing for Health.* Belfast.
[12] NISRA, 2004. *Equality and Inequalities in Health and Social Care in Northern Ireland: A Statistical Overview.* Belfast.
[13] The extent of poverty and social exclusion in Northern Ireland were recently documented in the report, “Bare Necessities: Poverty and Social Exclusion in Northern Ireland” published by Democratic Dialogue, Oct. 2003.
[14] The relationship between poverty and social exclusion and our health and well-being was outlined in “Investing for Health”, published by DHSSPS 2002.

Key Population Health Outcomes

Everyone deserves the opportunity to enjoy life in an environment free of tobacco smoke. If we are to achieve this, we will need to increase the proportion of 11-16 year old children who do not smoke from 86.9% in 2003 to 95% in 2025.[15]

We will also need to increase the proportion of adults (16+) who do not smoke from 74% in 2002/03 to 95% in 2025.[16]

Binge drinking will be seen as socially unacceptable. To do this it would be necessary to reduce the proportion of male drinkers (aged 18-75 years) who engage in at least 1 binge drinking session a week from 48% in 2002 to 20% in 2025; and women drinkers who engage in at least 1 binge drinking session from 35% in 2002 to 10% in 2025.[17]

The harm caused by all forms of alcohol misuse will be significantly reduced. This will be achieved by reducing (by 2025) the number of men and women drinking above the recommended limits from 33% and 11% (2002/2003) respectively to 10% and 5%.[18]

We will seek to free society from the harm caused by illegal drug misuse by reducing the number of people who have taken illegal drugs during the previous year from 10% for men and 3% for women in 2002/2003 to 5% for men and 1% for women in 2025.[19]

People will be encouraged and supported to avoid the full range of harmful, risk-taking behaviour that leads to sexual disease, teenage parenthood, obesity and the risk of accidents and other forms of harm.

We will seek to reverse the current increase in the level of obesity in men and women so that by 2025, the proportion of men who are obese is less than 15% and the proportion of women who are obese is less than 17%. (In 1997 17% of men and 20% of women were obese).[20]

Harm will also be avoided by stopping the increase in levels of obesity in children by 2010 and reducing it by 50% by 2025.[21]

We will reduce the rate[22] of serious injuries from accidents in people of all ages by at least one fifth between 2002 and 2025. (The admission rate for serious injuries in 2002/03 was 349 per 100,000).[23]

We will increase the level of 5-year-old children with no dental decay experience to 75% and reduce the gap between the best and worst decayed/missing/filled scores by 25%.[24]

15. NISRA, *Young Persons' Behaviour Attitudes Survey.*
16. NISRA, 2003. Continuous Household Survey. Available from http://www.csu.nisra.gov.uk/archive/Surveys/CHS/Results/9_Smoking/Prevalence_of_cigarete_smoking_by_sex_Trend.htm
17. Health Promotion Agency, 2002. *Adult Drinking Patterns in Northern Ireland.* Belfast.
18. NISRA, 2003. Continuous Household Survey. Available from http://www.csu.nisra.gov.uk/archive/Surveys/CHS/Results/10_Drinking/Level_of_%20alcohol_consumption_by_sex_Trend.htm
19. Department of Health, Social Services and Public Safety and National Advisory Committee on Drugs, 2003. *Drug Use in Ireland and Northern Ireland: First Results from the 2002/2003 Drug Prevalence Survey.*
20. Health and Wellbeing Survey.
21. Survey measure to be developed. (Department of Health in GB reported that in 2001 some 8.5% of 6 year olds and 15% of 15 year olds were obese – NHS Health Development Agency). The Child Health System records BMI for most P1 children. These measurements are carried out by the School Nurse at the Primary 1 Health Appraisal, which includes vision and hearing screening plus height and weight measurement. In 2002/03, 5.9% of Primary 1 children (aged 4-5) were obese according the international definition (Cole et al. 2000). The National Survey of Children's Dental Health 2001/02 found that 5.6% of Year 11 students (aged 14-16) in NI were obese according to the international definition. This survey also examined Primary 1, Primary 4 (aged 7-10) and Year 8 (aged 11-13) children. The overall obesity rate for all children surveyed was 5.8%.
22. Age-gender standardised.
23. Admissions data from HIS and Mid-year pop estimates.
24. Community School Screening database (annually from 2005). UK Child Dental Health Survey every 10 years.

1(iii) What Are We Doing About it?

1.19 **Policy Direction 2: We remain committed to *Investing for Health*, as the overarching cross-governmental policy for promoting population health and wellbeing and reducing health inequalities.**

1.20 Much has been done to improve our health and wellbeing including health promotion, screening campaigns and vaccination programmes. In recent years there has been a greater emphasis on partnerships across Departments, Agencies and the community and voluntary sector to develop joined-up programmes and initiatives. A local Investing for Health Partnership has been established in each area while Healthy Living Centres and Health Action Zones are all examples of community-driven initiatives to promote health and wellbeing.

The Tullycarnet Healthy Neighbourhood Project
The Tullycarnet Healthy Neighbourhood Project was developed to increase greater community health related activity, raise awareness of health related issues and address unmet health and social needs and gaps in services. A local Tullycarnet Health Project football team, for example, has been established by 2 local male volunteers and this has proved very successful as 12 local men/fathers have now been identified to undergo football coach training.

Western Health Action Zone (HAZ)
The Strabane Ageing Well Network, with the support of the HAZ, is developing the Strabane Befriending Project to counter rural isolation among older people. The HAZ is establishing a pilot for a Hospital Appointment Journey Planning Project with Altnagelvin Hospital Trust. The aim of this pilot will be to reduce non-attendance by supporting people to plan their journey to their appointment. Patients will be offered the opportunity to avail of Community Transport to attend out-patient appointments at orthodontics, paediatrics and dietetics clinics.

1.21 The promotion of health and wellbeing is now integrated into the plans and priorities of all Government Departments through the Executive's *Programme for Government* and, more recently during Direct Rule, *Plans and Priorities*. These multi-sectoral commitments are embodied in a major over-arching strategy, *Investing for Health*.

1.22 *Investing for Health* has provided for a step change in the priority given to population health and wellbeing across Government. It has set an agenda for improving the quality of life of people across Northern Ireland. This Regional Strategy is committed to the messages of *Investing for Health* and, in keeping with the spirit of the policy, includes longer term population health outcomes which will be reviewed when *Investing for Health* is reviewed. The Regional Strategy also affirms that promoting health and wellbeing is the responsibility of everyone across the HPSS, including commissioning organisations (i.e. HSS Boards) and service delivery organisations (i.e. HSS Trusts).

1.23 **Policy Direction 3: Promoting health and wellbeing is the responsibility of everyone across the HPSS, including commissioning organisations and service delivery organisations.**

1.24 Health and social services workers are in a unique position to influence people's attitudes and behaviours related to health and wellbeing. Accordingly, all of the aims and objectives set out in the Regional Strategy should be seen as supporting and working towards the implementation of *Investing for Health.*

Key Action: Fluoridation and Oral Health
Fluoridation of the water supply could make a significant impact on the unacceptably high levels of dental decay in Northern Ireland. We will review the possibility of introducing fluoridation.

1.25 The Strategy places a special emphasis on promoting health and wellbeing amongst vulnerable groups for whom preventative measures could provide the greatest impact. These include: boys and young men, who are less likely to seek health and social care advice, and who are more prone to suicide; girls and young women amongst whom smoking and alcohol-related harm are increasing; victims, homeless people, people with disabilities, older people, carers and Travellers.

Key Population Health Outcomes
Improve male and female life expectancy here towards the levels of the best EU countries.

Reduce by two thirds the gap in life expectancy between those living in the most deprived 20% of electoral wards and the average life expectancy here for both men and women between 2000 and 2025.[26]

Reduce the standardised death rate per 100,000 people under 80 years of age for cancer by 20% from 178 deaths for males in 2002 and 143 deaths for females to 142 deaths and 115 deaths respectively.[27] [28]

Increase the 5-year cancer survival rates to the levels of the best European countries. [29] [30]

Reduce the death rate per 100,000 people under 80 years of age for coronary heart disease from 130 deaths for males in 2002 and 66 deaths for females to compare with the European country with the lowest death rate.[31] [32]

Reduce the death rate per 100,000 people under 80 years of age for respiratory disease by 50% from 49 deaths for males in 2002 and 43 deaths for females to 25 deaths and 21 deaths respectively.[33] [34]

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[25] The Government Actuary Department predicts life expectancy at birth in Northern Ireland in 2025 to be 79.8 years for males (75.2 years in 2001) and 83.9 years for females (80.1 years in 2001). In 2001, life expectancy for males here was 2.4 years worse than in Sweden (the best in Europe for males). For females, life expectancy was 2.8 years worse than in France (the best in Europe for females). (Government Actuary Department).

[26] Government Actuary Department and Census of Population.

[27] In 2001 the standardised death rate (all ages) for cancer in Finland was 150 deaths per 100,000 of the population, compared with 190 per 100,000 in Northern Ireland.

[28] Deaths data from GRO and mid-year population estimates.

[29] For those diagnosed in 1993-1996 in Northern Ireland, the 5-year survival rates for all cancers (ex NMS) were 38% for males and 51% for females. For males diagnosed in 90-94 in Austria (the best in Europe at that time), the 5 year cancer survival rate was 55% and for females diagnosed in 90-94 in France (the best in Europe at that time) the 5-year survival rate was 59%. (Note: European survival rates for all cancers have been weighted by site while NI figures are unweighted).

[30] Cancer Registry.

[31] In 2001 the standardised death rate (all ages) for coronary heart disease in Luxembourg was 77 deaths per 100,000 of the population, compared with 149 per 100,000 in Northern Ireland.

[32] Deaths data from GRO and mid-year population estimates.

[33] In 2001 the standardised death rate (all ages) for respiratory disease in Latvia was 29 deaths per 100,000 of the population, compared with 88 per 100,000 in Northern Ireland.

[34] Deaths data from GRO and mid-year population estimates.

Reduce the death rate per 100,000 people under 80 years of age for Stroke by 50% from 38 deaths for males in 2002 and 36 deaths for females to 19 deaths and 18 deaths respectively.[35 36]

Ensure that everyone with diabetes is screened annually for the risk of kidney disease so that problems can be identified early and managed in a community-based setting. We will also aim to address current trends towards 10% growth in haemodialysis per year, recognising that some of this growing need will be the result of inevitable demographic trends.[37]

Reverse current trends towards a doubling in the prevalence of diabetes over the next ten years and reduced the number of people with diabetes from current levels (30,000 to 50,000 in 2002) to levels comparable to European countries with the lowest prevalence.[38]

Reduce the number of people with a preventable visual impairment from current levels (estimated 24,000 people in Northern Ireland) to be comparable with EU countries which have the lowest levels of blindness and visual impairment.[39]

Reduce the number of suicides for all persons per 100,000 by 50%[40] and reduce the number of suicides for males aged 15-44 per 100,000 by 50%.

1(iv) Partnerships Across Government

1.26 Other Government Departments and the full range of partners in *Investing for Health* will have a crucial role in implementing *A Healthier Future* over the next twenty years. Their contribution will be maximised and focused by the use of Health Impact Assessments in the development of all new policies, but their mainstream work will make a very positive impact across a range of key areas.

Protecting Health

1.27 The Department of Agriculture and Rural Development (DARD) will continue to play a significant role in safeguarding public health through the detection and control of zoonotic (animal originating) diseases. Through activities such as research and development and education, DARD will encourage the production of high quality food. DARD aims to reduce the level of serious animal disease by a reduction in brucellosis outbreaks to less than 75 per year and the level of tuberculosis reactors to less than 12,000 per year by 2008.

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35. In 2001 the standardised death rate (all ages) for stroke in Sweden was 56 deaths per 100,000 of the population, compared with 67 per 100,000 in Northern Ireland.
36. Deaths data from GRO and mid-year population estimates.
37. There were 550 patients in March 2003 receiving haemodialysis. DHSSPS Information and Analysis Directorate.
38. DHSSPS, 2003. *Annual Report of the Chief Medical Officer.*
39. In setting this target, it is recognised that many forms of visual impairment are not preventable. There are, however, forms of visual problem associated with diabetes or cataracts that can be either prevented or addressed with appropriate early intervention. Royal National Institute for the Blind.
40. In 2002 the age standardised suicide rate was 9.5 deaths per 100,000 for all persons and 25.8 per 100,000 for males aged 15 - 44. Deaths data from General Registrar's Office.

Enterprise, Economic Development and Investment

1.28 The aim of the Department of Enterprise, Trade and Investment (DETI) is a balanced, competitive, innovative, knowledge-based and fast growing economy where there are plentiful opportunities for all. There is a direct correlation between economic activity and health and wellbeing. By encouraging economic growth, DETI has a critical role in promoting health and wellbeing.

1.29 DARD, in promoting sustainable development of the agri-food sector and the countryside, aims to create a net increase of 1000 Full Time Equivalent (FTE) jobs in disadvantaged rural areas under the *Rural Development Programme (2001-06)* by 2008.

Promoting Workplace Health

1.30 The role played by the Health and Safety Executive in Northern Ireland (HSENI) is also pivotal in tackling the burden of ill health caused by or made worse by work. Two of the most prevalent problems attributed to work generally are musculoskeletal disorders, such as back pain, and work-related stress, which can lead to anxiety and other mental health illnesses.

1.31 HSENI has developed, with key stakeholders, a long-term and cross-cutting workplace health strategy for Northern Ireland, *Working for Health*, which was published in 2003. The Workplace Health Strategy Implementation Group will continue to work with key stakeholders in ensuring that workplace health issues are prioritised and addressed.

Physical Activity and Sports

1.32 The overall aim of the *Northern Ireland Physical Activity Strategy,* which is being led by DHSSPS in partnership with a range of other Departments, including the Department of Culture, Arts and Leisure (DCAL), is to increase levels of health related physical activity, particularly amongst those who currently exercise the least. DCAL, through the Sports Council for Northern Ireland, aims to offer the widest possible range of opportunities for physical activity and encourage the maximum use of facilities such as those provided by District Councils and voluntary sports clubs, and our natural assets such as inland waterways and rivers.

1.33 The new *Community Sport Programme* will target socially disadvantaged areas where participation is known to be low. The scheme is designed to meet the needs of all ages and those with a disability as well as the able bodied. The aim of the scheme is to increase participation by 10% by 2007. DCAL is also represented on the Childhood and Young People Obesity Taskforce in recognition of the role that participation in sport and physical activity can play in promoting health and wellbeing.

Arts, Creativity, Health and Wellbeing

1.34 Arts and creative activities, which the DCAL actively promotes, play an important role in stimulating physical and mental wellbeing and contributing to the whole environment and health of people and society. The work of organisations such as ArtsCare and Open Arts ensure that the arts can be an important factor in improving mental health for a range of people including older people, people who are unemployed and people with disabilities. DCAL and DHSSPS will work closely over the coming years to strengthen the contribution of the arts to promoting health and wellbeing.

Improving Skills, Employability and Learning

1.35 The Department for Employment and Learning (DEL) aims to promote learning, to prepare people for work and to support the Northern Ireland economy. This includes helping people with literacy and numeracy difficulties and people with no qualifications, as well as raising skills and qualifications at all levels from Level 2 up to degree standard.

1.36 Through its employability strategy, DEL is increasingly helping those people who face a range of barriers to find work. Co-operation with DEL will, therefore, be important both in addressing workforce issues within the health sector and, as importantly, improving health and wellbeing by tackling social exclusion and the harm associated with it.

Environmental Issues

1.37 The Department of the Environment (DOE), the Department for Regional Development (DRD) and DETI are all remitted to tackle environmental stressors which lead to poor health. Government will continue to seek to improve air quality, water quality and fuel poverty by reviewing and extending the targets in *Investing for Health* relating to these areas.

Road Safety

1.38 DOE has amongst its strategic objectives to improve and promote road safety and ensure the proper regulation of drivers, vehicles and operators.

Road Safety
Each year more than 13,000 road traffic casualties occur on Northern Ireland's roads. Of these, approximately 150 people die and 1,600 are seriously injured. In the early 1970s twice as many people were killed each year and 50% more were seriously injured than now. Although the level of road deaths and serious casualties has fallen substantially over the past thirty years it remains unacceptably high and there is much to be done to achieve further reductions.

1.39 Whilst Northern Ireland has a better road safety record than many European countries, it has the worst record within the UK. To focus cross-Departmental efforts, targets have been set in the *Northern Ireland Road Safety Strategy 2002-2012* to reduce deaths and serious injuries by 33% and, within that overall target, the numbers of children killed or seriously injured by 50%.

Regional Development

1.40 The work of DRD includes the provision of a spatial framework, the *Regional Development Strategy*, which addresses a range of social, environmental and community issues which are relevant to promoting sustainable development and social cohesion. Central to this is an integrated, sustainable and safe transport network which will facilitate the rapid, predictable and efficient movement of people and goods.

Social Development

1.41 The Department for Social Development (DSD) is working in partnership with other Departments and Agencies in the statutory and the voluntary and community sectors to implement its *People and Place: A Strategy for Neighbourhood Renewal*. The outcome should see improved social conditions for the people who live in the most deprived neighbourhoods through better co-ordinated public services and the creation of safer environments. *People and Place* anticipates health benefits in terms of life expectancy, for example halving the gap in life expectancy between those living in the most deprived wards and the life expectancy for Northern Ireland. Full implementation is planned by 2010 and we will work together with DSD in taking this forward.

Housing

1.42 The *2001 House Condition Survey* shows that some 30,000 houses, mainly in the private sector, were unfit, and over half of the unfit houses were in rural areas although not all of these were occupied. DSD, primarily through the Housing Executive, provides a range of services and assistance in this area (including: grant aid to the private sector for adaptations for disabled people; wheelchair housing; and support for the development of lifetime homes) which meet the changing needs of the occupier throughout their lifetime.

Education

1.43 The Department of Education (DE) is taking active steps to provide, for all children and young people, opportunities to acquire the critical skills and information necessary to make informed decisions about their personal behaviour, be it on diet and hygiene, care of their environment, alcohol or other drug-taking, smoking or danger of abuse by others.

1.44 These skills are already an integral part of most schools' pastoral care and personal development programmes, and are intrinsic to the new revised statutory curriculum. They are also integral to the purpose and curriculum of the youth service, where they can be reinforced in informal settings.

1.45 DE will continue to work to enable all people and young people in particular to develop the skills and attitudes that will give them the capacity to reach their full potential and make healthy choices. In doing so, we will work towards the current *Investing for Health* targets.[41] For example, DE is contributing to the aims of *Investing for Health* by introducing its new nutritional standards for school meals. The standards provide for an appropriate quality and quantity of food, thereby promoting both a healthy diet and the benefits that this brings.

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[41] Target (i): In the 25% of Primary Schools with the highest percentage Free School Meal Entitlement, to reduce the proportion of pupils not achieving the expected level (level 4) at Key Stage 2 to 25% in both English and Mathematics by 2005/06. Target (ii): In the 25% of Secondary Schools with the highest percentage Free School Meal Entitlement, to reduce the proportion of year 12 pupils achieving no GCSEs to 5% by 2005/06.

Special Education

1.46 DE is determined that all children with special educational needs receive the very best start in life by ensuring that their education provision is tailored to their very different individual needs.

1.47 A Regional Strategy Group for Special Education promotes commonality and consistency between Education and Library Boards and a joint DHSSPS/DE Interdepartmental Group helps to ensure that children with special educational needs are provided with appropriate services. This Group provides the forum to discuss and address issues such as the provision of nursing services to children with special educational needs and also speech and language therapy provision.

Equality, Anti-Poverty and Human Rights

1.48 The Office of the First Minister and Deputy First Minister plays an important role in co-ordinating the *Programme for Government*, economic policy and equality and human rights. Coordinated actions to promote equality and human rights will have a powerful impact on the factors which underlie ill health and social harm. Key strategy areas include proposals for a new Anti-Poverty Strategy, the Victims Strategy, the development and implementation of the Children and Young People's Strategy, strategies for Travellers, Homeless People, Carers and Older People.

1(v) Can Our System Cope?

1.49 No matter how much progress is made in making our society healthier there will always be a need for health and social services. Pressure on our services is great and has been increasing dramatically. Trolley waits and waiting lists often understandably hit the headlines but they only represent part of the story.

1.50 Our health and social services are treating and caring for more people than ever before. People are spending less time in hospital and, consistent with trends across the world, more and more patients are being treated without having to stay in hospital. The number of day case admissions has increased by 35% (almost 39,000) from 111,800 in 1998/1999 and stood at 150,800 in 2003/04.

1.51 The number of ordinary inpatients admitted to hospital has decreased by 1% (almost 3,100) from 334,800 in 1998/1999 to 331,700 in 2003/2004. Over the same period the number of outpatient attendances increased by 4% (54,100) and stood at 1,482,000 in 2003/2004.

1.52 These demands have required additional resources but there have been improvements in efficiency also. For example, comparing 2003/2004 with 1998/1999 the average length of stay in hospital decreased by 1% from 7.9 days to 7.8 days. Over the same period the number of patients treated per hospital bed each year increased by 5% from 38.0 in 1998/99 to 39.7 in 2003/2004.

Health Action Zones

The purpose of a Health Action Zone (HAZ) is to act as a catalyst to bring together in a working partnership all those contributing to the health of their local population – including health organisations, District Councils, other statutory organisations and the voluntary, community and private sectors. HAZs also represent an opportunity to engage services with the wider community to deliver well-targeted local strategies which:

- involve new and innovative ways of tackling persistent health problems and health inequalities;
- result in real health benefits for the targeted group; and:
- have the potential to develop into mainstream practice in the future.

The first two HAZs were established in April 1999, one in North & West Belfast and the other in Armagh & Dungannon. Two more were created in 2001, covering priority neighbourhoods and population groups in the Northern and Western Health and Social Services Board areas.

There are plans now to establish Education Action Zones, based on similar principles but designed to tackle the links between inter-generational disadvantage and educational attainment. We will be working closely with DE and other key stakeholders in this initiative to see how the HAZs can best contribute to the development of these, and how they can help to support them once up and running.

1.53 When people think about health services, they tend to think about hospitals. This is only part of the picture. The majority of people who use our services do so in the community in the form of primary and community health and social care services (e.g. services involving general practitioners (GP), social services, community health nurses, community pharmacists).

1.54 Every day in Northern Ireland nearly 19,000 people consult a general practitioner (GP)[42] and each working day 120,000 people visit a local pharmacist.[43] Every year over 1 million courses of dental treatment are started and 300,000 eye tests are carried out. In 2002/03 over 25 million prescriptions were dispensed.[44]

1.55 When people are vulnerable or need daily assistance to live, they may be supported through integrated packages of care delivered in people’s own homes, residential or nursing homes. These community care packages may involve several different workers including care workers, community nurses and social workers.

1.56 As the population is growing older and living longer and family structures are changing with fewer families fulfilling an informal caring role, the demand for these services is growing. For example, the number of community care packages increased by 36% between March 1998 and March 2003.

1.57 An imbalance or problem in one part of the system creates problems for the system as a whole. If, for example, there are not enough community care packages to cope with people leaving hospitals, the ability of hospitals to treat more patients is compromised. Similarly, lack of early hospital treatment when it is required (e.g. hip replacement) can lead to greater dependence and demand for community care packages.

[42] PSAB/ Continuous Household Survey

[43] PricewaterhouseCoopers, 2000. Community Pharmacy Activity Survey. Belfast.

[44] Source: Central Services Agency.

1.58 The demands for community based care are not restricted to older or infirm people. A higher proportion of children experience poverty compared with the adult population and many children are at greater risk in terms of abuse, neglect, road accidents and other forms of harm. Between March 1998 and March 2003 the number of children on the Child Protection Register increased by 16%.

1.59 Public expectations of what the health and social services can do and what they should do are constantly growing. The resources available, and consequently the capacity of the system, have not kept pace and this has been reflected in a number of areas. Large numbers of people wait long periods for treatment. At the end of June 2004 the total number of patients waiting to be admitted to hospitals in Northern Ireland stood at 50,975.

1.60 This problem is exacerbated by a lack of community provision leading to delayed hospital discharges. At 31 July 2004 there were 421 patients in hospital whose discharge was delayed. Of those patients who specified a care package, 56% were awaiting a nursing care package, 29% a domiciliary care package and 16% a residential care package. In addition, at 31 March 2004 there were 920 people in the community (at home or in a residential or nursing home) awaiting a care package. Where the type of care package was specified, 70% of service users were awaiting a domiciliary care package, 17% a residential care package and 13% a nursing care package.

1.61 One of the most visible symptoms of these pressures occurs when patients are forced to wait for access to a hospital bed on trolleys or in other inappropriate places. Similarly, some of our sickest patients who require intensive care are on occasion unable to access critical care beds and are treated temporarily under less appropriate conditions.

1.62 There are also difficulties in recruiting and retaining staff in key areas across our services. For example, a destination survey of nurses who have graduated indicates that approximately 10% do not enter the HPSS upon graduating.[45] This skill shortage is also evidenced by the number of staff from overseas who are joining the HPSS.[46]

1.63 All of these problems are further exacerbated by inadequate levels of provision and deficiencies in HPSS equipment and facilities. Services are often provided in buildings that are in need of modernisation and repair, sometimes without access to the most up to date equipment and technology.

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[45] Department of Health, Social Services and Public Safety, 2002. *Review of Nursing, Midwifery and Health Visiting Workforce.* Belfast.

[46] Numbers of overseas nurses employed in the HPSS as of 31st December 2003. Source DHSSPS response to Parliamentary Question

1(vi) Some Good News...

1.64 These pressures and problems are important and must form part of the agenda for action. However it is also important to understand the performance of our services in a wider context.

1.65 The World Health Organisation (WHO) uses three key criteria in evaluating the performance of health services[47] – criteria which can equally be applied to social care services. The criteria are:

- ability to improve health and wellbeing;
- fairness; and:
- responsiveness to people's expectations.

1.66 Using this approach the WHO found that services in the UK ranked 18 in the world in terms of overall performance, compared with 37 for the USA, 25 for Germany and 1 for France. Part of our goal must be to create a health and social services system in Northern Ireland which ranks with the best in the world but we must also recognise the strengths in the existing system.

1.67 In Northern Ireland there have been significant improvements in recent years in the health and wellbeing of the population. Both men and women are living longer. In fact since 1950 life expectancy has increased by nine years for men and 11 years for women. Furthermore not only are people living longer, they are enjoying better health in their old age. This can largely be attributed to the success of improvements in public health measures and new medical treatments.

1.68 Since 1985 infant mortality rates have decreased by 47% from 9.6 deaths per 1,000 births to 4.6 deaths per 1,000 births in 2002. Improvements in care and treatment, immunisations and improved advice from health and social service professionals have made a significant contribution to this achievement.

1.69 Despite the problems, when people receive treatment in our system public satisfaction with the services they receive and the staff who deliver them is high. A telephone survey undertaken in 2003 demonstrated that almost everyone in Northern Ireland uses health and social services in the course of a year and that overall some 74% of people were either satisfied or very satisfied with the service they received.[48]

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47. World Health Organisation (2000). World Health Report
48. Research and Evaluation Services (2003) Public Consultation Survey to Inform the DHSSPS Regional Strategy on Health and Social Wellbeing

LOOKING AHEAD:

A CHANGING WORLD

2. LOOKING AHEAD: A CHANGING WORLD

2.1. The next twenty years will bring an ever greater pace of change and, with that change, we will face increasingly difficult prioritisation dilemmas in the health and social services. This will mean deciding who will benefit first from our finite health and social care resources. We will in all cases seek to use resources to improve longevity and quality of life but these decisions will become more difficult. Rather than waiting passively for the tough choices to come to us, we need to look ahead, act now and address the pressures which we will face through effective planning. So what will we face?

2.2. There will be fundamental changes in the population which the health and social services serve and from which the workforce will be recruited. People will generally be older and live longer. Whilst this is a positive development, we can expect an increase in age-related chronic diseases. This may be exacerbated by changing behaviours.

2.3. Twenty years from now we will be wealthier, although there may be a greater gap between the rich and poor. We will also be more ethnically and culturally diverse and our society will be more interlinked with the rest of the world. Globalisation - the integration of economies internationally - is bringing with it tremendous cultural and economic change along with increased travel and cultural interchange. It is also bringing with it more uniformity across cultures, for example in relation to a greater use of technology and a ‘fast food’ culture.

2.4. On current trends, we can expect less physical activity and growing obesity, particularly amongst the most socially and economically disadvantaged in society. Chronic diseases and conditions such as diabetes, cancers, heart diseases, respiratory diseases and arthritis look set to grow in prevalence.[49]

2.5. Global trends indicate that the burden of mental ill health will grow significantly over the next twenty years.[50] This may have particularly serious consequences for Northern Ireland as it is currently estimated that our mental health needs are approximately 25% higher than in England.[51]

2.6. Within a more interdependent world there will be a danger of greater exposure to global risks. Recent fears of bio-terrorism and the spread of Severe Acute Respiratory Syndrome (SARS) bear witness to the need for our society and our services to be able to respond quickly to global threats as well as opportunities. We must also be prepared for the emergence of new diseases, as our experience of new variant CJD has shown.

2.7. Consumerism, and the demand for goods and services which it feeds, has been identified as increasing the standard of living in many countries but at a cost of a breakdown in traditional family and community relationships, social alienation and greater gaps between the rich and the poor. People, particularly those who are able to express their needs more effectively, will expect more and will have greater access to information, both generally and through the use of the Internet. In contrast, people on the other side of the ‘information divide’ risk greater social exclusion and disaffection.

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[49] Although a key aim of this Regional Strategy is to reverse the trends in many of these conditions - see Section 1.
[50] The Global Burden of Disease, The World Health Organisation
[51] Department of Health, Social Services and Public Safety, 2003. *Needs and Effectiveness Evaluation: Health and Social Care Report.* Belfast.

2.8. The spread of new technologies and new medical techniques across the world will provide opportunities to deliver services in different settings and in different ways. But again, this will lead to demands for potentially very costly services, some of which have not yet been invented.

Key Actions: Health and Social Services as a Focus for Investment
With DETI we will ensure that the HPSS, which employs internationally recognised experts in health and social care, provides an important locus for inward investment. We will do this by working with DETI and Invest NI to promote Northern Ireland as a centre of excellence in health and social care research and development. Through partnerships with businesses and universities, we will develop and implement treatment and care programmes based on cutting edge technologies and techniques and seek, where possible, to secure their commercialisation. The HPSS will lead the way in promoting new technologies such as nanotechnology (small technology) and genetic therapies.

2(i) Technology

2.9. Rapid advances in technology will impact on the HPSS by providing for (potentially costly) new forms of treatment and care. These will allow some terminal illnesses to be treated as chronic conditions and provide cures for some chronic conditions. New information technologies will support service users by providing ready access to information on conditions and treatment. They will also support more effective and integrated working across the health and social services.

2.10. The last century saw unprecedented advances in medical treatments and technologies. While we cannot predict the exact impact of emerging technologies, we can be certain that they will over the coming decades have a fundamental impact on our ability to treat currently untreatable diseases and on where and how we can deliver services.

2.11. A prime example of the potential impact of technology is in the area of biotechnology and in particular gene therapies. The current application of genetics is only at the margin of what can be achieved in the future, particularly in relation to chronic diseases. The main opportunities include: highly sophisticated diagnostic tools which are tailored to the individual genetic codes of patients; novel forms of treatment based on the analysis of gene function (e.g. highly targeted new forms of antibiotics); and the directed growth of stem cells to provide tissues or even organs that can be used to repair or replace damage caused by disease, trauma or ageing.

2.12. Genetics is already exerting an influence on medicine primarily in relation to inherited conditions. Some genetic tests are available now, principally for the purposes of pre-natal diagnosis and pregnancy advice and for informing various forms of treatment. This is relevant where there are missing gene products (e.g. haemophilia) or where treatment with a modified diet is required (e.g. phenylketonuria), and in some cases can be used to inform surgical treatment for high risk patients.

2.13. In the future, genetic testing and screening may significantly shift the point of intervention for many conditions. Where we currently can diagnose and treat only after the emergence of symptoms, in the future we will be able to intervene earlier and our interventions will increasingly be in the form of health promotion and protection activities.

2.14. Other expected developments relate to the areas of repair, regeneration and transplantation as well as nanotechnology (small technology) for the purposes of sophisticated non-invasive microsurgery.

Advances in Imaging

Advances in enhanced image resolution, and extension into both 3-dimensional and real-time tele-diagnosis are occurring now. These facilitate sophisticated forms of micro-surgery assisted by robotics. In recent years, imaging has progressed quickly from x-ray to the availability of Computer Tomography (CT) scanning and Magnetic Resonance Imaging (MRI). More recently a more sophisticated form of metabolic imaging has been introduced in the form of Positron Emission Tomography (PET). In each case, these imaging tools will provide opportunities to operate in cases where previously surgery would not have been a viable option.

2.15. The impact of technology will not be restricted to medical techniques. As the population becomes more highly educated, people will be more effective at accessing information and more proactive in making decisions regarding their health and social care needs.

Increasing use of the Internet

- 1,147 cancer-related mailing lists - 308 active;[52]
- In GB half a million online transactions take place every month with NHS Direct;[53]
- 10% of cancer patients have used the net to gain information on their condition and/or treatment.[54]

2.16. Compared with other knowledge-intensive service industries, the health and social services here, across the UK and to some extent internationally have fallen behind in implementing new information technology solutions. There are a number of reasons for this under-investment, amongst which is a focus, over the last few years, on hospital waiting lists, staffing and equipment.

2.17. As a result we have a reduced ability to integrate services across professional groupings, organisations and sectors. Fortunately this trend is currently reversing and investment is increasing. We are moving towards more integrated information technology systems and a better foundation for multi-disciplinary, inter-agency and team working.

2.18. These advances have been considered by the Judge Institute[55] which has concluded that there will be a greater concentration of specialist expertise and equipment in a smaller number of larger centres dealing with complex cases. This concentration will be driven by the increasing sophistication of medicine in areas such as genetics, biotechnology and bioengineering, image guided surgery, robotics and transplantation.

52. Potts, HWW, Ramirez, AJ, 2002. Who Benefits from Using Internet Support Groups for Those Affected by Cancer?. *Psychological Oncology*, 12, 641-2.
53. Department of Health, 2003. *Developing NHS Direct: A Strategy Document for the Next Three Years.*
54. Mills, ME, Davidson, R 2002. Cancer Patient Sources of Information: Use and Quality Issues. *Psychological Oncology*, 11 (5), 371-8.
55. Policy Futures for UK Health 1999 Technical Series No 4: Science and technology trends and issues forward to 2015: *Implications for Health Care*. Glenn, R. The Nuffield Trust and the Judge Institute of Management Studies

2.19. New technologies will also allow for enhanced health monitoring and self-treatment with more complex care taking place at home. An increasing proportion of common conditions will be treated locally in small centres linked telemetrically to specialist centres leading to increasingly blurred distinctions between primary, secondary and tertiary care.

Technology Enhancing Service Provision

The Going Home project is a partnership between Fold Housing Association, Foyle Health & Social Services Trust and the Northern Ireland Housing Executive. The project covers three strands, which include:

a) enablement to support early discharge of older people home from hospital;

b) assistive technology provision to older people in their own homes including a range of sensors from alarm emergency to fall and heat sensors, linking people to a 24-hour help line;

c) vital signs monitoring in partnership with Altnagelvin Hospital, facilitates the early discharge of older people who have suffered an acute episode of Chronic Obstructive Pulmonary Disease (COPD);

Once stabilised the patient can receive support and training to monitor and manage their condition at home. The scheme has already demonstrated cost savings in terms of lower requirement for bed days.

Similarly, a project has been piloted in South and East Belfast Health and Social Services Trust, where people with congestive heart failure are assisted to manage their own condition by using technology at home. The project involved patient’s vital signs being transmitted directly to the hospital cardiac unit, twice a day; early signs of heart failure were identified and changes to drug treatments managed through primary care with the patient at home. The aim of the project was to achieve reduced admissions and reduced lengths of stay in hospital.

2.20. Lengths of hospital stay will be further reduced as more diagnosis, treatment and monitoring are able to take place outside the hospital. Developments in telemedicine will also provide greater opportunities to deliver services locally.

2.(ii) Demographics and Lifestyle

2.21. Over the next twenty years there will be an increase in the demand for health and social services associated with age and social trends. Family structures will change with more people living alone, in part as a result of the decline in marriage, the rise in separation and divorce and the rise in lone parents.

2.22. The number of marriages in Northern Ireland has been declining steadily, falling from 12,000 in 1971 to 7,000 in 2001. There has also been an increase in the incidence of re-marriage and divorce. The divorce rate has increased from around 1,500 divorces in the mid-1980s until stabilising at around 2,300 since the early 1990s.[56]

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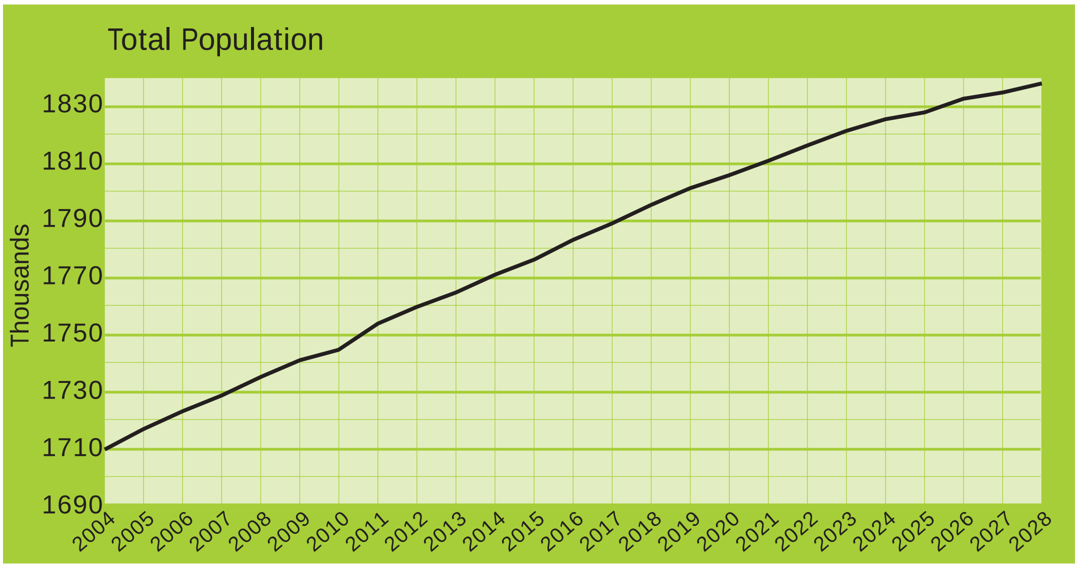
[56] NISRA, 2003. *Annual Report of the Registrar General.* Belfast.

2.23. Children of separated and divorced parents have a higher probability of experiencing poverty and poor housing. They are also more likely to express depressive symptoms or engage in risk taking behaviours such as high levels of smoking, drinking and drugs misuse during adolescence and adulthood. Family conflict during and after separation can contribute to these and other problems.[57]

2.24. Population trends will immediately impact on services for children and young people but will also impact on our increasing older population. Overall the population of Northern Ireland is projected to have increased[58] from 1.710 million in 2004 to 1.825 million by 2024. (see Figure 2.1).

Figure 2.1.
2003 Based Population Projections for Northern Ireland



2.25. Our slightly younger population would, other things being equal, suggest a relatively lower level of need for health and social care than in GB. This, however, is more than offset by higher levels of need driven by deprivation and rurality, higher levels of physical and psychological morbidity and higher levels of disability.[59]

2.26. Over the next twenty years, children and older people will continue to exert considerable pressure on existing service profiles and resources. While numbers of young people will fall, higher levels of fertility will slow this reduction. The greater longevity and the ageing of post-war 'baby boomers' will result in growing numbers of older people.

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57. Joseph Rowntree Foundation, 1998. Divorce and Separation: *The Outcomes for Children.*
58. NISRA (2003). Population Projections.
59. Department of Health, Social Services and Public Safety, 2003. *Needs and Effectiveness Evaluation: Health and Social Care Report.* Belfast.

Our Future Population
The population twenty years from now will:

(i) have grown in number;
(ii) live longer and be older;
(iii) contain more people of working age;
(iv) experience much higher levels of chronic disease, particularly those conditions associated with old age such as some cancers;
(v) die in greater numbers (due to the greater proportion of older people);
(vi) be more ethnically diverse; and:
(vii) have greater expectations of the type of services they wish to receive.

2.27. The average age in Northern Ireland is expected to rise from 36.8 years in 2004 to 41.3 years by 2024. In 2003 there were 118,000 more children aged under 16 than people of pensionable age. By 2026 the population of pensionable age is projected to exceed the number of children. The number of children aged under 16 is projected to fall over this period of time by 11.6 per cent and continue to decrease gradually for some years thereafter (see Figure 2.2). During this same period the number of older people will increase dramatically (Figure 2.3). The working age population is, however, also set to increase and will peak around 2020 (see Figure 2.4).

Ageing and Lifestyle
A 1999 World Health Organisation report identified the following:

"The steep projected increase in the burden of non communicable diseases worldwide – the epidemiological transition – is largely driven by population ageing, augmented by the rapidly increasing numbers of people who are at present exposed to tobacco and other risk factors, such as obesity, physical inactivity and heavy alcohol consumption."

Figure 2.2.
2003 Based Population Projections for Northern Ireland
(Children Aged Under 16)

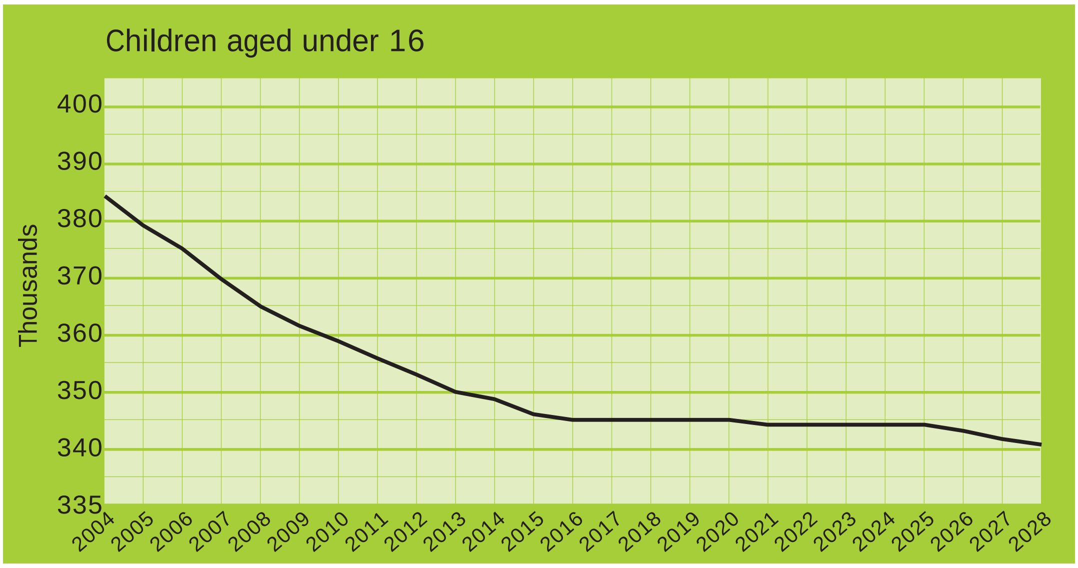


Figure 2.3.
2003 Based Population Projections for Northern Ireland
(Pensionable Age Population)

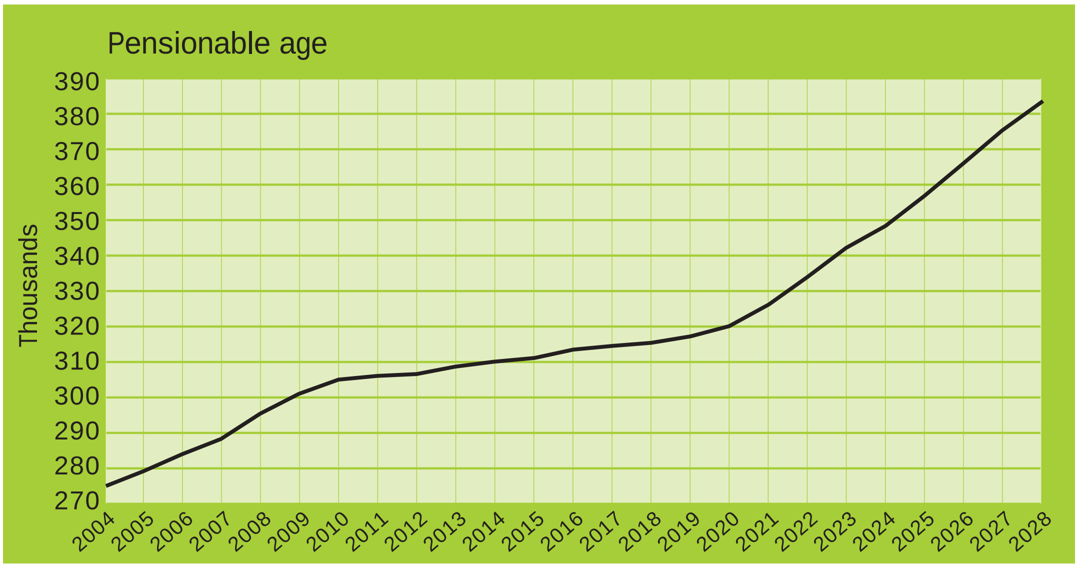
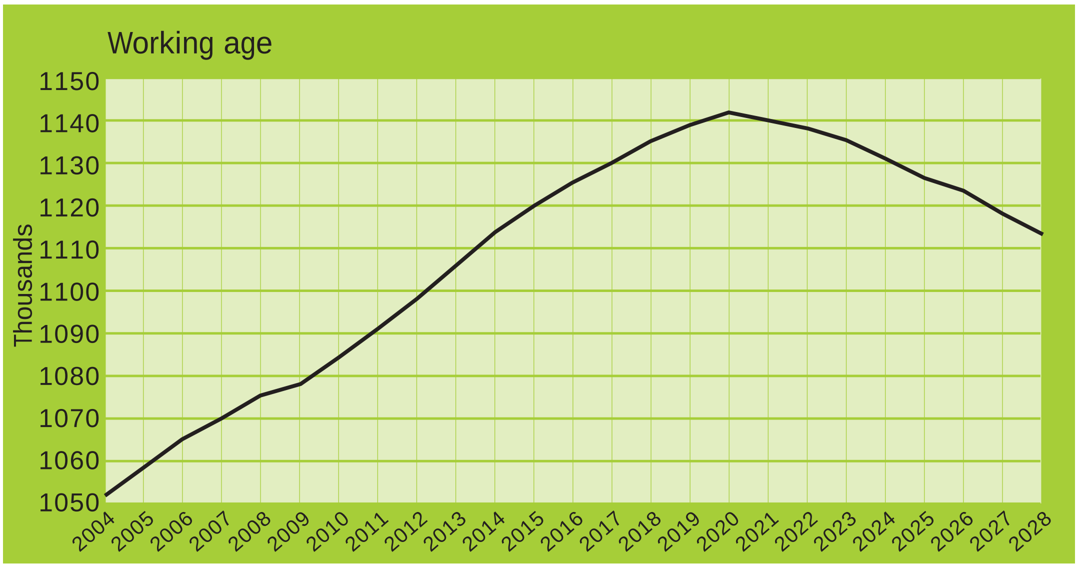


Figure 2.4.
2003 Based Population Projections for Northern Ireland
(Working Age Population)

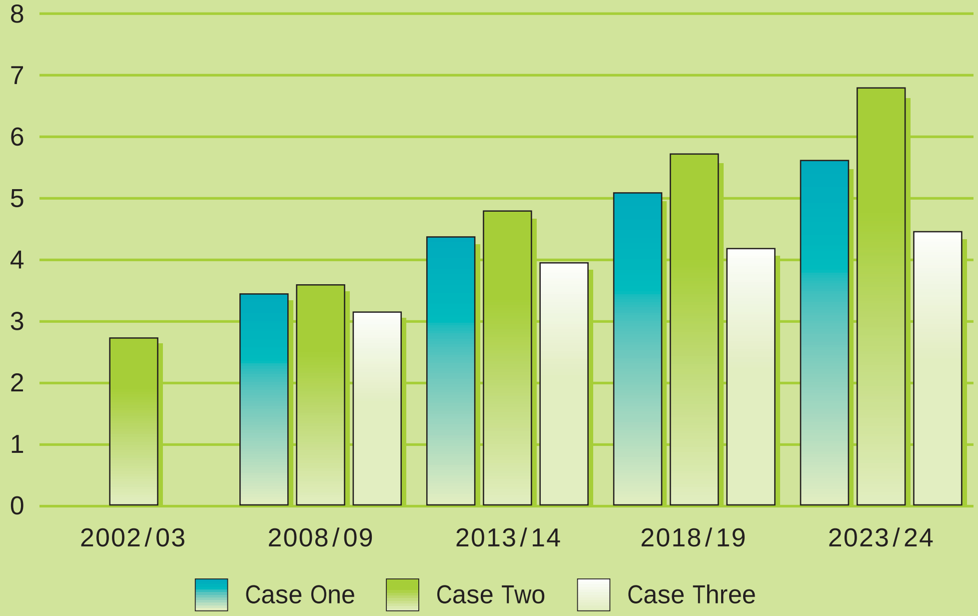


2.28. The extent to which these changes in population size and structure will increase demand will depend on the health and wellbeing-related behaviours of people now and in previous decades.

The Impact of Health Related Behaviours

Three scenarios demonstrate the impact on expenditure of our ability to tackle the causes of poor health.[60]

Figure 2.5.
Projected Health and Social Services Expenditure



Case One:
Progress against Investing for Health targets would be achieved but at a slow pace with full achievement of 2010 targets by 2025.

Case Two:
No further progress achieved in improving public health behaviours;

Case Three:
Current Investing for Health targets would be achieved by 2010 and progress would continue steadily over the next twenty years;

There are several major assumptions built into this analysis and there are other significant factors which may undermine the projected figures. However, they do illustrate two important points:

(i) health and social care needs and associated costs are likely to increase significantly over the next twenty years for demographic and other reasons;

(ii) depending on our ability to engage with the public in managing their health and wellbeing, the impact of these costs could be substantially mitigated.

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60. In Securing our Future Health: Taking a long term view (2002) Derek Wanless's assumptions on future funding were used to project forward the Base Case (demographics, costs of implementing the five NSF's, change in the use of care, reduced waiting times, technological developments and productivity). Case Three and Case Two scenarios above have been modelled using Economics Branch – Unhealthy Living Model, 2nd Edition (ULM-2). ULM 2 is a population based model of N. Ireland adults, risky lifestyle (smoking, high cholesterol, hypertension, obesity, lack of exercise, high alcohol consumption, pre-existing type 2 diabetes and non update of screening programmes) and their proven impacts on chronic disease.

2(iii) The Future Service

2.29. Over the next twenty years there will be two distinct forces defining the shape of services in the future, namely:

(i) Greater specialisation required in order to promote the quality of some services by ensuring that professionals deal with a ‘critical mass’ of similar cases to achieve sufficient expertise. This will particularly impact on acute hospital services. New specialised medical technologies and techniques will keep more people alive who would otherwise die through illness or trauma.

(ii) Greater provision of, and emphasis on, more holistic ‘generalist’ services, provided in communities or on a day-patient or outpatient basis than is the case at present. These will include primary care services, chronic disease management, social services maintaining and enhancing independence, and much of the surgery currently provided on an inpatient basis.

2.30. The extent to which the health and social services as a whole will become more specialised or more general will depend on many factors such as global trends in practice. However, the role of government in setting resource priorities will be of over-riding importance. The distinction between specialist and general services will be reduced by much more team-working across professional, organisational and sectoral boundaries, in recognition of the complex needs of patients and other service users.

2.31. Services will increasingly focus on the complex interaction between the physical, psychological, and social needs of people. The performance of people working in the health and social services will be judged primarily on their effectiveness at providing a coordinated team-based response to these needs. This will be underpinned and managed through the incorporation of clinical and social care governance into the planning, delivery and culture of the health and social services.

2.32. Carers, both formal and informal, will be seen and valued as an integral part of the team. All of these changes will depend critically on the capacity, knowledge, skills and structure of the future workforce across all sectors – including the statutory, community, voluntary, and private sectors.

2.33. The primary challenge facing the leaders of our health and social services over the coming decades will be recruiting and retaining adequate numbers of staff. Global economic and labour market trends are causing labour and skills shortages in health and social services across the western world, and Northern Ireland is no exception. We are experiencing key shortages of skills and labour across a range of areas. Our current problems could also be exacerbated if there is a major growth in private sector provision.

2.34. Again in common with other countries in the west, Northern Ireland has begun to import significant numbers of health and social care professionals, most notably nurses, from abroad. The future HPSS workforce will be much more ethnically diverse than it has been in the past – a situation which will create many new opportunities in terms of encouraging effective teamwork and communications but also additional responsibilities in terms of ensuring that these staff are fully involved in our organisations and society and not subjected to racism in any form.

2.35. Current professional boundaries will change over the coming decades. We can see some of this happening already, for example, in relation to increased prescribing by nurses, pharmacists or allied health professionals. Change will be driven by: increasing consultant specialisation; the need to manage a burgeoning workload more effectively across the entire workforce; the higher levels of qualifications and skills amongst non-medical health and social care workers, and the pressure for more efficient working. Workers at all levels in future services will require enhanced and new skills in order to achieve these changes as well as new protocols to clearly define those roles.

The Health and Social Care Worker – A View of the Future

One view of the kind of worker who will deliver person centred health and social services in the future has been suggested by the Future Healthcare Workforce Group.[61] They have proposed that a new type of practitioner should replace many types of existing staff who provide health and social care.

Among the tasks that would be undertaken by this new practitioner would be taking a comprehensive health and social care history, physical examination, diagnosis, developing and implementing care plans, co-ordinating services across health and social care settings, evaluating users responses to care, health promotion and education and audit.

The new practitioners could be supported by assistants who would work directly with people, for example taking blood samples and carrying out ECGs as well as co-ordinating services like shopping or providing meals.[62]

This concept of a generic health and social care worker represents only one possible scenario. Set against this are increasing trends towards specialisation across health and social care fields. The vision does, however, demonstrate how radical the change could be.

2.36. There will be a greater emphasis on core learning and competencies across all health and social care workers, for example in relation to communication, team-working and leadership. Joint education and training will be common for all workers both in the workplace and, for professionals, in pre-registration education. This will need to be balanced, however, against the need for ever greater specialist knowledge which is a result of more medical and care specialisation.

2.37. More health and social care workers will be based in community settings. To some extent this is happening already. There has been an increase in nurses and allied health professionals based in the community. In the future a broader range of services will be provided closer to people's homes on an outpatient or day-patient basis. For example, the introduction of general practitioners with special interests will support the delivery of many more forms of care in the community.

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[61] Cochrane D et al. 2002. *The Future Healthcare Workforce: The Third Report*. Chamberlain Dunn Associates. London.

[62] Adapted from IPPR, 2003. *The Future Healthcare Worker.*

2.38. We have described the potential for a massive expansion in both need and demand for health and social services over the next twenty years. Without a proportionate increase in public funds available, it is likely that there will be a growth in provision outside of the public sector. There is the strong possibility in particular that private sector provision will develop, driven by a growing and wealthier population with higher expectations. If this situation is not managed, a two-tier system could develop, whereby public sector workers leave the HPSS in favour of better terms and conditions which private sector employers could offer under these circumstances.

2.39. Private capacity may also be actively encouraged and resourced by government to supplement public provision. Already there are major plans across government to promote the use of Public Private Partnerships in order to address the public sector infrastructural investment deficit and this will be a growing trend.

2(iv) Making Sense of it All: The New Regional Strategy

2.40. The world is changing more rapidly than ever before and our health and social services are at the centre of this change. Global forces in economic development, technology and population demographics will impact tremendously on our population and our health and social services. We cannot ignore these impending changes and must seek to prepare for them.

2.41. To meet the challenges that lie ahead, and to build upon our many achievements in improving health and wellbeing, we need to work to a shared strategy for the health and social services over the next twenty years. If this strategy is to be successful it must be developed with the full involvement of the public, health and social care workers and the community and voluntary sector groups who contribute in many different ways to the health and wellbeing of our society. In the following sections we set out our vision of what can be achieved in the area of health and wellbeing.

OUR VISION

FOR THE FUTURE

3. OUR VISION FOR THE FUTURE

3.1. In facing whatever challenges the future may hold, our principal aim remains to improve the physical and mental health and social wellbeing of the people of Northern Ireland.

3.2. Our focus will be on tackling chronic diseases and the social and economic disadvantage that give rise to poor health. The majority of this will be managed in a community setting, in partnership with service users. Our services will also focus on supporting, protecting and promoting the quality of life of those least able to protect themselves, including looked after children, vulnerable older people and people with disabilities or any other form of potential barrier to living a full life.

3.3. This will mean tackling smoking, binge drinking, obesity and other serious and growing public health and social problems by engaging communities and working with them to promote real change. In particular we will work with those communities who experience poorer health and wellbeing. We will also need to work with communities and our people working in health and social services to develop services which genuinely respond to need. We will ensure immediate access for community-based and emergency services and people will not wait more than three months for any form of treatment or care.

3.4. Our vision for how this will happen is as follows:

Investing for Health and Wellbeing

3.5. In twenty years time the health and wellbeing of the people of Northern Ireland will be amongst the best in Europe. Levels of smoking, binge and excessive drinking and illicit drug use will be at their lowest ever. People from all backgrounds will view a healthy diet and physical activity as normal. The health gap between the rich and poor will have been substantially reduced.

3.6. Improving the health and wellbeing of the population will remain at the heart of the Government agenda and will be pursued through taxation, subsidy, service provision, regulation and information guided by a sound evidence base of what works and what doesn’t. This will require close cross-Departmental working towards the shared goal of improving health and wellbeing. We will respond to increasingly global health risks by developing and enhancing our ability to take effective action to limit the impact of communicable diseases.

Involving People - Building Caring Communities

3.7. Fully engaged people and communities, actively influencing decision-making at all levels will be widespread twenty years from now. Our planning and delivery of services will be truly person, family and community-centred. People will be able to take control of their own care and will take an active role in promoting their own health and wellbeing and that of their communities. Caring communities will feel that their services belong to them and will play a central role in designing and managing them. Individuals will use their services responsibly, contributing to their overall efficiency by doing so.

Responsive Integrated Services

3.8. Community-based services include those provided by general practitioners, social workers, carers, community pharmacists, community nurses and allied health professionals such as physiotherapists and dieticians. People will, when they need them, have immediate access to these health and social services based in their communities and to any form of emergency care. They will never wait more than three months for any form of treatment or care. These access standards will apply equally across all of our people and across all areas, including urban and rural areas.

3.9. Flexible immediate access may consist of face to face consultation, telephone helpline consultation, text or internet depending on the level and type of need. By having this immediate access to community-based services, people will not need to use accident and emergency services unless absolutely necessary.

3.10. Whenever possible, we will act first to prevent illness, disease and social harm. When such prevention is not possible we will work to minimise the impact of illness and social harm on people’s quality of life. When people have a long term (chronic) illness they will be supported, where possible, to manage that illness outside of hospitals or residential care. Where people have a terminal illness we will treat them with the utmost dignity and respect, working to ease their pain and anxiety. We will also work to increase choices for people near the end of their lives regarding how and where they receive services.

3.11. Services will be accessible and easy to find. When prioritising services a balance will be struck between services for those who are most in need now and services which will prevent or reduce future harm.

3.12. Services will continuously respond to people's individual and collective needs by listening to them and learning. People will be fully involved in decisions and will be provided with meaningful information about every aspect of their care or treatment.

3.13. People will have immediate access to emergency treatment and care, including new flexible emergency services such as ‘first responders’ where people in communities are trained to deliver a first response in an emergency. People who need to stay in hospital will have access to an appropriate bed in a modern environment. But people will have more and more of their needs met in communities, including many services currently delivered in hospitals.

3.14. People will not need to undergo repeated assessments and will find that, when they use different parts of the service, information will have been shared. People who are most vulnerable may have access to tele-monitoring in their home and, through the use of information technology, distance will no longer be a communication issue between health and social care workers based at different locations. Service users and carers will not experience disruptions in the delivery of services arising from organisational, professional, sectoral and other boundaries.

3.15. Our health and social services protect the most vulnerable in our society such as children in need or many older people. We will ensure that our staff are vetted to the highest standards and that they live up to these standards in working to protect those who are least able to protect themselves. We will, in particular, seek to protect and promote a full life for people with disabilities, for children in need of care or additional support, for people with mental health problems or a learning disability and for older people by assisting them to build their own capacity for independence.

Teams Which Deliver

3.16. In the competitive labour market of the future, working for the health and social services will be an attractive choice. Our workforce, whether employed in the public, private or voluntary sector will feel valued and respected by society. Excellent working conditions will promote the health and wellbeing of employees and provide continuous growth and development.

3.17. Creativity and innovation will be supported and recognised in all settings leading to new job roles and professions, new ways of working and new skills and knowledge. Our teams will work in partnerships with individuals, carers, families and communities. Our staff will take every opportunity to prevent harm, and maintain and enhance the independence of service users.

Improving Quality

3.18. Our aim is to provide a comprehensive range of services open to all on the basis of need – universal care – but we will be honest and clear about what can and cannot be provided within the resources available. We will also maintain a clear sense of overarching and transparent direction and prioritisation.

3.19. Services will be accountable and instil confidence in all those who use them. Should services fail to measure up to these standards, we will respond quickly, comprehensively and effectively.

3.20. When people have to visit health and social services facilities these buildings will be clean, comfortable and welcoming. They will be designed primarily to meet the needs and preserve the dignity of service users, their families and staff.

INVOLVING PEOPLE

- CARING COMMUNITIES

4. INVOLVING PEOPLE - CARING COMMUNITIES

4.1 **Policy Direction 4: We will make it a strategic priority to fully engage with, and support the development of, people and caring communities who will: (i) actively promote health and wellbeing; (ii) have a central role in managing chronic conditions and (iii) be partners in the design and management of our health and social services.**

4.2 The relationship between the people who use health and social services and the people who deliver them has changed significantly over the last twenty years. Increasingly the public will not accept the views of health and social care professionals without questioning them.

4.3 Communities are not prepared to accept decisions about the planning or design of services without being involved in the making of those decisions. More people will become adept in challenging our services to meet their individual needs. Furthermore policy makers and those who deliver services realise that there are real benefits to entering into a partnership with people who use services and their communities. This section sets out a new agenda for engaging with people on their health and wellbeing and on their health and social services.

Advantages of Engagement
Individuals feel better about themselves, and their care and treatment, when they have been listened to. They are also more likely to complete treatment and care programmes if they feel a sense of ownership.

There is less risk of providing inappropriate services to individuals and communities and more chance of providing services in the way that people want them.

Working with individuals and communities is the best way of ensuring a truly person-centred service. Approaching issues from the unique perspective of service users will often result in more imaginative and innovative solutions.

Effective public engagement can help to create a better understanding of the complexities involved in managing our services. This in turn can lead to increased public confidence and to services being used more appropriately.

4(i) Building Caring Communities

4.4 Needs for, and demands on, health and social services will increase tremendously over the next twenty years. If we fail to engage meaningfully with the public the result may be a system which is increasingly unresponsive, unable to meet its obligations under equality and human rights legislation, skewed towards the needs of those who ‘shout the loudest’ and are most articulate, and for which it is not possible to plan over the longer term.

4.5 We need to find ways for the public to take ownership of, and become actively involved in: promoting their health and wellbeing and preventing illness and harm; the delivery and management of their own care and the design of services which respond flexibly to their individual needs; and health and social care policy, including the prioritisation of finite health and social care resources.

Community-Pharmacy Partnerships: Professionals Engaging with Communities

The Community-Pharmacy Partnership Project is an example of innovative community development. It focuses on local communities working together with community pharmacists to develop services and schemes tailored to meet local needs and priorities, particularly in areas of social need. The projects have focused on a wide variety of people including men, older people, carers, students, mothers and toddlers. Issues covered range from sexual health to mental health and drug use to obesity.

One of the most striking features of the programme has been its success in reaching out to the most vulnerable people in our community. Health and social care services have been brought to people who may find it difficult to access other forms of care.

Community pharmacies are being seen as an important resource with a number having been adapted to include consultation rooms for other practitioners such as nutritionists and reflexologists.

4.6 If this engagement is to be meaningful the way decisions are made at all levels in the HPSS needs to be transparent. Participation must make a difference to decisions that are taken. People need to be meaningfully engaged at all levels and public engagement needs to be an active and continuous process.

4.7 But the process cannot be one way. In the relationship between the health and social services, and those who receive those services, everyone has rights and responsibilities. Appropriate support needs to be provided to staff, communities and individuals involved in the engagement process. Caring communities are those who equip themselves with the knowledge and skills to promote their own health and wellbeing and communicate their needs effectively. We must assist communities to develop if we are to have two-way dialogue with people built on a relationship of equality.

4.8 Engagement with everyone is a necessary pre-requisite for the development of a responsive HPSS. However, people from a range of groups find it difficult to engage with our services, and we need to take steps to ensure that everyone has an opportunity to be heard and that services are accessible to all.

Engaging With Potentially Excluded People
There are many different reasons why some groups of people have difficulty engaging with our services. It may be because they are socially excluded, there are communication barriers or they are stigmatised in some way by society. Groups who will require a particular focus in terms of the HPSS and public engagement include:

- People with Disabilities;
- Carers;
- Some Children and Young People;
- Travellers and people from Black and Minority Ethnic Communities;
- People with Mental Health Problems;
- Asylum seekers and refugees;
- People with Alcohol and Drug dependency problems;
- Gay, Lesbian, Bisexual and Transgender People;
- Older People;
- Homeless People;
- Victims.

4(ii) What We Will Do

4.9 Our approach will consist of three main strands. Firstly, we will seek to give a new, unified focus to engaging with people, including an overarching policy and a programme of innovative projects to promote meaningful dialogue. People will be involved in the assessment of need, planning and designing services and the management of bodies delivering services. This will build on existing arrangements for involving people such as Investing for Health Partnerships, Health Action Zones and service user forums.

4.10 Secondly, through our chronic condition management programmes (see Chapter 5) we will work with those people who are frequent users of our services to help them acquire the confidence, knowledge and skills to manage their conditions better and make the most of their relationships with health and social care professionals.

4.11 Thirdly, we will build on our existing policy *Mainstreaming Community Development,* to ensure that a sustainable programme of community development is at the heart of our services. This will include actively examining the scope for increasing the number and type of services that are delivered through the community and voluntary sector.

4(iii) A Policy of Involvement

4.12 We are not starting from a zero base in developing our integrated policy for public engagement. Significant progress has been made across the health and social services in engaging the public including service user forums, equality partnerships and consultation on policies. Prevention, treatment and care programmes have been established in partnership with communities and many of these support and enable people to take control of their own health and wellbeing.

4.13 In developing our overarching policy, we will establish a regional Public Involvement Steering Group for health and social services to drive a coordinated programme of engagement supported by a service-wide training and development programme. A key aspect of this will be the development of strong citizen advocacy arrangements in partnership, in the first instance, with the four existing Health and Social Services Councils. It is envisaged that these arrangements will be further developed and enhanced with new regional health and social care advocacy arrangements arising from the ongoing Review of Public Administration.

Key Action: Citizens Rather than Patients
DHSSPS will work with DE, DEL, the Council for the Curriculum, Examinations and Assessment, the Universities, Colleges of Further and Higher Education, youth services, organisations representing service users and other stakeholders to develop a health and social services component for the citizenship curriculum. This will form the basis for a new relationship between the HPSS and Citizens, setting out the rights and responsibilities of each in relation to the other.

4(iv) Community Development in Health and Wellbeing

4.14 In Northern Ireland, we have a vibrant culture of community development which is helping to counterbalance global trends towards an 'information divide' between the rich and the poor. But efforts to engage the public through community development approaches are hampered by: the complexity of health and social services; the difficulty in influencing decisions and decision-making; and perceptions that the management of the HPSS is dominated by professional lobbies/professional representatives.

4.15 The community and voluntary sector is going through a period of transition, associated with a series of factors including the ending of a number of European funding programmes. This will lead to change. The challenge is to ensure that this change supports and enhances the delivery of effective health and social care services.

4.16 Specifically, there is a need to build the capacity of the community and voluntary sector[63] by sharing skills, knowledge and experience between it and the HPSS. Within the HPSS, there is a need to develop and maintain open and transparent funding criteria and processes. Where appropriate, we must ensure that community and voluntary sector organisations are given an opportunity to take on responsibility for areas of work currently undertaken by the HPSS.

4.17 To achieve this, however, we must also ensure that common standards and protocols are developed so that HPSS staff are able to make appropriate referrals to community and voluntary sector organisations. We must also ensure that resourcing strategies are employed which promote sustainability in community and voluntary sector organisations – for example, by focussing a longer term commitment on proven programmes.

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[63] Adapted from Department for Social Development, 2003. Government's Strategy for Support of the Voluntary and Community Sector.

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RESPONSIVE

INTEGRATED SERVICES

5. RESPONSIVE INTEGRATED SERVICES

5.1 **Policy Direction 5: We will break down organisational, sectoral and professional boundaries over the next twenty years to improve the ability of our services to respond to people's individual and collective needs.**

5.2 Our primary challenge over the next twenty years, in delivering integrated services which genuinely respond to needs, will be to cross boundaries. We must break down professional, sectoral and organisational barriers. But perhaps most importantly, we must break down the barriers between services delivered in communities (Primary Care and Community-based Care) and services delivered in hospitals (Secondary, Acute or Tertiary Care). This section describes how these joined up services will develop.

Key Outcome: Consumer Satisfaction
By 2025, at least 90% of the public to be satisfied or very satisfied with the health and social services - the 2003 level was 74%.[64]

5(i) Services Delivered in Communities

5.3 **Policy Direction 6: We will place an emphasis on delivering effective community-based services with a special focus on chronic condition management and the problems associated with disadvantage.**

5.4 **Policy Direction 7: We will work, over the next twenty years, towards providing services against clear standards of access. Our vision is that, when people need health and social care, they will have immediate access to services based in their communities and to an appropriate form of emergency care. People in the future will not wait more than three months for any form of treatment or care. Access standards will apply equally across all dimensions and across all areas, including urban and rural areas.**

5.5 Promoting and maintaining people's health and independence, protecting people from harm and intervening early when care is needed, requires access to appropriate health and social care based in communities.

5.6 There are major advantages in community-based services. We can remain at home with our families and maintain our independence, and as far as possible carry on living our lives as normal. When these services are of a high quality, and delivered at the right time and in the right way, they can significantly reduce the need for people to use acute services or greatly facilitate their discharge from them.

Key Outcomes: Primary and Community-Based Care
By 2010, at least 90% of the public to rate access to primary care services as good or excellent.[65] [66]

By 2010, at least 90% of the public to rate the quality of primary care services as good or excellent.[67] [68]

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[64] HPSS Public Attitudes Survey.
[65] Baseline in 2003 was at least 75% across all primary care services.
[66] Public Attitudes Survey.
[67] Baseline in 2003 was at least 75% across all primary care services.
[68] Public Attitudes Survey.

5.7 Chronic conditions will, over the next twenty years, be a major focus of attention for our health and social services. All chronic disease will, where appropriate, be managed in communities with support from our hospital services.

Chronic Disease Management – Peter's Story Part 1

The following is a story, based on a true life case, to illustrate how our services could work at their best in the future. This is happening already in some communities but the vision is for this quality of service to be provided everywhere. The story is also designed to illustrate the incredible impacts which technologies and new techniques will make over the next twenty years in everyday treatment and care.

Peter is a sixty year old man who lives on his own and has smoked most of his life. He suffers from frequent violent coughing fits, breathlessness and occasional bouts of depression brought on by his inability to participate in everyday activities. He has tried to give up smoking but finds it difficult to remain abstinent when he is depressed.

He takes to his bed with a serious chest infection, and, following a visit, his GP prescribes steroids and antibiotics. He always seems to be in the GP's surgery but this is his worst bout of illness in a while. It is clear that, as a result of the smoking, his lungs have suffered long term damage.

During the visit, Peter's GP provided him with information on a new Chronic Condition Management (CCM) Programme for Chronic Obstructive Pulmonary Disease (COPD). When he has recovered, Peter calls the Programme helpline and is given the time of a local session to be held in the Health and Care Centre.

5.8 An increased emphasis on primary and community care will mean that these services will become even more flexible in the future than they are today. We will expand capacity in primary and community care, both in terms of investing in more staff and in significantly improved infrastructure.

5.9 These services will be provided across a range of settings including people's homes (domiciliary care) in local primary and community care facilities and in local hospitals. The latter will be particularly important in providing for intermediate care, or rehabilitative services which must be significantly expanded. We need to ensure that, following acute hospital treatment, everyone has access to services which can get them back to their optimum state of independence as soon as possible.

5.10 Through this investment, we will develop a wider range of services that can be delivered in the community including more diagnostic testing and minor surgery. We will also increase the number of ways in which this care can be accessed to provide more immediate responsiveness.

5.11 In designing these services, we will ensure service users play a central role in managing their own long term chronic conditions. Each of us is uniquely placed to influence our own health and wellbeing and that of our families and this will become ever more important as the numbers of people with these conditions increase.

5.12 Living with long-term or chronic conditions can often mean physical and psychological difficulties, socio-economic problems, reduced quality of life and sometimes social exclusion. People have to deal with issues specific to their individual illness but there is also a core of common needs: for example knowing how to recognise and act upon symptoms, dealing with acute attacks or exacerbations of the disease, making the most effective use of medicines and treatments, accessing social and other services, dealing with fatigue, managing work and developing strategies to deal with the psychological consequences of the illness.

5.13 In order to improve our approach to the management of chronic conditions we need to change the way we work and interact with service users. Professionals need to understand that service users have a unique understanding and experience of their condition which should help to shape decisions regarding treatment and care. People with chronic conditions need to be able to relate to a single professional who in addition to directly providing advice, treatment and support will take a proactive case management approach to their care.

The Benefits of Chronic Condition Management
Good chronic condition management offers real opportunities for improvements in patient care and service quality and reductions in cost. The results of an evaluation of a pilot of active management of conditions at Castlefields Health Centre in Runcorn[69] clearly demonstrate the possibilities:

- 15% reduction in admissions for older people;
- reduction in average length of hospital stay by 31%;
- total hospital bed days used by the target group reduced by 41%.

Key Action: Implementing Chronic Condition Management
Initially seven major service-wide Chronic Condition Management (CCM) Programmes will be established to promote chronic condition management across the HPSS. These will focus on the enhanced management of: diabetes, coronary heart disease, stroke recovery, arthritis and muscular-skeletal problems, chronic obstructive pulmonary disease and asthma, depression and stress management.

The programmes will build on the experience of the Cancer Network and will be tailored to reflect the fact that many people suffer from more than one condition at once (co-morbidity). It will not, for example, be feasible or a sensible use of resources to staff up separate programmes in some areas.

5.14 Through self-management or Chronic Condition Management programmes people can take greater control over their lives, reduce the severity of symptoms and improve confidence, resourcefulness and self-efficacy.

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[69] Department of Health Press Release Ref 2004/009 A Better Life for People with Chronic Diseases.

Challenging Arthritis

Arthritis Care has been running self-management courses across Northern Ireland for over six years. Research on their programme, Challenging Arthritis, shows that regardless of age you are likely to be less depressed, less anxious about your health and more independent as a result of attending a course. Challenging Arthritis courses:

- are delivered by local people who have arthritis themselves;
- last six weeks, with a two and a half hour session each week;
- focus on what people can do for themselves;
- helps people get the most from their healthcare team;
- provide information on handling pain, fatigue and depression, relaxing and exercising;
- give people the opportunity to meet and share learning with a small group of others with arthritis.

5.15 While our services will increasingly focus on chronic conditions, it is important to stress that the need for integration and teamworking applies equally to social care. We have made great progress in recent years in protecting vulnerable members of our society. Increasingly, however, we are more aware of the risk of exploitation and abuse that some of us face.

Key Outcomes: Primary and Community–based Care

By 2025 60% of people receiving care management services should be cared for in their own homes (50% by 2015).[70]

By 2025 every person assessed as requiring care management will have been offered the choice of Direct Payments.[71] While take-up will be voluntary, we would hope and expect that there will be a substantial increase in the number of people availing of direct payments.[72]

An Integrated Approach – Sarah's Story Part 1

The following story illustrates the future benefits for service users of Health and Social Services, Housing, Education etc working together from local community settings, providing an integrated approach to public service provision.

Sarah is ten years old and lives with her mother Marie and her half brother Aaron who is one year old. Sarah's family have recently moved to a new area and she is having difficulty settling in. Teachers find that she is a very quiet girl who has not made many new friends. Her appearance is unkempt, she is very overweight and she does not do homework. Two requests for a meeting with her mother to discuss how Sarah is doing have not received a response.

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70. At 31 March 2004 37% of packages were in respect of domiciliary care. Source: DHSSPS Information and Analysis Directorate.
71. Direct Payments are cash payments made in lieu of social service provisions, to individuals who have been assessed as needing services. Access to Direct Payments as a means of delivering social services in Northern Ireland has been available since 1996 under the Personal Social Services (Direct Payments) (Northern Ireland) Order 1996. The Carer's and Direct Payment's Act (NI) 2002 extends the provision of Direct Payments and imposes a duty on Trusts to offer Direct Payments.
72. Baseline 2003/4 is 1.5% of total care managed domiciliary care packages (6,959) are provided by Direct Payments. Source to be developed by DHSSPS Information and Analysis Directorate.

Sarah's mother, Marie, feels she cannot cope and is becoming increasingly depressed. At a visit to the GP in her local Primary and Community Care Centre to have Aaron treated for a chest infection she breaks down and says she wants her children taken into care.

Sarah's GP is a member of the Children's Primary Care Team and has substantial experience of child protection issues. Following an extended consultation she prescribes medication to help Marie with depression. The GP also arranges for a social worker from the team to visit that day who makes an initial assessment of the situation and who will coordinate protection and support services for the family.

By accessing electronic records the social worker finds that Marie's previous health visitor had been concerned at how socially isolated the family were. The social worker talks to Marie about these concerns and discusses support available to Marie in the area including a parenting project being run in the local community centre. Later that week they visit the project and meet staff and other participants.

Marie tells the social worker how worried she is about her daughter, Sarah. She describes increasing difficulties she is experiencing in communicating with her daughter and constant rows between them. Sarah's weight has grown over the past year.

When the social worker meets Sarah she is uncommunicative and makes little eye contact. Marie is constantly angry with her daughter during the meeting. The social worker suggests that a family therapist from the extended Primary Health and Social Care Team could meet and work with Sarah and Marie.

Information from this meeting is entered onto a hand held computer, which automatically prints a copy for Marie and Sarah. The social worker on her return to the resource centre, where the local area housing and social security staff are also based, attaches her computer to the main system. Notes from the meeting that has just taken place are instantly transcribed onto the multi-disciplinary shared case notes.

5.16 We are seeking to minimise these risks while supporting and maintaining people in their communities. This can only be achieved through the provision of high quality, integrated health and social services working in close partnership with other agencies such as the police, housing and education as well as with local community and voluntary groups.

5(ii) Teams, Networks and Pathways Which Cross Boundaries

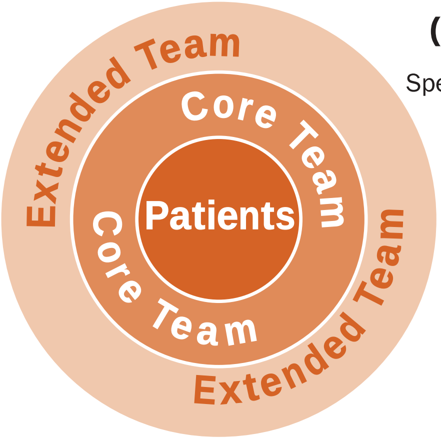
5.17 **Policy Direction 8: We will develop Multi-skilled Teams and Networks based primarily in communities but supported by, and including, people working in hospitals.**

5.18 As the level and complexity of services provided in the community increases, they will need to be provided by teams with a broad range of skills. We will ensure that these teams have the right number and mix of professionals and carers to meet the needs of the population they serve. The structure of teams will depend on a number of factors including: the size of the population; levels of deprivation; geographic spread and demographic trends.

5.19 These teams will focus on either adult or children/young people's services and be based in communities but will be deployed flexibly. Teams will include specialist staff whose workload may mean that they are members of more than one team and have a single point of management accountability.

Figure 5.1.
The Primary Care Team Within a Multi-Skill Network[73]

Core Team
General Practitioner
Community Nurse
Health Visitor
Social Worker
Community Pharmacist
Psychiatric Nurse
Receptionist/Admin



Extended Team (Multi Skill Networks)
Allied Health Professional
Specialist Community Worker
Public Health Worker
Health Promotion
Community Dentists
Home Help
Hospital Specialist
Care Workers

Chronic Disease Management – Peter's Story Part 2
Peter goes to the local Health and Care Centre to attend a CCM session. When he arrives Peter is greeted by Mary, a Community Nurse who specialises in chest problems. She explains that she is now his main contact with the health and social services and the CCM team and that she will be happy to provide him with any advice he needs, no matter what the problem.

The team includes a range of specialist health and social care workers based locally, including a Physiotherapist, an Occupational Therapist, a Psychologist and a Dietician. If Peter needs specialist help, including a hospital consultation, she can arrange this for him in partnership with and under the guidance of the GP.

During the session Peter undergoes a full health screen. Part of the screening involves him breathing into a health monitor which has access to his full genetic code and can provide a guide as to his current state of health. Peter's drugs are already specifically tailored to his unique genetic code but they need to be reviewed regularly in line with changes in his physiology. He has been on an individually tailored drug since he was fifty to protect against a range of common health problems in middle aged men such as coronary heart disease.

Results of Peter's various tests are immediately available and inform a drug therapy review with the Community Pharmacist. The Community Pharmacist talks through possible changes with Peter who agrees to them. The Community Pharmacist assesses Peter's technique for administering his inhalers and gives him some further information to improve his inhaler technique.

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[73] Allied Health Professionals include physiotherapists, occupational therapists, speech and language therapists, chiropodists, podiatrists, dieticians, prosthetists and orthotists, art drama and music therapists, radiographers, orthoptists and paramedics.

A Dietician reviews Peter's nutrition and makes some simple recommendations, which will help his physical health. After this, Peter receives a consultation with a GP who has a special interest in chest medicine. During the consultation it becomes clear that Peter also has a drinking problem.

The GP arranges a referral to the local addiction service. Other people with COPD are at the session and, following the individual screening and reviews they prepare for the main management programme meeting. The meeting is led by a person with COPD. Following introductions, Mary provides an information session on inhalers and nebulisers. Discussion ensues and, during this, the group asks Mary to arrange for smoking cessation packs to be provided to smoking members. She agrees to do this.

A social worker from the CCM Team joins the meeting to discuss the latest telemedicine equipment available to assist people suffering from COPD. This technology will help people to monitor their health and prevent admission to hospital by early identification of any health deterioration. Peter feels that this will help and puts his name down.

5.20 A primary and community care team established today would probably include General Practitioners; Social Workers; Practice Nurses; and Health Visitors. This membership will, however, vary depending on the population being served and the problems it must address. Over the next twenty years this will change as new jobs and roles emerge. Increasingly, these teams will be able to undertake care and treatment currently only available in acute settings.

5.21 Primary and community care teams will be supported by an extended team which, for adults, might include specialist community staff, health promotion and public health staff, domiciliary care workers and hospital-based professionals. The extended team for children's services may include representatives from other sectors such as education and the police. This broader Multi-Skilled Network (MSN) will work across several sites and will be potentially region-wide.

5.22 Networks depend both on the individuals in the teams and the employing organisations working together to stimulate innovation, share good practice, communicate, and provide a seamless service to patients. In these networks, the prime focus will be the needs of the service user. By sharing the workload and resources, including equipment, these Networks will be more efficient. They will reduce inequities and improve access to care, promote clinical and social care governance by focusing on team-based outcomes and provide a basis for standardising care in accordance with evidence-based guidelines.

5.23 One of the main attractions of the Network concept is its flexibility. It can be applied to many different situations in response to the interests of the patient, local circumstances, the nature of a particular disease or the most effective delivery of a specialty, and individual clinicians can be members of more than one Network. Membership of a Network promotes a way of working which crosses the boundaries between different professions, health and social care organisations and sectors.

NICaN: A Network Approach for Cancer Services
The Northern Ireland Cancer Network (NICaN) is working towards the continuous improvement in the quality of cancer care and cancer survival for people of NI through the creation of a "managed clinical network".

This approach challenges the way in which services are typically organised around traditional roles and boundaries all possibly working in isolation and unaware of the whole system of care. It offers a new way of delivering cancer services focused not from an organisational or clinical department viewpoint but on the whole patient's journey. User participation is a crucial element.

Evidence shows that networks promote a patient focus for the planning and delivery of cancer services. Other benefits include the potential to reduce inequities and improve access to care, support for new ways of working and networking across traditional boundaries and better use of scarce resources and expertise.

5.24 Previous hospital policy documents such as *Developing Better Services,* naturally emphasised the benefits of clinically oriented networks. However, the principles apply equally in social services settings, primary care settings and across other community-based care settings. Such networks will also increasingly play an important role in the protection of children, older people and vulnerable groups.

5.25 Setting up successful networks will require a balance between having direction and support from the 'top down' whilst depending on local commitment and leadership from the 'bottom up'. The specific 'top down' contribution which we will make to the development of networks includes the drive to establish the networks, the dissemination and roll-out of best practice and the provision of appropriate information technology. We will also ensure that education and training programmes focus on leadership and in working in multi-disciplinary settings and we will focus on team based performance measures through clinical and social care governance.

An Integrated Approach – Sarah's Story Part 2
The social worker informs the housing officer about a damp problem, that Marie pointed out during the visit and had asked to be followed up. He agreed to place this on the maintenance list and having accessed the recent file entry from the shared case notes, added a note to update the file.

Later that day Marie's GP said that she had seen the recent entries and would be arranging a follow up appointment for Aaron to monitor progress and see if there could be any links to the dampness, identified in Marie's flat and his chest problems.

The following day the Children's Primary Care Team manager contacted the local education link worker to provide an update, agreed by Marie, to Sarah's school and also advise them of the appropriate level of access to the shared case notes.

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During the next few weeks, regular meetings with the family therapist have led to a marked improvement in Sarah's level of communication. Marie and Sarah also agreed to meet with the health promotion worker from the Primary Health and Social Care Team. Information and advice on diet and exercise have helped both Sarah and Marie to improve their diets.

Sarah regularly attends a homework club after school. She says that she can concentrate better, without her brother always disturbing her. Sarah has also joined a youth club that her mum found out about at the parenting project.

The dampness in the flat has been sorted out and Aaron's chest has improved. The GP has continued to monitor his progress, accessing Health Visitor reports. The social worker has liased with the social security team in the resource centre and arranged a review of Marie's benefits to ensure that she is receiving all the benefits she is entitled to.

5.26 As people and organisations come together to establish MSNs they will develop a series of care pathways for the various conditions that they are concerned with. Care pathways clearly define what should happen in terms of care and treatment at any point in a patient's journey through the system. They are an important way of ensuring that a consistent standard of service is received by everyone who experiences a particular illness or condition and will be a foundation for Chronic Condition Management Programmes.

5(iii) Technology Supporting Change

5.27 This movement towards enhanced teamworking will be greatly improved by the developments in technology and care over the next twenty years.

Text Messaging – A New Role
Technology does not have to be futuristic to make a difference. A mobile messaging scheme being trialed at Addenbrooke's Hospital's dermatology clinic in Cambridge has helped to cut the number of missed appointments. Patients, who are invited to register for the scheme, receive a text message four days before their appointment, reminding them of the date and time. This has reduced missed appointments by half, to 4% of new patient sessions.[74]

5.28 We will seek to promote and roll out new technologies which have been proven to work as fast as possible across the system. Information and Communication Technology (ICT), and the changes in working practice which it will facilitate, will be a top priority for development over the next decade.

5.29 The increasing sophistication of medical technology will mean that, in the future, basic imaging and diagnostic capacity will be available closer to communities. Twenty years from now all care settings can expect to have enhanced imaging capacity as well as radically improved access to leading edge information technology.

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[74] BBC, October 2003.

A Vision of Information and Communications Technology (ICT)

"Citizens should be able to:

- *access reliable information on health and social care issues;*
- *access information on the health effects of different lifestyle choices;*
- *be identified through screening programmes to receive assessment/treatment where applicable;*
- *access information on their condition and any proposed care and treatment when receiving health and social care;*
- *find out what services are available to them and how to access those services;*
- *agree appointments during, or immediately following, a consultation;*
- *have electronic access to their own care records;*
- *make use of standard automated electronic services for routine interactions, such as repeat prescriptions;*
- *electronically consult with care professionals on specific issues;*
- *have a unique personal identifier used in all interactions with the HPSS.*[75]*"*

5.30 Some of the major ICT developments over the next twenty years will include development of three interlocking themes - Care Records, Care Communications and Information (for care professionals and the public). In the future data held on electronic care records will be the norm. Care professionals and the public will routinely use electronic services to access key information about services available, particular conditions of interest, and care and treatment advice.

5.31 Our ability to continuously renew and modernise our services will rely on a broad understanding as to what works and what is coming. Our evidence-base for decision-making is increasingly global. However, Northern Ireland has a key role in developing, promoting and disseminating its own Research and Development (R&D).

5.32 There are two reasons for this. Firstly Northern Ireland contains some world class R&D organisations and centres of excellence, including for example the new Cancer Centre at the Belfast City Hospital. Secondly the provision of local research is, in some cases, leading to the development of locally tailored solutions, for example in relation to community-based approaches to tackling deprivation.

5.33 By promoting innovation in the HPSS, we can promote innovation throughout Northern Ireland and attract high technology, high value added inward investment. We can also attract and retain leading health and social care professionals.

5.34 But R&D by its nature is not an isolated activity and must be seen as part of a wider framework. Innovation, creating and commercially exploiting new knowledge, fostering enterprise and improving the infrastructure and skills base are key to the competitiveness and the future success of the Northern Ireland economy.

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75. DHSSPS, 2003. *Information and Communications Strategy.*

Think / Create / Innovate
Think/Create/Innovate, the Regional Innovation Strategy, seeks to create a culture and environment within which Northern Ireland will prosper by using its knowledge, skills and capacity. The Strategy specifically identifies the need for the DHSSPS R&D Office to continue to enhance its research links with the Universities and to consider the application of Knowledge Transfer Partnerships to the health sector.

5(iv) Medicines Matter

5.35 Prescribed medication is the most common form of medical treatment in the UK and affects the majority of the population. At any one time 70% of the population is taking medicines to treat or prevent ill-health or to enhance wellbeing. However it is evident that medicines are not managed as effectively as they could be.

5.36 Unused medicines worth more than £90 million are returned to community pharmacies each year in the UK, this equates to approximately £2 million in Northern Ireland. Moreover, 11% of households have been found to have one or more medicine that is no longer being used. Studies have estimated the proportions of hospital admissions due to medicine-related problems range from 6% to 30%.[76]

People Managing Medicines
We must change the dynamic from what we do to patients to what we do with patients. One important area is in the whole area of medicines where the emphasis until recently as been on patients ‘complying’ with directions to take a medicine.

However, many patients do not comply – in some studies compliance rates are as low as 50%. In many cases people choose not to follow instructions because of beliefs they have about the effectiveness or otherwise of the proposed treatment regime.

Patients want to be more involved in decisions about treatment and are more likely to be motivated to take their medicines when they: understand and accept the diagnosis; agree with the treatment proposed; and have had their concerns about the medicines specifically and seriously addressed.

The processes necessary to achieve this have been described as concordance – a new approach to the prescribing and taking of medicines based on partnership. If patients are truly partners ‘concordance’ with treatment tends to be much better.[77]

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76. DHSS, 1997. *Drug Induced Hospitalisation: A Northern Ireland Perspective.* Belfast.
77. Cox, K, Stevenson, F, Britten, N, Dundar, 2004. *A Systematic Review of Communication Between Patients and Healthcare Professionals About Medicine-taking and Prescribing.* Medicines Partnership.

5.37 Medicines management encompasses the way that medicines are selected, procured, delivered, prescribed, administered and reviewed to optimise the contribution that medicines make to producing informed and desired outcomes of patient care[78]

5.38 We will embrace appropriate Medicines Management services to improve the way that medicines are used both by individual patients and by the HPSS. Each of these services will draw on the skills and expertise of many health professionals, but drawing particularly on the skills of pharmacists will make better use of medicines, through more cost-effective prescribing, more effective management of patients' medication after prescribing and improve communication at the interfaces.

5(v) A Primary and Community Care Infrastructure

5.39 If we are to achieve effective teamworking, people need to be educated and trained together and to work together. By far the most effective way to promote close teamworking is by having members of the team located in the same place. Obviously this will not always be possible. But we now have an opportunity to co-locate community-based teams who in the past were dispersed over a wide range of inappropriate facilities.

5.40 In the future, a network of primary and community care facilities will be the bases from which teams will deliver their services in communities. These centres will be of different sizes and configurations taking into account how local needs can best be met.

5.41 South and East and North and West Belfast Health and Social Service Trusts have pioneered models for serving large urban populations. Their new centres bring together diverse primary and social care teams to provide a one-stop service including treatment, care and information. Each centre is strategically located and will provide many of the services that are currently provided on an outpatient basis in acute centres.

5.42 For example, someone could attend a medical outpatient clinic, have a physiotherapy appointment and access social workers and nursing staff in one convenient location. They also provide space for community development activities and the opportunity to build in other services such as libraries and social security advice. The local hospitals planned under *Developing Better Services* may also include Health and Care Centres as a matter of course.

5.43 Health and Care Centres will be located in larger towns and cities. However, there will always be a need for local health and social care facilities based in smaller towns, villages and rural areas, networked through sophisticated communications systems.

5.44 In some instances facilities may be based on existing buildings. There is also an opportunity to utilise the wider health and social care infrastructure, however, such as the 500 community pharmacies that have an interface with over 10% of our population each day.

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[78] Audit Commission, 2001. *A Spoonful of Sugar.*

5(vi) We Will Always Need Hospitals

5.45 **Policy Direction 9: We will work to enhance the role of hospitals in supporting community-based services and in providing services which can not be provided appropriately in the community setting.**

5.46 No matter how effective our community-based services we will always need acute hospitals. Even with the significant additional resources that have been made available in recent years the very real pressures on the acute hospital sector continue to grow.

Key Outcomes: Hospitals
(Please see also the Access Standards set out in Section 3).

By 2025 ensure that all patients requiring a first outpatient appointment are seen within a month of being placed on a waiting list.[79]

By 2025 ensure that all patients requiring hospital inpatient or day case treatment are admitted within 3 months of being placed on a waiting list.[80]

By 2025 75% of all planned (elective) operations will be carried out as day cases.[81] [82]

By 2025 to have reduced the number of A&E attendances per 100,000 of the population to be on a par with the GB regions with the lowest number of per capita A&E attendences. (By 2015 to be performing as well as the average for England)[83]

5.47 The role of hospitals is to support community-based care services in promoting health and wellbeing. An effective hospital system will always be required and we will continue with the major programme of development which was announced in *Developing Better Services*. But the supply of hospital beds may never be able to meet all the needs of people waiting to fill them. If we are to be better able to manage demands on the system, community based services need to be significantly enhanced and this will have opportunity costs in terms of acute hospital development.

Chronic Disease Management – Peter's Story Part 3
Subsequently Peter asks the Chronic Condition Management Team to help him with depression. He goes to visit the psychologist, who is a member of the team, to discuss his depression The psychologist has all Peter's details on his hand held computer.

Six months later Peter has maintained close contact with the CCM Team through Mary and regular meetings with other people with COPD. He has been able to identify the onset of chest problems, through the appropriate use of the monitoring equipment that has been made available to him in his own home, and nebulisers and drugs. He has not had any acute admissions to hospital during this period. He has also had some success in stopping smoking and reducing his drinking.

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[79] Source: DHSSPS Information and Analysis Directorate.
[80] Source: DHSSPS Information and Analysis Directorate.
[81] Consistent with the NHS plan.
[82] Source: DHSSPS Information and Analysis Directorate.
[83] Source: DHSSPS Information and Analysis Directorate.

At one of his sessions Mary notices that Peter is losing weight and he reports blood in his sputum. The CCM GP arranges for a scan to check for cancer – again the consultant has all Peter's details immediately to hand. On this occasion the scan is clear, but regular scans are added to Peter's six monthly check ups.

Some years later, despite stopping smoking, Peter's chest condition deteriorates and because of breathlessness he finds it hard to cope with everyday life. He spends a week in hospital until his condition is stabilised through intravenous antibiotics. The hospital team liaises closely with Mary on admission and has access to all Peter's notes which had been entered onto the system by the CCM community team.

The CCM's social worker arranges care and support in liaison with the CCM community nurse, Mary, and facilitates an early discharge. She recommends that the best way to meet his care needs is through Direct Payments and Peter agrees. The social worker puts him in contact with a community organisation, who assist and support people to manage their care through the Direct Payments approach. They assist him to arrange for two locally based care support workers to visit him each day to assist with shopping, cleaning and personal care.

The Primary and Community support team also organise housing adaptations for Peter's flat. He is linked into a 24 hour emergency alarm centre and his flat is fitted with assistive technology to alert the centre if he falls or is in any type of difficulty. Through this assistance, Peter finds that he is able to maintain his independence. He may not be able to stay independent forever but he has already achieved five years more high quality life than he would have predicted. He feels at least he can face the future with confidence.

5.48 When the HPSS is reported in the media it is frequently about the demand for acute services outstripping the supply – for example in reports on 'trolley waits' or waiting lists for planned (elective) treatment. This is often simply seen as the result of having too few acute hospital beds.

5.49 But in an effective and integrated system the most expensive component: hospital services, must be used as efficiently as possible. This cannot be achieved through the continuous expansion of the availability of acute beds. We need to adopt a whole systems approach to ensure that we get the right balance of investment in services both in the acute sector and in the primary and community sectors.

5.50 People over 65 years of age account for 53% of hospital bed days and 31% of hospital admissions.[84] Although we will become better at managing the growing number of terminal and chronic conditions associated with our ageing population, these conditions will often lead to periods of hospitalisation as they deteriorate. Increasingly also it is likely that planned treatments in hospital will be required to support people into older age. For example, older people currently enter hospital for hip replacements.

84. Hospital in-patient system DHSSPS 2002-3

Demand for Intensive Care

"Demand for intensive care continues to increase. This is partly the result of advances in medicine and surgery, which allow patients with more complex problems to be treated. It is also the result of a population of hospital patients that increasingly has multiple clinical problems. Until fairly recently surgical patients accounted for the majority of the patients admitted to intensive care units. Capacity was therefore based on the needs of patients undergoing major surgery or who had suffered major trauma. Now more and more medical patients are benefiting from intensive care, particularly patients with respiratory problems." [85]

The Impact of Community Care

"At the start of the flu outbreak, some patients who might more appropriately have been cared for in the community were in hospital. As the winter crisis deepened, community care services came under severe pressure to assess and transfer large numbers of patients to nursing homes and other community provision at the end of their hospital treatment." [86]

5.51 Increasingly children and young people are also using these acute services. In the UK the average number of days that children and young people spend in hospital, when they are admitted, has dramatically decreased but the numbers attending for emergency assessment has significantly increased. Serious infections and illnesses are much less common than they used to be but they have been replaced by more complex and longer-term disorders that in the past would have been fatal.[87]

5.52 We will proceed with plans to reform and modernise our acute services. This will mean implementing the integrated programme of investment and reconfiguration set out in *Developing Better Services*. In February 2003 some £1.2 billion of capital expenditure was announced in support of the programme, and at the time of writing, a major programme of work is underway to take this work forward.

Developing Better Services

The current configuration of 15 acute hospitals will be replaced by a network of nine acute hospitals[88] supported by seven local hospitals[89], with additional local hospitals in other locations, as appropriate.

Particular regional specialities within the Eastern Board area (dermatology, plastics and rheumatology) are being relocated and consolidated.

Fracture inpatient services are to be developed at Antrim and Craigavon, with fracture clinics at all acute hospitals.

Consultant-led maternity services are to be delivered at the network of nine acute hospitals, with the potential for development of midwife-led maternity units adjacent to consultant units.

Protected elective capacity is to be developed at Lagan Valley, South Tyrone, the new South West hospital and elsewhere, as appropriate.

Increasing availability and access to day surgery will be a priority.

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[85] Department of Health Social Services and Public Safety, 2000. *Review of Intensive Care.*

[86] Department of Health Social Services and Public Safety, 2000. *Facing the Future: Building on the Lessons of Winter 1999/2000.*

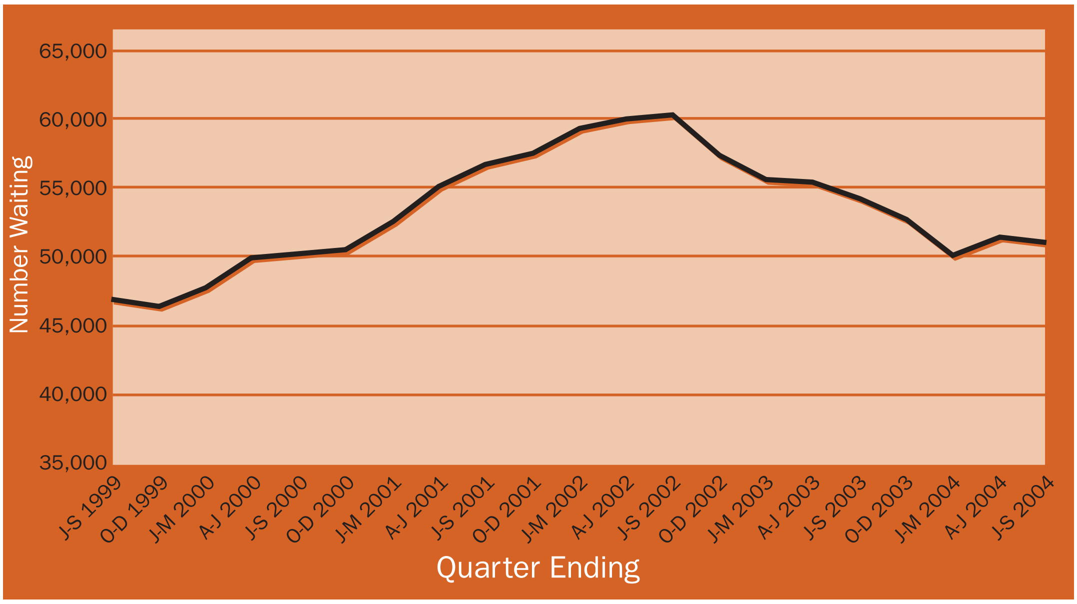
[87] Royal College of Paediatrics and Child Health, 2002. *Old Problems, New Solutions 21st Century Children's Healthcare.*

[88] Royal, Belfast City, Ulster, Antrim, Causeway, Altnagelvin, Daisy Hill, Craigavon and the new SW hospital.

[89] Whiteabbey, Mid Ulster, Lagan Valley, Downe, South Tyrone, Omagh and the Mater (although the Mater is to "continue to deliver a full range of acute services for a considerable period ahead").

5.53 We also need to ensure, as a matter of priority, that we build up our capacity for planned (elective) hospital treatment. Doing this will provide one of the most effective methods of managing future demand for the service. Many non-urgent hospital procedures improve quality of life, maintain and enhance independence, and prevent the onset of more serious illness brought on by inactivity, pain or lack of social contact (eg. hip replacements, cataract operations).

Figure 5.2
Quarterly waiting lists
(Five yearly trends September 1999 – September 2004)



Northern Ireland has the longest per capita waiting lists for elective treatment in the UK. The differences are even more pronounced for the number of people waiting more than 12 months. However, following sustained additional investment in recent years, along with new ways of working, waiting times and numbers of people waiting for treatment have fallen from their peak. We need to sustain this effect.

To set this in context, in a recent public survey access to overnight stay in hospitals was deemed to be either good or excellent by 77% of those respondents who had either an overnight stay in a hospital or had attended a hospital out-patient appointment in the previous 12 months.

5.54 Our current plans allow for additional planned (elective) hospital capacity over the next decade. We must make these developments a priority and continue to use a flexible approach in addressing the back-log of procedures. Where necessary, we will buy additional capacity into the system from the private sector here, in GB or in mainland Europe. We will also consider establishing a ‘waiting list hotline’ to support people and seek alternatives for them when they have been waiting more than 3 months for admission.

5(vii) An Effective Emergency Response

5.55 While much of our planning must focus on promoting long term health and wellbeing, our health and social services are also at the forefront of our response to new threats against the health of our population – including new communicable diseases and biological attacks. We will continue to enhance this response while at the same time seeking to improve the effectiveness of our Accident and Emergency and Ambulance Services. An important component of this over the next twenty years will be finding ways to reduce inappropriate usage of our emergency services, especially in cases where primary or community based care would be more appropriate.

Key Action: Investing in a Renewed Ambulance Service

A major programme of investment and modernisation is underway in the Northern Ireland Ambulance Service (NIAS) following a strategic review of the Service in 1998. Additional capacity in terms of additional ambulances and crews, along with investments in control technology and communications will lead to improved response times. Arrangements are also underway for enhancing the skills of ambulance staff and establishing a formal system of clinical governance within NIAS.

5.56 Following the attacks on 11 September 2001 and the subsequent dispersal of anthrax through the US postal system in October 2001 we have come to a new assessment of the potential threat here. At that time in Northern Ireland, more than sixty suspect parcels and letters were examined for the presence of anthrax: all were negative but the numerous hoaxes diverted the emergency services away from essential and life-saving work.

5.57 Since then, we have enhanced our emergency planning arrangements by obtaining supplies of antidotes to various poisons, as well as vaccines and antibiotics for use in some types of bio-terrorist attacks and emergency equipment to assist with decontamination and respiratory support of victims. New personal protective equipment has been issued to A & E departments and the ambulance service.

5.58 We are also developing Northern Ireland's Emergency Medical Assistance & Rescue Team (EMART). This comprises a multidisciplinary group of individuals from the health and emergency services who have volunteered to make themselves available to manage casualties at the scene of large scale disasters and to augment the hospital response.

5.59 We will continue to build on these developments and enhance our response. Our aim must be to ensure that preparations are in place to protect as large a proportion of the population as possible in the event of a biological attack or the natural occurrence of contagious diseases.

5(viii)Men and Women

5.60 **Policy Direction 10: We will place a special emphasis on meeting the needs of key groups by tailoring services to those needs and by placing a greater emphasis on them.**

5.61 Our future health and social services will be more responsive to the individual needs of everyone who use them. Services will be individually tailored to take into account each person's circumstances, preferences and requirements - in other words, more person centred. People's needs, however, depend on a range of factors.

5.62 Men and women have very different needs during the course of their lifetime even from an early age – see Section 1. Suicide tends to be more prevalent amongst adolescent boys and young men compared with adolescent girls and young women. Men of all ages tend to be less likely to seek services at an early stage in the course of an illness. There are also some forms of illness which are unique to men's physiology such as testicular cancer.

5.63 Increasing numbers of young people are smoking and drinking heavily. More young women find themselves as single parents with all the health and social consequences associated with that. As with men, there are certain illnesses which predominately impact on women – illnesses such as cervical cancer and post-natal depression.

5.64 A single service will not fit everyone's needs. Even the differences between men and women require tailored services. But within the population, there are people with more acute needs, or with complex needs which require more attention – for example, some people with physical or sensory disabilities. Others, such as children and young people, are of strategic importance because their health and wellbeing will be a driver of future service needs. We must seek to address the specific needs of these people, especially where people find it difficult to have their voice heard.

5.65 Inevitably, there is some cross-over between equality dimensions. For example, children with learning disabilities or older people who experience poor mental health. Tailoring services for these people should also lead to broader improvements as we listen and become more responsive.

5(ix) Carers

5.66 Large numbers of people are dependent on the care and support of a carer. Carers provide an invaluable contribution to our health and social services and at the same time represent one of the most vulnerable groups of people in our society.

Carer's Health and Wellbeing

A report on carers health and wellbeing in 2001 found that[90]:

- 18% of respondents act as carers and 6% provide care for 20 or more hours per week.
- Women were more likely than men to be carers (20% compared to 14%). More women than men provided care for 20 or more hours per week (7% compared to 5%).
- 8% of carers provide care for someone living with them compared with 10% who provide care for someone living outside the home. Women were more likely than men to care for someone living outside the home (12% compared to 7%).
- Most carers provide care for only one dependant (88%), with 12% of carers providing care for two or more dependants.
- Nine out of ten carers care for someone related to them. 46% provide care for a parent and 22% care for a partner or spouse.
- 85% of carers were looking after someone with a physical disability.
- Half of all carers (49%) who look after someone living with them had a long-standing illness, compared to only a third (36%) of those who look after someone living elsewhere. This was the case for both male and female carers.
- Carers were more likely to suffer from a great deal of stress (17%) than non-carers (9%). This applied to both men and women.
- Among carers looking after a dependant in their own home, 24% of men had a severe lack of social support in comparison to 15% of women.

5.67 The reality is that three in five of us will become carers at some point in our lives. There are in the region of 250,000 carers in Northern Ireland. Demographic trends have implications, however, in terms of both increasing demand for care and availability of carers.

5.68 The DHSSPS is working to develop a Carers Strategy that will build on the Valuing Carers Report[91].This highlighted the need to protect the interests of carers and to foster a climate where people can continue to provide care for as long as they wish without jeopardising their own health or financial security or reducing their expectations of a reasonable quality of life.

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[90] Department of Health, Social Services and Public Safety, 2001. *Informal Carers.*

[91] Department of Health, Social Services and Public Safety, 2001. *Valuing Carers.*

5.69 The key principles developed in the report that will form the foundation of a Carers Strategy for Northern Ireland include:

- Carers being recognised as real and equal partners in the provision of care;
- Carer's need for flexible and responsive support;
- Carers have a right to life outside caring;
- Caring should be freely chosen;
- Investment in carers.

Key Action: Valuing Carers
We will significantly improve the health and wellbeing of Carers by ensuring that the recommendations set out in "Valuing Carers" have been implemented and in particular that carers have access to the following practical support:

(i) Training, development and 24 hour support;
(ii) Appropriate respite care provision per annum in line with their assessed needs;
(iii) Provision of appropriate housing modifications and equipment;
(iv) 'Crisis' care services, developed in each Trust to ensure that support and assistance is available when circumstances change for the carer and/or their family.

Key Outcome: Carer's Wellbeing
To have improved the mental health and wellbeing of Carers by a quarter between 2001 and 2025 as measured by the General Health Questionnaire (GHQ) 12 score. This will be a proxy for overall health and wellbeing.[92]

5.70 Specific areas for action prioritised are: development of information and training, support services, employment and help for young carers. Carers must be a key priority as we move ahead in implementing the New Regional Strategy.

5(x) Older People

5.71 Twenty years from now, we can expect people who live longer lives to be healthier, more active and more educated. Given current trends in retirement and pensions, we can also expect more people to be economically active into older age.

5.72 On the other hand, health and social wellbeing in older age groups will, as in the population as a whole, continue to depend on a variety of factors. These include deprivation, housing and environmental conditions, gender[93] and lifestyle choices.

5.73 We will prepare the health and social services for the challenges that an increasingly older population will bring. More importantly, we will focus on ensuring that services assist older people to experience the best quality of life possible, no matter what their personal circumstances.

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[92] Results on GHQ12 from the 2001 Health and Wellbeing Survey revealed that some 30% of people in this group had the potential to develop or to have developed a psychological disorder.
[93] Women have a higher life expectancy.

5.74 We will achieve this by building on existing partnerships across organisations which promote the health and wellbeing of older people. This will require active participation by older people and age sector representative organisations in the design, planning and management of services. We will ensure full access to a range of integrated services. This will require a supportive and realistic partnership in the design, planning and management of services, between Health and Social Services, older people themselves and organisations representing their interests

Ageing in an Inclusive Society[94]
The consultation report of the Promoting Social Inclusion Working Group on Older People, *Ageing in an Inclusive Society*, includes a range of recommendations based around five overarching objectives. Proposals include: economic inclusion of older people; health and social services which address the distinctive needs of older people; increasing the safety of older people and improving access to services; promoting equality and full participation in civic life; and ensuring work in a coordinated fashion inside and outside government. The aims of *A Healthier Future* are consistent with these objectives.

5.75 Age and ageing should not prevent anyone from pursuing a healthy, active and fulfilling life. Older people must be recognised as valuable members of society who have contributed in the past, and who continue to contribute, to the quality of life of everyone in society. Legislation will underpin a fundamental change to society's approach to the retirement age in the future[95].

5.76 Older People who remain active socially and physically tend to live longer and experience a better quality of life. We will build on the work taken forward in the Ageing Well networks and projects that have been established over the last few years in Northern Ireland. These, and other initiatives have been supported and developed by Investing for Health Networks, Health Action Zones and Healthy City Projects.

5.77 Older people will have full access to a range of integrated services that promote physical and mental health and wellbeing. Tailored care services will be developed to meet the changing needs of older people. Many of these services will be available locally or on an outreach basis to older people living in rural areas.

5.78 Research has consistently shown that around 80% of older people would prefer to remain independently in their own homes. The first report of the *Review of Community Care (2002)* highlighted good practice in the identification and assessment of need and in the co-ordinated delivery of services.

5.79 This includes rehabilitation and intermediate care, or other care options that provide support or convalescence to allow people to recover following an acute episode in hospital; as well as the creative use of new technology, such as assistive technology and telemedicine. Evaluations carried out on a number of projects using these new technologies have demonstrated positive promotion of independence for older people.

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[94] OFMDFM, 2004. *Ageing in an Inclusive Society.*

[95] Under Section 75 of the Northern Ireland Act (1998), public bodies have a duty to promote equality of opportunity in terms of age and people with and without dependents. There is, therefore, a strong legislative basis within which action needs to be taken to promote equality of opportunity and access for older people. In addition, by 2006 the age strand of the European Employment Directive, will be implemented in Northern Ireland making age discrimination in employment and vocational training unlawful. Consultation is due to be carried out on these changes and extending the compulsory retirement age to 70 years.

Maintaining Independence
South and East Belfast Trust provide a Rapid Response Service to more than 130 people a month. Rapid Response involves the use of specially trained nurses with expertise and skills, which are used to help acutely ill patients to remain at home, rather than be admitted to hospital.

Similarly the Evercare programme developed in the US, also involves the use of specially trained nurses to identify and monitor at-risk older people, so that treatment can be given before a visit to hospital is necessary. In the US, Evercare has reduced hospital admissions by 50%, with more care being provided in the community instead. The Evercare Programme is currently being piloted in England.[96]

5.80 We need to provide a comprehensive range of supported housing and long-term care in partnerships across sectors and in a continuum from high levels of ability to high levels of disability and the contrasting care needs associated. This will mean planning services that include housing with a choice of different levels of support around a core residential/nursing/day and social support centres.

5.81 To achieve this, we will need to organise effective networks between different agencies at a local level, accessing supporting people schemes and funding opportunities. We will promote a "locality systems" approach to the management and integration of services for older people. Likewise other cross-Departmental and multi-agency actions, will be required to promote health and wellbeing amongst older people, in areas such as transport and community safety.

5.82 We will promote tailored support and advocacy services to meet the needs of older people from black and minority ethnic communities or those with complex or multiple needs other than those associated with age. We will focus our efforts on tackling perceived discrimination against older people in the health and social services. A recent public survey found that some 26% of people feel that some groups are treated unfairly by the health and social services. Seven out of ten of these (70%) were of the opinion that older people are treated unfairly[97].

5.83 Specific barriers identified by older people in relation to the use of health and social services include: lack of transport services / inaccessible vehicles; embarrassment or stigma associated with 'having' to use some services (e.g. meals on wheels) and lack of information about services provided.

5.84 We must ensure that vulnerable older people in our community are safe. Regardless of whether they receive services in their own homes or in residential, day care or hospital settings. Policy and guidance in this area must be robust and all staff should receive training.

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[96] Information on Evercare in the UK can be found at: www.natpact.nhs.uk
[97] DHSSPS, 2003. *Public Attitudes Survey.*

5.85 We will set out clear standards of care that will be guided by the principles established in the National Service Framework in England: (i) respecting individuals, (ii) joining up care and promoting timely access to best specialist care and; (iv) promoting healthy and active living. These high quality and transparent standards of care will be centred around initiatives such as “The Essence Of Care” and developed to standards that will meet the specific needs of older people in Northern Ireland.[98]

5.86 Standards will also be developed to manage transitional arrangements for service users, who have received Health and Social services prior to reaching retirement age. These standards must include consultation and agreed transition planning with service users and providers.

Key Outcome: Health and Wellbeing of Older People
To have improved the mental health and wellbeing of people aged 65 or over by a fifth between 2001 and 2025 as measured by the General Health Questionnaire (GHQ) 12 score. [99]

5.87 Over the next twenty years we can expect to see more of the social issues which are sometimes associated with older age such as isolation and depression. Increasing numbers of older people experience the effects of alcohol related harm or the misuse of prescribed medication. As family structures change there is a danger that isolation will become more prevalent with age. Importantly, the needs of older people with mental ill health are being considered within the Review of Mental Health and Learning Disability. We will examine the recommendations from that process and seek to implement a coordinated programme on the basis of these recommendations.

Key Action: Integrated Health and Wellbeing Policy for Older People
Advocates/Champions for older people will be identified throughout all HPSS organisations, where possible through the reorganisation of existing staff. These will focus on the full range of interventions and services as they relate to older people including primary care, community care and acute care sectors. They will work with HPSS staff and the voluntary, independent sector to develop, promote and monitor an overarching strategy for older people’s health and wellbeing: *Meeting the needs of Older People* that focuses on maximising choices available for Older People and independence.

Key Action: Dementia Services
1 in 4 people over the age of 85 years suffer from dementia. While the onset of dementia is not restricted to older age groups, it remains prevalent amongst older people. We will therefore see increasing numbers of people with dementia, as the population ages. We will respond to the challenges this will bring by putting dedicated support services for people with dementia and their carers, in place.

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98. The Essence of Care was launched in February 2001 by the NHS Modernisation Agency in England. reinforced the importance of “getting the basics right” and of improving the patient experience. The Essence of Care has been introduced as a benchmarking tool to help practitioners take a patient-focused and structured approach to sharing and comparing practise. The development of these benchmarks for care will be integrated into the range of standards, which will be introduced by the new Health and Social Services Regulation and Improvement Authority in Northern Ireland.
99. A threshold score of 4 or more on the GHQ12 has been used to identify respondents with a potential psychological disorder. People with a score below this are considered less likely to be at risk. Results on GHQ12 from the 2001 Health and Wellbeing Survey revealed that some 17% of people in this age group had the potential to develop or to have developed a psychological disorder.

Multi-disciplinary dementia teams, with specialist staff, such as Nurse Consultants will have been established in each Board area. Early Diagnosis and Support services will have been set in place for people with dementia and their carers and a needs assessment will have been completed to assess the availability of appropriate housing with care, residential and nursing home accommodation for people suffering from dementia. A review of palliative care services for people with dementia will also be completed.

5(xi) Children and Young People

5.88 One of the best ways we can improve the health and wellbeing of the population is by improving the health and wellbeing of children and their parents. A good start in life is the best way of reducing the likelihood that we will experience illness and social harm. Perhaps one of the greatest achievements of the last century has been the extent to which childhood has become safer. Today's children are far less likely to suffer from sudden illness such as life threatening fevers and serious infections than any previous generation. It is also clear that our approach to improving health and social outcomes must stem from a joined-up approach across Government and at local level.

Key Outcomes: Positive Outcomes for Children and Young People

By 2025, 70% of all infants will be breast-fed by one week after birth (50% by 2010).[100]

By 2025, 40% of all infants will still be breast-fed at 6 months (20% by 2010).[101]

To have improved the mental health and wellbeing of young people aged 16 and 24 years by a fifth between 2001 and 2025 as measured by the General Health Questionnaire (GHQ) 12 score.[102]

By 2010 to have ensured that all children and young people requiring care and treatment will receive it in an age-appropriate setting and to continue to achieve this as standards develop up to 2025.[103] [104]

To improve the life chances of children in care initially by ensuring that they are placed in an appropriate setting and that this is reflected by continuity of care (measured by a reduction in movements between placings). While a stable environment will have immediate benefits, we would expect and hope, in the longer term, that these benefits will lead to[105]:

a) 95% of young people in care experiencing no more than three placements during any one continuous period in care;

b) The proportion of young care leavers in education, training or employment at age 19 to be at least 75% of the level for all 19 year olds;

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100. The baseline was 37% in 2000. Source: Infant Feeding Survey or maternity hospital data.
101. Baseline was 10% in 2000.
102. Results on GHQ12 from the 2001 Health and Wellbeing Survey revealed thatsome 15% of males and 25% of females in this age group had the potential to develop or to have developed a psychological disorder.
103. This target will need to be assessed against an agreed standard.
104. An age appropriate setting may be one where only children and young people are catered for or where both adults and children receive services and staff are competent in specifically meeting the needs of children and young people.
105. DHSSPS Information and Analysis Directorate.

c) The rate of looked after children adopted in each HSS Trust to be at least 7%.

These longer term outcomes must not, however, cloud the primary aim which is the longer term health and wellbeing of children in care. They are consistent with that aim, but must never be sought at the expense of that aim.

By 2015, to protect children in danger of suffering significant harm by ensuring that 100% of all child protection cases which should be reviewed during the year are reviewed and, as necessary acted on.[106]

Improve support for children and their families by ensuring that all children with a disability are registered on a new register which will facilitate improved assessment of needs, service planning and outcomes.[106]

By 2015 no more than 25% of those on child and adolescent psychiatry waiting lists to be waiting for 3 months or longer for a first appointment at the end of each quarter.[106]

By 2025 all children requiring specialised child and adolescent mental health services will be able to access them in 3 months or less.[106]

By 2005 to have ensured that 75% of children and young people requiring in-patient hospital treatment will receive their care and treatment in an age-appropriate setting.[106]

5.89 Improvements in public health, screening, immunisation and new medical treatments on the one hand, and the development of the rights of children and young people along with a growing awareness of the risk of child abuse on the other, have all been major steps forward.

5.90 However many challenges remain and new ones are emerging. For example the growth of childhood obesity may be storing up health problems for generations to come as well as resulting in young people developing diabetes now.[107] Suicide and deliberate self-harm among adolescents and young people are serious issues requiring both professional and societal action.[108] Children with behavioural difficulties and conditions such as autistic spectrum disorders appear to be more widespread than was previously thought.[109] A quarter of all rape victims are children[110] and every week in the UK a child dies as a result of abuse and hundreds more are added to the child protection registers.[111]

5.91 We must ensure that all our community, primary and secondary care services grow and develop to meet these and other needs of our children and young people. But perhaps even more importantly, through cross-government approaches we must seek to reduce the poverty amongst children and young people which underpins the unacceptable levels of health and social inequality in our society.

5.92 Our services must recognise children and young people are important in their own right and have needs that are distinct and different from those of adults. If we are to ensure that the services we provide meet the needs of children and young people they must be active partners in the design, delivery and review of those services.

106. Measures to be designed
107. Parliamentary Office of Science and Technology, 2003. *Childhood Obesity.* Post Note No. 205.
108. BMJ 2002;325:1207 1211 (23 November).
109. Medical Research Council, 2001. *Review of Autism Research: Epidemiology and Causes.*
110. Home Office Statistical Findings 1/96 Victims of Violent Crime Recorded by the Police in England and Wales 1990-1994 (1996) Watson, Home Office.
111. http://www.nspcc.org.uk/html/home/newsandcampaigns/factsandfigures.htm

Key Actions: New Strategy for Children and Young People
The Office of the First Minister and Deputy First Minister has been working with all other Departments including the DHSSPS to produce Northern Ireland's first overarching Strategy for Children and Young People due for publication in 2004. This strategy aims to make sure that children and young people will be given a higher priority when policy is being made and they will be given opportunities to play a part in shaping what the government does. Two areas have been identified for early shared action:

We will work more closely with DE and DEL to improve the integration of education and vocational training and the HPSS, particularly in relation to vulnerable people who often have needs which stretch across organisational boundaries such as socially excluded young people, and children and young people with a range of disabilities.

Closer coordination and working arrangements will also be developed at all levels between the HPSS, DE and the Police in the areas of child and youth protection to ensure that these issues are identified at the earliest possible stage and that an effective coordinated response is quickly implemented.

5.93 We must continue to work with parents to develop more confidence in their own abilities and to assist them to respond more positively to their children's needs. By improving their skills, parents will be better able to improve their children's health and educational attainment, as well as their own confidence and self-esteem.

Key Action: A Family and Parenting Strategy
We will develop a family and parenting strategy which will focus on a range of preventative and universal measures to improve the quality of children's lives through supporting parents. The strategy will include approaches to promoting positive parenting and be targeted on all families in Northern Ireland. Currently, an information leaflet is being developed which will be made widely accessible across Northern Ireland. This leaflet will assist parents in dealing with situations which routinely arise during the course of bringing up their children. We will also be seeking to complement the strategy by developing a Childcare Information System to assist parents find childcare services which are most appropriate to meet the needs of their children.

Supporting Families

5.94 The best place for children and young people will nearly always be with their families. In order to provide support for children and young people within their families we will develop a coherent family support strategy, drawing together both universal and targeted services and supports. This will build on the work of the Childcare Partnerships and the Children and Young People's Committees at Board area level.

5.95 Sometimes, however, the best interests of the child are served by their being looked after by Health and Social Services. At any one time 2,500 children are looked after. Some 67% of these children live with a foster family, 21% will live with a member of their own family and 12% are in residential care.[112]

5.96 When health and social services take on parental responsibility for children we must make every effort to provide them with stability, protect them from further harm and be ambitious for their futures. In order to achieve this we will strengthen arrangements for the vetting of staff and regulating the quality of services provided for children.

5.97 This will include significantly investing in fostering, adoption, residential care and child protection services to ensure that as many children as possible have the experience of stable parenting in a family setting. DHSSPS will seek to ensure that these services are being delivered in the most effective way through the development of a Strategy for Children and Young People in Need and an associated Adoption Strategy over the next year. We will also seek to develop partnerships with education authorities to have a coordinated approach to improving educational outcomes for looked after children.

Children's Services Planning

Children's Services Planning in Northern Ireland is a process for bringing people together to plan services for children, across agencies and groups. The aim of is to meet the needs of children and young people who are vulnerable, so that they can reach their full potential and be socially included members of the community, as children and as adults. The process is managed by partnerships in each Board area, which are made up of statutory, voluntary, community and black and minority ethnic groups and includes the young people themselves, their parents and carers and communities.

Wraparound

“Wraparound” is a partnership project about partnership in the planning and provision of services for disabled children and their families in the Southern Health and Social Services Board. A range of partners are involved including play adviser, family adviser and a Royal National Institute for the Blind (RNIB) worker. Services and projects range from additional respite provision to user participation to an early intervention service for autism. Key diagnostic and assessment services, such as the Child Development Clinic, empower parents and promote a “holistic” approach to the needs of the child and the family by bringing services together.

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[112] Family and Child Care, Programme of Care 3, Community Statistics 1st of April 2002 - 31st March 2003 Regional Information Branch NISRA

Health and Social Services Planning for Children and Young People
To promote an integrated approach to planning for children and young people, at Departmental level, an overarching Children's Task Force will be established bringing together all functions and professional input relating to children's health and social services. This will be replicated across the HPSS with an overarching Children's Directorate within each organisation. Representatives of these Directorates will play a key role in regional arrangements for planning children's services. The role of these Directorates should also be set within the context of arrangements to ensure clinical and social governance arrangements, which will give effect to the roles and responsibilities of Children's Directors.

Children and Young People's Health Services

5.98 Although children and young people are frequent users of healthcare compared to adults, most interventions are for routine healthchecks, immunisations and for when they are briefly unwell. For example, in a typical year a pre-school child will see their general practitioner about six times with a child of school age attending two or three times.[113]

5.99 Sometimes children will need more specialist services. Where possible these will be provided in the community, where greater use will be made of nurses and GP's with enhanced skills. At other times they may need to use hospital services. In either case the important thing is that the services are designed and delivered around the person using those services and not the organisation providing them. This will be greatly facilitated by the allocation of a key worker to act as a first point of contact for children and their families and the use of a single assessment framework.

5.100 One of the most challenging issues facing our healthcare system will be how to sustain specialist paediatric services and maintain clinical skills in the face of emerging pressures on the workforce. In some specialties, such as Child and Adolescent Mental Health Services, we know that historical resourcing problems have exacerbated these problems leading to staff shortages. In the short to medium term this will require us to look carefully at service redesign and using staff more effectively.

5.101 As with services for adults it will mean making greater use of managed networks for a number of specialist services. These networks will require: building pathways of care around the child and family; seeing services through their eyes; breaking down traditional boundaries, for example between the family doctor and the hospital; and delivering more flexible and responsive care. Some examples of service areas which will benefit from this approach include paediatric gastroenterology and the transfer of critically ill children and newborn infants.[114] Networks will also be developed for a range of chronic conditions affecting children including epilepsy.

113. Department of Health, 2003. *Getting the Right Start: National Service Framework for Children, Young People and Maternity Services: Standard for Hospital Services.*
114. Royal College of Paediatrics and Child Health, 2004. *Commissioning Tertiary and Specialised Services for Children and Young People.*

Key Action: Developing Specialist Services for Children and Young People
Services for children and young people with disabilities are currently provided in the overall context of adult services. This is incompatible with a child centred approach which sees children with a disability as children first and foremost. To address this, there needs to be an overarching review of services for children with a disability. This review should, amongst other actions, establish:

(i) Integrated workforce plans for the provision of the necessary health and social care support for children with special needs within special school and mainstream school settings. This work will be undertaken in the context of the forthcoming Special Educational Needs and Disability (SEND) Order.

(ii)Systems for the improved collection of information relating to the numbers of children and young people with disabilities to enable more accurate assessment of need and improved service planning.

5.101 In order to achieve this "child centred" approach, wherever possible, age appropriate services will be developed. When children and young people have to be admitted to hospital for care, that care should be provided in an appropriate location and in an environment that is safe and well suited to the age and stage of development of the child or young people.

5(xii)People With Physical and Sensory Disability

5.102 Despite the enactment of the Disability Discrimination Act in 1999 and the almost universally held belief that people with disabilities should have the same opportunities in life as people who are not disabled there remains a significant problem of discrimination and unequal access to goods and services.

5.103 Our first aim, in line with *Investing for Health*, is where possible to reduce the prevalence and severity of disability by tackling the key causes. For example, we need to reduce the high level of traffic injuries here as well as potentially disabling conditions such as stroke, diabetes and coronary heart disease. However we must also recognise the valuable contribution that people with disabilities can and do make to as citizens. In particular we should celebrate the way they contribute to the enrichment of society through diversity.

Key Outcomes
By 2025 to have reduced the percentage of people aged 16 years and over with long-term limiting illness[115] from 25% in 2002/03 to 20% (by 2015, 23%). This will effectively reverse the increasing prevalence of long term limiting illness, which is partly associated with demographic trends.[116]

By 2025 to have reduced the percentage of people aged 16 years and over in the lowest SEG (unskilled manual) with long term limiting illness from 38% in 2001/02 to 30% (by 2015, 34%).[117]

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[115] Limiting long-term illness covers any long-term illness, health problem or disability which limits daily activities or work. (Note: Figures are standardised to 2002 population).

[116] Continuous Household Survey.

[117] Three-year rolling average. Figures cannot be age-standardized so they will be affected by demographic trends. Continuous Household Survey.

To have improved the mental health and wellbeing of people living with a disability (limiting long-term illness) by a quarter between 2001 and 2025 as measured by the General Health Questionnaire (GHQ) 12 score.[118]

By 2025 to ensure that anyone with a disability who wants to live independently can do so.[119]

By 2025 to have reduced the percentage of people aged 16-74 years with a limiting long term illness and who are economically inactive because they are permanently sick / disabled from 42% to 20%.[120]

5.105 This contribution is often limited by the exclusion of people with disabilities from aspects of daily life leading to significant disadvantages compared to the rest of society. For example although people with disabilities account for nearly a fifth of the working age population they only make up one eighth of people in employment.

Key Action: DHSSPS Disability Task Force
We will appoint a Task Force to develop recommendations for people with physical and sensory disabilities which will report to the DHSSPS. The key terms of reference for the task force will include the following objectives:

- Address as a matter of urgency the outstanding recommendations of recent reports on the provision of wheelchairs and prosthetics.
- Develop, in partnership with others, effective vocational rehabilitation services for people with physical and sensory disabilities;
- Refocus statutory day support services on the promotion of independence and inclusion and meeting the needs of people with complex care needs;
- Develop, in partnership with others, a range of housing and accommodation options to provide independence and choice for people with physical and sensory disabilities;
- Encourage an increase the uptake of direct payments for people with physical and sensory disabilities;
- Develop the appropriate balance of service provision for people with physical and sensory disabilities, between statutory, voluntary and independent providers.
- Improve the collection and analysis of information, at local and regional level, on the numbers of people with disabilities and their needs.

5.106 We believe it is the responsibility of our services to adapt to disabled people's needs. The disabling factor is not the individual's physical limitations but rather the interaction of the wider society with the individual. For example taking this approach the reason a wheelchair user cannot access a building is not because they are in a wheelchair but because of the planning and design of the building. Similarly, the reason a partially sighted person is unable to read a printed document is not because of their lack of visual acuity but because the document was not supplied in an appropriate format.

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118. Results on GHQ12 from the 2001 Health and Wellbeing Survey revealed that some 36% of people in this group had the potential to develop or to have developed a psychological disorder.
119. This will require sensitive specialised measures to be developed in order to determine accurately the percentage of people who would wish to live independently when given an appropriate range of options.
120. Census of Population.

Key Action: Acquired Brain Injury
There continues to be significant progress in the development of integrated services for people with acquired brain injury. In order to achieve the necessary level of coordination, these services will be joined together in a network of service providers including: community brain injury teams; vocational training and support programmes; specialist residential services and hospital based provision including acute hospitals, the new regional rehabilitation service and specialist services for those people in minimally responsive states.

5.107 On a practical level health and social services need to ensure the wide availability of the latest prosthetics and physical aids to people with disabilities. We will also build on existing work to improve physical access to health and social services in line with our responsibilities under the Disability Discrimination Act.

5.108 However, in addition to removing physical barriers, we must begin the process of redesigning services for people with physical disabilities, brain injuries and sensory impairments. Although there have been many examples of excellent disability services at a local level, there is a need for greater strategic direction at a regional level. If we are to ensure that services promote independence while at the same time providing the support and care that individuals need we must take a fresh approach.

5.109 This approach will be developed through a partnership between people with disabilities, those who provide health and social services (both statutory and voluntary sectors) and those in other sectors such as education, housing and employment. If this new approach is to be successful it must address issues such as how to increase the number of people with disabilities living in their own tenancies, in education, training and employment, taking control of care needs through the use of Direct Payments as well as improving the way the full range of health and social services respond to people with disabilities, brain injuries and sensory impairments.

5(xiii) People with Mental Health Problems

5.110 People in Northern Ireland experience relatively high levels of mental health problems compared to GB. Some 24% of women and 17% of men here show signs of possible mental ill health.[121]

To have improved the mental health and wellbeing of the public by a fifth between 2001 and 2025 as measured by the General Health Questionnaire (GHQ) 12 score.[122]

5.111 Social and economic deprivation is one of the possible reasons for the high levels of mental health problems in Northern Ireland. For example unemployed people are almost twice as likely to show signs of a possible mental health problem (30%) as those in employment (16%).[123] It has been estimated that nearly 40% of homeless people in Belfast have mental health problems.[124]

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121. NISRA, 2002. *Northern Ireland Health and Wellbeing Survey 2001.*
122. A threshold score of 4 or more on the GHQ12 has been used to identify respondents with a potential psychological disorder. People with a score below this are considered less likely to be at risk. Results on GHQ12 from the 2001 Health and Wellbeing Survey revealed that some 17% of men and 24% of women had a score, which indicated the potential to develop or to have developed a psychological disorder.
123. NISRA, 2002. *Northern Ireland Health and Wellbeing Survey 2001.*
124. McGilloway, S. and Donnelly, M. 1996. *Don't Look Away: Homelessness and Mental Health in Belfast.* Council for the Homeless. Belfast.

Homelessness

Homelessness is one of the most extreme forms of social exclusion. It is more than a housing issue: it can occur as a result of poor health or poverty, for example. Being homeless can have a significant impact on mental health although it is important to stress that not everyone who is homeless experiences mental ill health and vice versa. Homeless people report feelings of loneliness, stress and depression as well as experiencing lower levels of physical health.[125] A partnership approach is essential to tackling homelessness and a number of partnership initiatives are currently underway, including the Promoting Social Inclusion Working Group on Homelessness, which is led by DSD.

5.112 Another factor which has affected the mental health of the population here has been the impact of 30 years of civil conflict. Many people perceive themselves in some way or another to be victims and this perception is associated with lower levels of psychological wellbeing.[126]

5.113 Our attitudes to people with mental health problems and how to meet their needs for care and treatment have undergone radical change in recent decades. In particular there has been growing movement away from the provision of services in institutionalised hospital settings, requiring inpatient admission to more local community based interventions. This shift has been driven both by professional views as to what constitutes good practice and a greater responsiveness to service user's preferences for where and how they receive care and treatment.

5.114 Another factor which has influenced our changing attitudes to mental health has been the developing human rights agenda which has both shaped attitudes and set legal requirements in relation to care and treatment.

5.115 In 2002 an overarching review of the policy, practice and legislation relating to mental health and learning disability was initiated. This review will make a number of recommendations for the future of services and policy when it issues in final form. The Review is considering every aspect of mental health including: Mental Health Promotion; Legal Issues; Alcohol and Substance Misuse; Adult Mental Health; Dementia and Mental Health Issues of Older People; Child and Adolescent Mental Health and; Forensic Services. This will involve other Departments and agencies playing their part in addition to the health and social services.

The Review of Mental Health and Learning Disability:[127] A New Vision for Mental Health Services

The vision is to give a real and meaningful priority to the challenges of mental health, embracing a reduction in the incidence and prevalence, a reduction in mortality and in the extent and severity of problems associated with mental ill-health. Central to the vision is a valuing of people with mental health needs, their rights to full citizenship, equality of opportunity and self-determination. It anticipates a process of reform, renewal and modernisation of services.

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[125] Simon Community Northern Ireland, Northern Ireland Health and Socal Services Councils, 2000. *Opening the Door to Health: Access to Primary Healthcare Services for Single Homeless Pleople in Northern Ireland.*

[126] Cairns, Ed., and Mallet, John. 2003. *Who are the Victims? Self-assessed Victimhood and the Northern Irish Conflict; Nio Research and Statistical Series.* Report No. 7.

[127] Abridged from the Review of Mental Health and Learning Disability website

People with mental health needs and their carers should look forward to a response from services which: respects their individual autonomy; and demonstrates justice and fairness. Mental health services will be based on partnership with users and carers and the delivery of high quality, effective treatment, care and support.

Services will be accessible with continuity of care and support for as long as is needed. They will be comprehensive and coordinated taking account of the needs and views of carers, where appropriate, in relation to assessment, treatment, care and support. The promotion of independence, self-esteem and social interaction and the promotion of the safety of service users, carers, providers and members of the public will be central. Staff will be provided with the necessary education, training and support and services will be subject to quality control, informed by the evidence.

5.116 When the Review of Mental Health and Learning Disability is published we will explore the best ways of progressing the recommendations in partnership with people with mental ill health, learning disabilities, their families and service providers.

5(xiv)Learning Disability

5.117 Due to the different ways in which data is collected it has always been difficult to establish exactly how many people there are in Northern Ireland with a learning disability. However, recent research has identified a likely total population of people with moderate, severe and profound learning disabilities of some 16,400.[128]

5.118 Over the next twenty years a number of factors are likely to have an impact on the numbers of people with a learning disability. On the one hand the advent of gene therapy and improved care and treatment for children at risk will have the effect of decreasing numbers. On the other hand however people with a learning disability are living longer than ever before, more babies are being born to older mothers and more children at risk are surviving due to improved care and treatment.

5.119 When all these factors are taken into account it seems likely that overall there will be some increase in the population of people with a learning disability and that within this there will be an increase in the proportion who have complex needs.

5.120 An understanding of human rights is central to valuing people with a learning disability, their rights to full citizenship, equality of opportunity and self-determination. This approach reflects changing expectations. We have come a long way from the days when services for people with a learning disability meant separating them from the rest of society. We must strive to ensure that people with a learning disability get the same chances and choices as everyone else.

Learning Disability: Key Outcomes
By June 2010 all People with a Learning Disability living in Long Stay Hospitals should be able to re-locate to appropriate and supportive community accommodation, with the option of holding their own tenancy.[129]

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[128] McConkey R, Spollen, M, Jamison, J. 2003. *Administrative Prevalence Of Learning Disability in Northern Ireland.* DHSSPS

[129] Measure to be developed.

5.121 Regionally, policy has not always kept pace with these changing views. This is why in 2002 an independent review of law, policy and service provision affecting people with mental health needs or a learning disability in Northern Ireland was commissioned – see also 5(xiii) above. As part of this process, the review team established a working group, the Equal Lives Group, made up of people with a learning disability to provide advice and comment on issues.

'Equal Lives' Values for Addressing Learning Disability[130]

Social Inclusion	People with a learning disability are valued citizens and must be enabled to use mainstream services and be fully included in the life of the community.
Citizenship	People with a learning disability are individuals first and foremost and each has a right to be treated as an equal citizen.
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 helps them to be as independent as possible.

5.122 These five core values represent a significant change in the way services have traditionally been provided to people with a learning disability. We believe that they should underpin the future development of services and that they are applicable regardless of age, gender, severity of disability or complexity of needs.

5.123 The review team have also identified a number of core objectives for future policy for the next 15 years.

'Equal Lives' Objectives

Objective 1	To ensure that families are supported to enjoy seeing their children develop in an environment that recognises and values their uniqueness as well as their contributions to society.
Objective 2	To ensure that children and young people with a learning disability get the best possible start in life and access opportunities that are available to others of their age.
Objective 3	To ensure that the move into adulthood for young people with a learning disability supports their access to equal opportunities for continuing education, employment and training and that they and their families receive continuity of support during the transition period.
Objectives 4	To enable people with a learning disability to lead full and meaningful lives in their neighbourhoods and have access to a wide range of social, work and leisure opportunities.

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[130] Provided by the Review of Mental Health and Learning Disability

Objective 5	To ensure that all men and women with a learning disability have their home in the community and that, where they live with their family, their carers receive the support they need.
Objective 6	To consider the need for an extended range of housing options is developed for men and women with a learning disability.
Objective 7	To secure improvements in the mental and physical health of people with a learning disability through developing access to high quality health services that are as locally based as possible and responsive to the particular needs of people with a learning disability.
Objective 8	To ensure that men and women with a learning disability age well in their neighbourhoods.
Objective 9	To enable people with a learning disability to have as much control as possible over their lives through developing person-centred approaches in all services and ensuring wider access to advocacy and direct payments.
Objective 10	To ensure that health and social services staff are confident and competent in working with people with a learning disability.
Objective 11	To encourage staff in other settings to develop their understanding and awareness of learning disability issues and the implications for their services.
Objective 12	To promote improved joint working across sectors and settings in order to ensure that the quality of lives of people with a learning disability are improved and that the Equal Lives values and objectives are achieved.

5.124 When the Review of Mental Health and Learning Disability is published we will explore the best ways of progressing the recommendations in partnership with people with learning disabilities, their families, carers and service providers.

TEAMS WHICH DELIVER

6. TEAMS WHICH DELIVER

6(i) Workforce at the Top of the Agenda

6.1 **Policy Direction 11: We must ensure that health and social services employers become 'employers of choice' in order to recruit and retain adequate numbers of staff.**

6.2 Our health and social services cannot function without the dedication and skills of the people who work in them. This includes all those staff directly employed in the HPSS as well as those working in the private sector, the independent sector and the community and voluntary sector who provide the treatment and care so vital for our health and wellbeing. This network of people also includes the thousands spouses/partners, parents, children and others who provide care to loved ones at home. We must recognise and value these informal carers. Without them our system of health and social care could not cope.

6.3 Possibly the biggest constraint our health and social services will face in the future will be a shortage of staff. Although the working age population will increase over the next twenty years, growing economic development and growing demand for services will make it increasingly difficult for our health and social services, no matter which sector, to compete for staff. If we are to manage this we will have to adopt new ways of working, organising and employing our staff.

6(ii) Working Across Sectors

6.4 The need for more teamworking will mean increasing the opportunities for people to train together. It will also mean increasing the opportunities for people to work in different sectors and, when we plan for our future workforce, our plans will have to take into account the whole of the workforce delivering health and social care.

6(iii) Developing Our Teams

6.5 **Policy Direction 12: We will promote the development of shared learning and common competencies throughout the health and social services including the HPSS, the private sector, the independent sector and the community and voluntary sector.**

6.6 Our services will support the development of new knowledge and skills across the workforce. Where appropriate we will ensure that our people are educated and trained to the highest standards and in the most modern ways of working.

6.7 We will place a particular emphasis on developing skills in the management and treatment of chronic conditions. Where possible, specialist education and training will be tailored towards emerging issues and threats. In particular, we will seek to build on our skills in areas such as gerontology (the science of ageing), communicable disease and new genetic techniques.

6.8 We will also promote shared learning in a range of competencies which are relevant across our services including the prevention of illness and harm, team-working, Information Technology and cross-sectoral working. For those with responsibility for managing services there will more opportunities to develop leadership skills.

6.9 In taking forward shared learning, we will place a special emphasis on competencies relating to the protection, support of and promotion of independence for vulnerable people. This has always been a key role for our social services and as we build on the strengths of our integrated system of health and social care we will ensure that all our staff are supported through training in protecting the most vulnerable members of our society from harm.

6.10 The balance between specialist and generalist skills will be a continuing dilemma. Getting this balance right is a major challenge but we believe the best way to meet it will always be to adopt a person centred approach to the design of our services.

Key Action: An Integrated Common Learning Framework
We will develop an Integrated Common Learning Framework. This will include mutual codes of conduct and ethics across the workforce and a common development framework. It will include a range of programmes linked to all health and social care professional and vocational training. Inter-disciplinary training will be planned at both pre and post qualifying levels with people spending more time together learning the competencies and knowledge common to all as well as developing their understanding of each other's work.

Specific pilots will be developed for new professional roles. Emerging contractual arrangements will provide the basis for these, namely the new General Medical Services Contract, the Consultants' Contract and Agenda for Change, which applies to a comprehensive range of HPSS employees.

Courses will be established to provide for a practice-based approach to receiving accreditation. These will include flexible graduate entry programmes for medical training and the potential for an enhanced loan scheme designed to encourage mature students to consider medicine, nursing and social work as a change in career path.

6.11 Traditionally the HPSS has delivered models of care based on rigid demarcations between different professions and job roles. These demarcations grew when a degree-level education in health services was largely constrained to the medical profession. Clear distinctions between professions helped to ensure that services were safe and delivered to a certain standard.

6.12 It also meant that at times resources were not used as efficiently as they could have been and that the needs of the service user were not addressed as well as they could have been. Now a much higher proportion of people working in the health and social services are highly educated, many to degree level.

6.13 Growing pressures on the service mean that increasingly we must utilise these people's skills to their full potential. These changes are also driven by developments in the medical profession with: the systematic implementation of clinical governance; more specialists being located outside hospitals; General Practitioners with a greater role in the strategic management of health care; and more joint working with social care and other related services. All of these developments, against a background of increasing demand and moves to improve the work-life balance of medical professionals, are driving a move towards spreading medical competencies across a range of other professionals.

New Roles and Competencies
Nurse practitioners represent a major development in the nursing profession. They are defined by the Royal College of Nursing (RCN) as somebody who has 'undertaken specific graduate study, who is responsible for autonomous clinical decisions, who uses skills not usually exercised by nurses in differential diagnosis, screens patients for diseases, develops preventive care management and who may refer or discharge patients'. Nurse practitioners work in a variety of locations including GP surgeries and acute, community and mental health settings and there is a range of evidence which supports the expansion of their role. It has been suggested that between 20 and 32 per cent of the services provided by GPs could safely be provided by nurse practitioners at potentially lower costs.[131]

Inter-professional Education at Queens University Belfast (QUB)
The Schools of Nursing and Medicine at QUB offer an interprofessional shared learning programme to undergraduate medical and nursing students. An important feature of this initiative is that it combines classroom-based learning with learning on clinical placements.

Participants in the programme include students from the Children's Nursing Branch Programme (3rd year, pre registration nursing students) and Paediatrics and Child Health (4th year undergraduate medical students). These students are brought together to be taught by an interprofessional team including University lecturers from both professions, medical practitioners, clinical nurse specialists and nursing mentors and social workers.

The first two weeks of this eight week programme take place in the classroom with the remaining time being spent on joint clinical placements. Together they learn about areas of practice common to both professions and they jointly participate in ward rounds and other practice tasks. Among the benefits of the programme are the development of team working skills and a deeper understanding of the different roles of each professional group.

6.14 We will actively promote the appropriate movement of skills and competencies across professions to ensure that our resources are used to optimum effect. Where necessary, we will develop new roles to meet the new demands on our services.

6(iv) An Employer of Choice

6.15 The health and social services include services in the private and voluntary sectors, as well as the HPSS. However, with some 60,000 employees the HPSS represents the largest single employer in Northern Ireland. If we are to attract people into the health and social care sector, and retain them, we must ensure that working conditions and career prospects are viewed as attractive in an ever tighter labour market. Quite simply we need to ensure that when faced with choices people will choose to work with us.

6.16 Being the best employer is about more than attracting the right numbers of people. Improving the lives of our staff contributes directly to improving services. People want to be treated and cared for by well motivated, fairly rewarded staff. Achieving this will require investing in training and development, managing stress, flexible contracts, improving working environments, reducing absenteeism, adopting a zero tolerance approach to workplace violence and improving communication.

[131] Department of Health, Social Services and Public Safety, 2003, *The Future of Health and Social Services in Northern Ireland: Key Trends in Population, Service Delivery and Workforce.*

6.17 All of these actions will be vital in improving recruitment and retention but they won't be enough in themselves. The reality is that, in common with many other European and Western countries, many of the people working in the health and social services here will be immigrants, often from less developed countries. The HPSS workforce is already becoming more ethnically diverse and we must welcome this as we compete for people in the global labour market.

6.18 The recruitment of staff from overseas must, however, reflect the high ethical standards that are associated with the HPSS and in particular we must avoid creating staff shortages in other countries, especially those developing nations whose healthcare systems are vulnerable.

6.19 If we are to maintain continuity of services, the abilities and contributions of everyone working with us must be valued. Cultural and ethnic differences must be respected and welcomed. As an employer and provider of services we will not tolerate any discrimination or harassment of our staff from whatever quarter for whatever reason. And as Northern Ireland's largest employer we will be at the forefront of efforts to eradicate racism. Our ambition is to be recognised as an example of "best practice" as an employer of a diverse workforce.

6.20 The HPSS will also continue to be active in providing opportunities for those who experience barriers entering the labour market. Long-term unemployment is a major cause of social isolation and deprivation, both of which contribute to poor health and wellbeing and which disproportionately impact on people with disabilities, people who experience poor mental health and people with learning disabilities. In the future the HPSS must find new ways to tap into this potential human resource.

Key Action: Health and Social Services as Employer
The HPSS family of organisations will continue, in partnership with DEL and other Departments, to ensure that those least able to access the labour market are provided with meaningful employment opportunities. This will mean the HPSS providing active support for those who are unemployed or economically inactive, or who lack basic skills as a result of illness or chronic conditions: for example through programmes to promote the health and wellbeing of those seeking employment.

The HPSS will also continue to proactively seek to employ those who have the most difficulty accessing the labour market because of illness, disability or any factor which leads them to be excluded. We will do this through active participation in the Local Strategy Partnerships and any other fora designed to promote a joined-up approach to promoting employment and employability such as the Taskforce on Employability and Long-term Unemployment.

We will, with the DEL Skills Unit, develop sophisticated models of labour market research to inform these efforts and seek to ensure that HPSS leads the way in promoting work-life balance and equality through flexible employment.

The HPSS will also support DARD by ensuring that employment opportunities are maximised in deprived rural areas and DSD in ensuring that HPSS employment supports efforts to promote urban and rural regeneration.

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With Trade Unions, the Northern Ireland Office (NIO), Police and criminal justice agencies, we will address attacks on health and social services professionals.

6.21 This will have a number of benefits, including helping to address vacancies, while at the same time contributing to wider Government policy on reducing poverty and social exclusion. DHSSPS is a member of the implementation group of the Taskforce on Employability and Long-term Unemployment, and will work with DEL and other Departments and Agencies to address these important issues.

6.22 The size of the HPSS workforce provides an important opportunity to address several key equality issues. The majority of those working in the HPSS and fulfilling caring roles are women, but the majority of those in senior medical posts are men. There is also evidence that work-life balance issues can be acting as a ‘glass barrier’ to women. Both of these issues must be addressed through workforce plans and effective human resource policies.

6.23 Carers are a particularly important group. The difficult role which carers fulfil impacts on their ability to participate in the labour market, to undertake education and training, to achieve an adequate income and pension, and indeed may impact adversely on their own health. Carers do not work for the HPSS, but they are essential partners. We will ensure that opportunities which are open to HPSS employees are also open to informal carers, so that they can benefit from the best training, development and support.

6(v) Planning An Integrated Workforce

6.24 **Policy Direction 13: We will build integrated workforce plans which cross professional, organisational and sectoral boundaries. These will provide for changing roles and competencies across the health and social services over the coming years.**

6.25 While efficiency must always be a key aim for our services, we need enough people working in the health and social services to allow for continuous 24/7 service along with a continuous training and development. This will mean filling current vacancies, building in capacity to meet the demands which of which we are already aware, predicting future demand as far as possible and allowing for some redundancy of capacity in the system.

Key Action: The Need for More Capacity
A number of uni-professional or uni-sectoral workforce reviews have been undertaken by the DHSSPS. These include reviews of likely demand and supply in the medical profession, the nursing, midwifery and health visiting group, social services, physiotherapists, occupational therapists, pharmacists and the technical workforce.

The reviews do not take into account the significant additional demands which will arise as a result of the longer term drivers set out in Section 2. While the impact of this demand on future workforce predictions is not clear, there is no doubt that the current predictions are conservative.

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Figure 6.1
Current Projected Demand for Additional Medical Posts
(Cumulative Additional Posts)

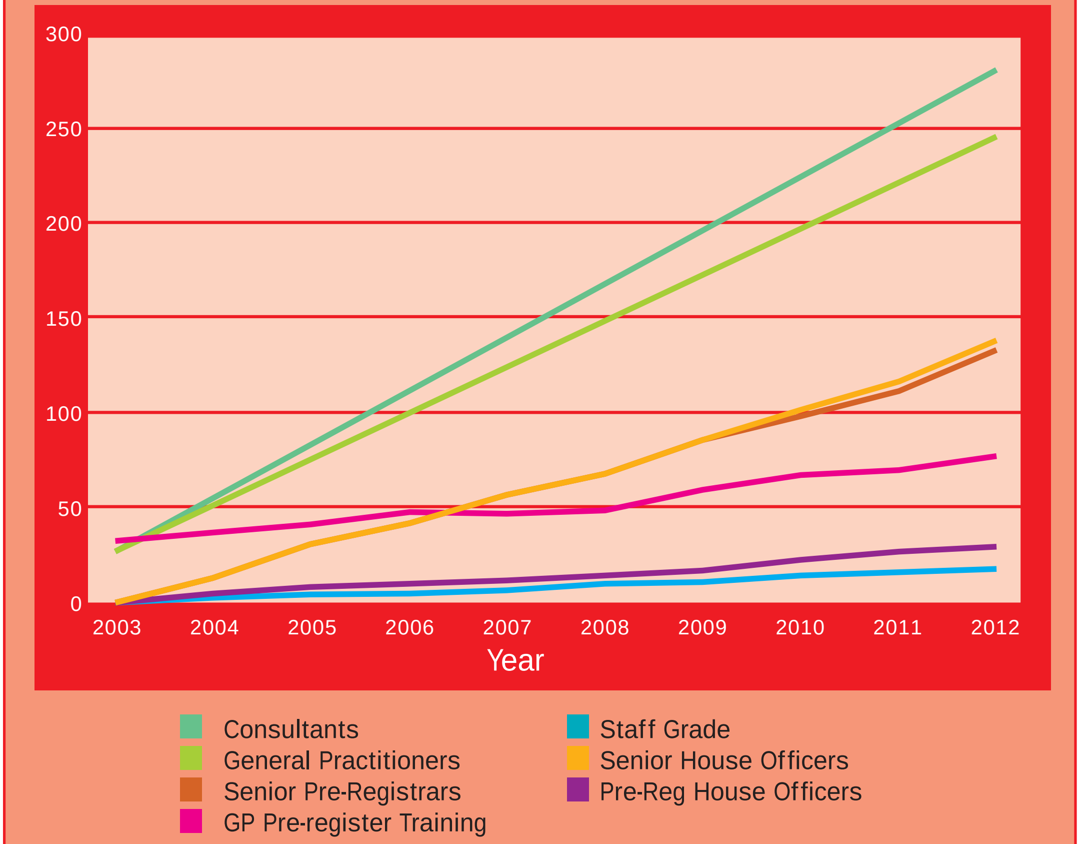
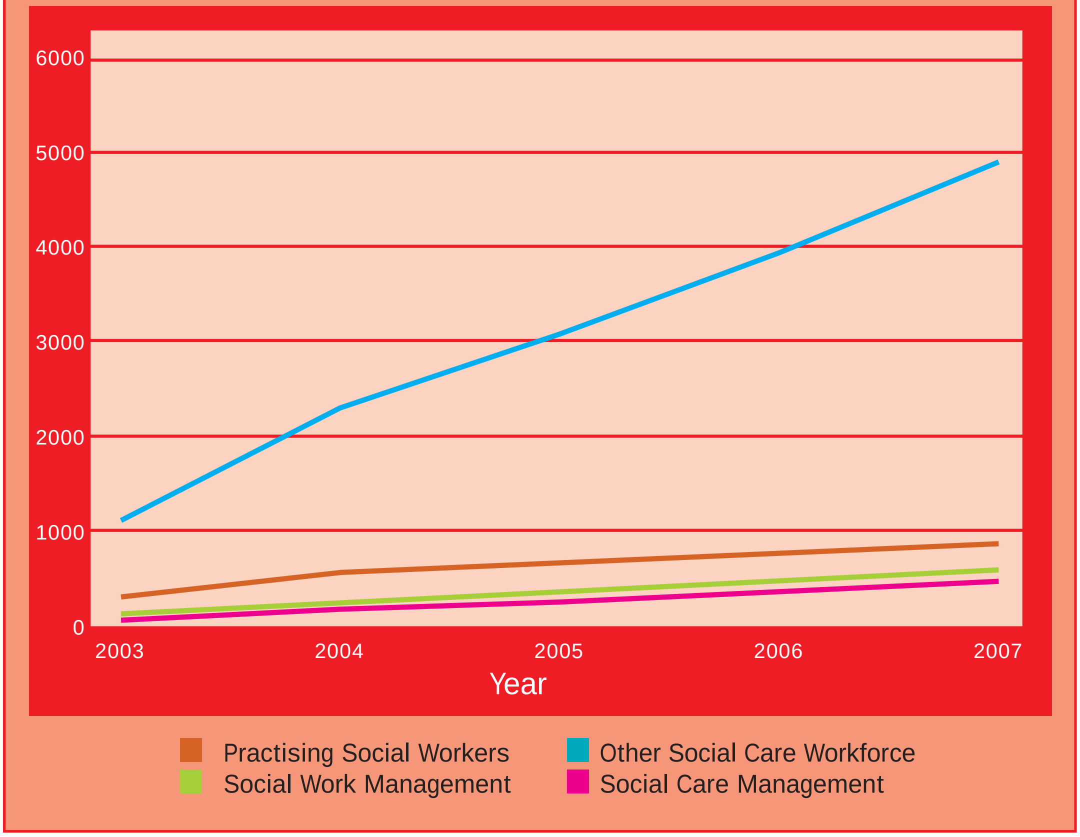


Figure 6.2
Current Projected Demand for Future Social Care Workforce
(Cumulative Additional Posts)



6.26 Much of the work so far in planning the HPSS workforce has been undertaken on a uni-professional or uni-sectoral basis. In the future, however, we will adopt a much more integrated approach to our workforce planning.

Changing Roles

"There is a body of evidence suggesting that there is a significant, untapped potential for fundamental changes to the mix of staff providing much health care. The most significant areas seem to be:

- *a substantial change in the mix of services provided by doctors and nurses. A review of the existing evidence suggests that between 25 and 70 per cent of doctors' tasks could be undertaken by nurses or other health care professionals. The evidence suggests that, while maintaining or reducing costs this could improve the scope for improved productivity; and*
- *much greater use of health care assistants (HCAs) to undertake much of the routine work undertaken by nurses."* [132]

6.27 The starting point for this planning process will be the need to be met and the service required. Integrated planning will allow for the movement of competencies and roles across professions and in particular it will facilitate the shift of focus towards primary and community based services.

Key Action: Integrated Workforce Planning

Individual workforce plans will be brought together into an Integrated Workforce Strategy (IWS), including revised projections to allow for the movement of competencies and roles across professions and allowing for a significant shift in focus towards primary and community based care services. Revised plans must also allow for increased capacity to enable the necessary training and development to have been implemented.

A standardised "Workforce Planning Data Set" will be developed for application throughout HPSS organisations. Workforce data should be collected at the same time in the year for all professional and support groups. This would go further than existing data sets to provide a fully functional and dynamic labour market intelligence system. We will work closely with DEL to produce a regular health and social care skills report.

A region wide programme will be developed, within which a series of new professional roles will have been rolled out across the service.

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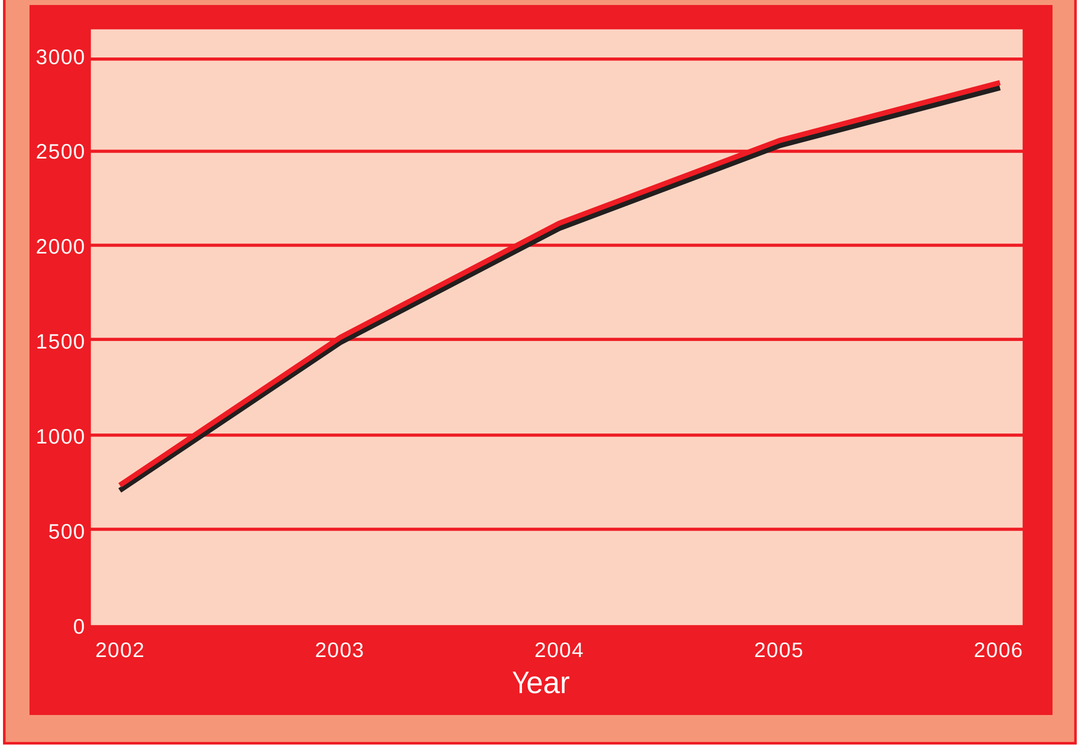
132. Wanless, D. 2001. *Securing Our Future Health:Taking a Long Term View.*

Figure 6.3
Projected Nursing and Midwifery Shortfalls
(Cumulative Additional Posts)



6.28 Increasingly, the emphasis will be on a broader range of professions than perhaps was the case in the past. A broad range of professionals will each provide a critical role in teams to manage chronic conditions.

Allied Health Professionals
Two examples of the impending role of Allied Health Professionals include the following:

Physiotherapists are playing an increasingly central role in the provision of health and social care. A number of scenarios of projected supply and demand have been produced ranging from an additional need over the next 5 years for 67 physiotherapists (based on agreed commitments) to 209 physiotherapists. As their role develops, in line with the need for more healthcare workers which cross professional boundaries and settings, we can expect even greater demands.

A similar situation is true for occupational therapists who, for example, are currently involved in a pilot scheme in Belfast City A&E to facilitate the prevention of admissions. Based on existing and likely demands, there are likely to be a need for an additional 44 to 108 occupational therapists.[133]

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[133] Department of Health, Social Services and Public Safety, 2003. *The Future of Health and Social Services in Northern Ireland: Key Trends in Population, Service Delivery and Workforce.* Significant increases for other professions such as podiatrists, speech and language therapists and dieticians are also anticipated.

IMPROVING QUALITY

7. IMPROVING QUALITY

7(i) Introduction

7.1 **Policy Direction 14: We will work to meet explicit quality standards in line with the new statutory duty of quality which has already been placed on the health and social services.**

7.2 The public needs to be confident about the quality of care they will get from organisations providing health and social services. People want services that are safe and are provided by competent staff who will always work in their best interests. People also have the right to assume that the HPSS will manage its affairs responsibly and get best value for public money.

7.3 In recent years, confidence in health and social services has suffered a number of setbacks. A series of local failures, combined with events in Britain, have undermined people's confidence. A key challenge is to restore confidence and, more importantly, to ensure that we are learning from the past. Risk cannot be eliminated entirely - health and social care is a complex and at times high-risk activity where decisions require a high degree of individual, professional judgement and outcomes cannot always be guaranteed. Nevertheless, risk can and should be managed and, when things do go wrong, we must make sure that we can learn from mistakes.

7(ii) Standards

7.4 Many health and social care services, including services for children and vulnerable adults, are not subject to any form of independent regulation or inspection at present. Those services that are regulated are often not delivered to common agreed standards - leading to unacceptable variations in the care and treatment that people are receiving.

7.5 This needs to change. In line with new legislation, a new statutory duty of quality has already been placed on Boards and Trusts. To underpin this, DHSSPS will be developing standards which all providers of health and social care will be expected to meet in the future. The standards will be overseen by a new independent, local body - the HPSS Regulation and Improvement Authority. It will be come into operation on 1 April 2005 and will inspect and report on the quality of health and social care services delivered by the HPSS as well as the independent sector.

7.6 Standards, which will be developed on a phased basis, will cover all aspects of service delivery, organisation and management. Links with the work of national bodies, such as the Social Care Institute for Excellence and the National Institute for Clinical Excellence, will ensure that Northern Ireland has access to the most up-to-date guidance available which can, where necessary, be tailored to local needs.

7.7 New arrangements to ensure the safety of service users and staff are also being developed, as well as procedures to ensure that we learn from mistakes and minimise risk from untoward events.

7(iii) Measuring Performance

7.8 The drive for higher, consistent, quality standards will be underpinned by a new approach to measuring performance. This will embrace the totality of investment in health and social care and establish clear baselines for measuring performance across key areas of organisation, management and service delivery.

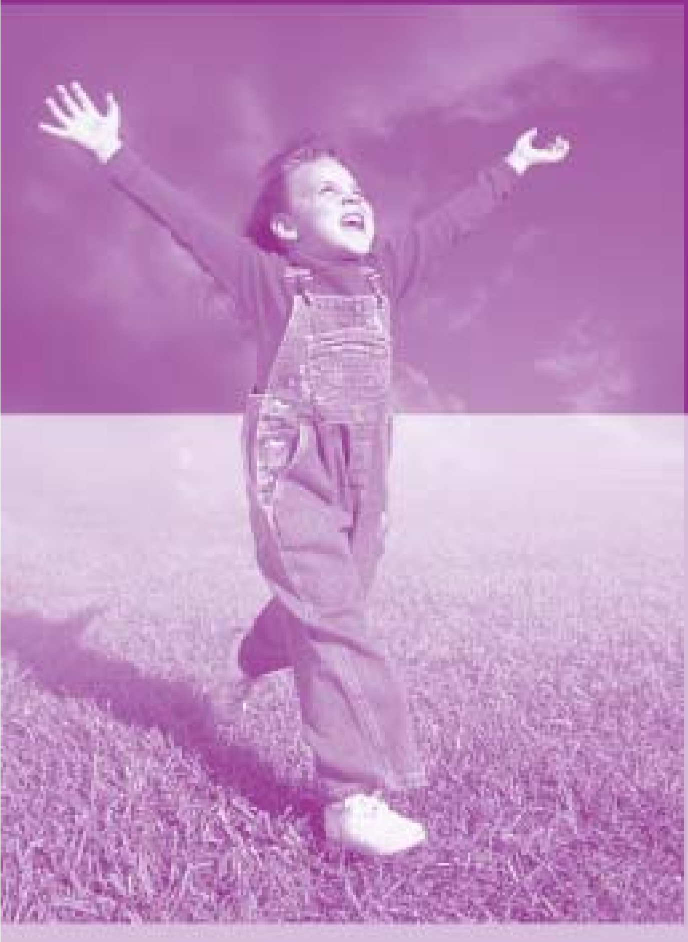
7.9 Many of the existing performance management arrangements are concerned with processes rather than outcomes, or the quality of services. The Department will, therefore, develop a new performance assessment and reporting framework which will let people see how well the HPSS is meeting the priorities set by Government and which will help to ensure that unacceptable variations in quality or performance are addressed.

7(iv) Complaints

7.10 Improving the way that complaints are dealt with is also an important element in improving the public's confidence in services. A recent review of the complaints procedure showed a lot of dissatisfaction at how long it can take for complaints to be dealt with and questioned the impartiality of the review stage.

7.11 As a result, DHSSPS is working with the HPSS and service users to design a new complaints procedure which is easy to access, is fair to all parties, and ensures that complaints are dealt with locally, effectively and speedily and don't escalate inappropriately.

7.12 The new arrangements will also be designed to ensure that, where a complaint needs to be reviewed, the process is seen to be truly independent. It will also be important that information about complaints and their causes is used more effectively to improve services in the future.



MAKING
IT HAPPEN

8. MAKING IT HAPPEN

8.1 Policy Direction 15: We will set in place flexible plans, appropriate organisational structures and effective, efficient processes to support the implementation of A Healthier Future.

8.2 This vision for our health and social services has been developed by listening to the views of people who use the services and those who deliver them. However knowing what needs to be done is only the starting point. We need flexible plans, appropriate organisational structures and effective, efficient processes to support the implementation of Our Healthier Future.

8(i) Planning for Delivery

8.3 We need to plan for change through a process which is flexible enough to allow for an annual review of priorities while at the same time promoting a stable, long term planning regime and preventing 'change for change's sake'. Rigorous performance management arrangements will ensure that our plans are taken forward and will demonstrate the links between longer term plans and priorities and day to day decision-making.

A New Planning Process
This strategy sets out a twenty-year vision which will be subject to a review every five years in order to ensure its continued relevance. Medium term objectives leading to the achievement of the vision will be presented in future implementation plans. These will be regional, produced by the Department in partnership with the HPSS, and will have five year horizons with a review every three years.

Implementation plans will be supported by area health and wellbeing plans (area plans). Under current arrangements there would be one for each Board area although this would be reviewed in the light of the outcome of the Review of Public Administration. These will be three year plans, produced by the family of HPSS organisations who commission and provide services for each area (ie. currently the Board along with relevant Trusts) and will replace the current Health and Wellbeing Investment Plans (HWIPS) and Trust Delivery Plans (TDPs). They will be updated on an annual basis although, as three year plans, many of the objectives will remain from one year to the next.

Each area plan, while HPSS-led, will involve and encompass all relevant health and social services provided for the area including private, community and voluntary sector services. The area plans will be designed to fit into the full suite of spatial plans across government. Accordingly they will be consistent with, and will feed into the agenda of, the Department for Regional Development's twenty five year Regional Development Strategy. Area plans will also fit into future local government community plans which have been proposed in the context of the Review of Public Administration.

On an annual basis each HPSS body will produce a performance report detailing its progress towards meeting the objectives of the current implementation plan.

8.4 Our plans will be developed through close engagement with the public, service users, their representatives and people working in the health and social services. Performance indicators will be designed to incorporate those measures that are valued highly by service users as well as those which are important for measuring health and social care outcomes.

8.5 Many people are concerned about a lack of joined up government. The lack of common boundaries across different government agencies is believed to have contributed to this. Our proposed approach allows for integrated planning within the HPSS and a greater degree of alignment with other public bodies such as district councils.

8.6 Area-based and participative approaches to planning, sometimes described as Community Planning, are particularly appropriate for health and social services because the factors determining our levels of health and wellbeing primarily fall within the remit of other departments and agencies.

8.7 While these plans will take time to develop and evolve, we must begin to make progress now towards the vision set out in this strategy. The following are short and medium term objectives against each of the key themes.

8(ii) Objectives for Investing in Health and Wellbeing

8.8 The strategy places a strong emphasis on promoting population health and wellbeing. There are three ways in which this will continue to be achieved, namely: strengthening the public health function; mainstreaming health promotion throughout the HPSS; and promoting cross-sectoral action to improve population health and wellbeing. The main contribution of this strategy is, however, that it places *Investing for Health* at the heart of the Government's health and social care agenda and commits to giving it due priority in health and care planning decisions.

Objective	**Contribution to Vision**
Improving population health and wellbeing by implementing the recommendations of the Review of the Public Health Function by 2010.	A review of the public health function is currently underway. This review will support the further implementation of cross-departmental action set out in Investing for Health. Public health will be prioritised throughout the HPSS at all levels. The outcomes will be reduced mortality and morbidity relating to coronary heart disease, cancers, stroke and chronic respiratory disorders.
Mainstreaming the commitment to population health throughout the HPSS by 2010.	On foot of the regional strategy, public health priorities will be reflected in all HPSS organisations. Performance measures for all HPSS organisations, including those which provide care, will include this as a core function. It will also be reflected in the training and development of all people working in the HPSS. Almost everyone in Northern Ireland comes into contact with the HPSS in the course of a year. This will ensure that we make the best use of that opportunity to promote health and wellbeing. ➔

Ensuring Investing for Health remains at the heart of the government agenda through a review of this cross-governmental policy by 2007.	*Investing for Health* includes cross-governmental actions in relation to promoting workplace health, improving housing, promoting physical activity and sports, improving employability through local strategy partnerships, improved water and air quality through regulation and enforcement and food and road safety (see also Section 1(iv)). These medium-term objectives will be renewed and re-focused following the review.
Implementing by 2010 the recommendations of strategies to promote health and wellbeing, including strategies relating to smoking, alcohol related harm, illicit drug use, physical activity, diet and sexual health.	These strategies, also encompassed within *Investing for Health*, include for example the further development of smoking information campaigns and smoking cessation services, measures to tackle under-age drinking and the sale of alcohol to minors, access to drug addiction therapy and community-based education in relation to drugs, diet and sexual health. We will also develop proposals to further control smoking in public places in Northern Ireland. We will ensure that these objectives are promoted and prioritised at all levels in the HPSS.

8(iii) Objectives for Involving People and Building Caring Communities

8.9 Our approach will consist of a new, unified focus to engaging with people; through our chronic condition management programmes (referenced in Section 5 and in Section 8(iv) below) we will work with those people who are frequent users of our services to help them acquire the confidence, knowledge and skills to manage their conditions. We will also build on our existing policy for community development, *Mainstreaming Community Development,* to promote productive partnerships between the statutory health and social services and the community and voluntary sector.

Objective	**Contribution to Vision**
By 2007 produce an overarching policy for involving people and building caring communities.	This policy will build on existing initiatives such as Health Action Zones, Investing for Health Partnerships and Community Pharmacy Partnerships. It will, however, go further in promoting a range of new initiatives and programmes based on a community development approach to promote engagement and dialogue between the public and the health and social services.
By 2008 have established seven region-wide Chronic Condition Management (CCM) programmes.	These programmes (see also Section 5 and Section 8(iv) below) will ensure that people and communities are fully involved in managing long term or chronic conditions. Within these programmes services will be designed to inform and support people by teaching them how to: monitor and understand their conditions; self-administer care and therapies; and seek care early on when problems are developing.

8(iv) Objectives for Developing Responsive Integrated Services

8.10 The strategy sets out specific long term outcomes which define services that genuinely respond to people's individual and collective needs and which do so by crossing professional, sectoral and organisational barriers. Some of the main actions are summarised below. However, detailed actions and shorter term outcomes are also set out in Section 5.

Objective **Community-Led Services**	**Contribution to Vision**
By 2008 seven major service-wide Chronic Condition Management (CCM) programmes will have been established across the HPSS.	These programmes will focus on the enhanced management of: diabetes, coronary heart disease, stroke recovery, arthritis and musculo-skeletal problems, chronic obstructive pulmonary disease and asthma, depression and stress management. (The Cancer Network which has already been established is effectively a CCM Programme). They will be person-centred, promote the involvement of people who use them (see Section 8(iii) above) and offer a personalised care plan for people most at risk. The programmes will be designed to be tailored locally and will reflect the fact that many people suffer from more than one condition at once (co-morbidity).
By 2010 to deliver to people within a minimum of 24 hours appropriate and equitable access to all primary care services. *By 2010 to provide a comprehensive primary care out of hours emergency care service providing access, as appropriate, not only to general medical, general dental and community pharmacy services, but also to community nursing, mental health and other social care services.* *By 2008 to be able to access an appropriate primary care professional within 2 working days.*	These programmes will be community-based, supported by hospitals. A key aspect in delivering them will be improved access to primary care services generally. This objective specifies that by 2008 if somebody requests an appointment at their local health and care centre, and is not an emergency case (in which case they will be seen immediately) they will be able to see an appropriate professional in the community within 2 working days. More broadly, a range of high quality services will be provided in the setting that is closest to where people live and work through the implementation of the strategic framework for the development of primary health and social care, *Caring For People Beyond Tomorrow.*

Promoting Independence

By 2007, two proactive Social Care Management Programmes (SCMP) will be piloted in relation to older people and carers.	A similar approach to the Chronic Condition Management Programmes will be used in developing programmes to address the complex social needs of groups identified through the Promoting Social Inclusion initiative (ie. Older People, People with Physical and Sensory Disabilities, People with a Learning Disability, Homeless People, Carers). Depending on the outcome of an evaluation in 2009, they will be rolled out across a range of other areas.
By 2008 promote independence for people who require care by facilitating independent living.	Improve the quality of life and independence of people in need so that 40 per cent of all people who received care managed community services and at least 88 per cent of people aged 75 years or older are supported, as necessary, in their own homes. This will also be promoted by the use of Direct Payments for social care (see Section 5(i)). This objective will also be supported by a focus on telecare provided in people's homes.

Modernising Services

By 2006, the current phase of the Service Improvement Programme will be implemented and reviewed with recommendations for roll-out.	The Programme will be reviewed with a view to (i) rolling out key practices and projects across the services; (ii) identifying any system-wide blocks to further improvements at local level; and (iii) increasing the Programme's emphasis on enhancing primary and community-based provision. The Service Improvement Programme is an important catalyst for change across the service. We will build upon it and ensure that all of the lessons learned by teams of front line staff are disseminated and implemented across our services.
By 2015 to have modernised primary, community and hospital services.	To have implemented the *Developing Better Services* policy by: • expanding the range of primary and community care services delivered in communities to keep people out of hospitals, unless necessary or appropriate; while: • providing for a transformation in the effectiveness and efficiency of our hospital services through the modernisation of our acute hospital infrastructure. (See also Section 8(viii) below).

By 2015 to have significantly changed the profile of mental health services and services designed to meet the needs of people with a learning disability.	When the Review of Mental Health and Learning Disability is published we will explore the best ways of progressing the recommendations in partnership with people with mental ill health, learning disabilities, their families and service providers. However, clearly there will be a major agenda for change arising from this Review and we will ensure that the agenda is reflected in all our priorities and decisions. Sections 5 (xiii) and 5 (xiv) describe the direction of the Review.
Integrating Across Services and Professions	
By 2015 to have implemented the Information and Communications Technology Strategy for the HPSS. (Most of the elements described opposite should be implemented by 2010).	This will include the following developments: a new Health and Care Number for each citizen; GP Practice ICT Modernisation including practice systems, hospital appointment booking, and basic electronic links; Cancer Chemotherapy Prescribing; Electronic Eligibility System to reduce prescription exemption fraud; Person-centred Community Information Systems to improve the quality of community health and social care through better communication and sharing of information between care workers; Electronic Prescribing; and Picture Archiving and Communications Systems which will lead to the introduction of a coherent digital imaging service across the HPSS.
By 2010 have developed, piloted and published a new integrated assessment process.	This will be a key element of the development required in implementing the major strategies and policies for service development and the chronic condition management / social care management programmes set out above. Building on the work of the Community Care Review protocols will be set out for integrated care pathways to enhance communication and coordination and streamline and standardise the care management process.

8.11 Also included are long term aims and outcomes relating to groups which have been identified as having additional or acute needs and which require services tailored to those needs. These are set out in Section 5(viii) to Section 5(xiv). Examples of selected actions from these Sections (all to be completed by 2008) include:

- ‘Crisis’ care services, developed in each Trust to ensure that support and assistance is available when circumstances change for the Carer and/or their family.

- To have ensured (by 2005) that 75% of children and young people requiring in-patient hospital treatment will receive their care and treatment in an age-appropriate setting.

- Address as a matter of urgency the outstanding recommendations of recent reports on the provision of wheelchairs and prosthetics.

8(v) Objectives for Developing Teams That Deliver

8.12 The agenda set out in the strategy will only be delivered by ensuring that health and social services employers can recruit and retain sufficient numbers of staff and by ensuring that everyone works to their full potential in the health and social services. Where appropriate, this will mean much closer team working, supported by team-based workforce planning and development which crosses professional, organisational and sectoral boundaries.

Objective	Contribution to Vision
By 2010 the HPSS Human Resources Strategy will be implemented.	The HPSS Human Resources Strategy will be implemented in full with the following actions arising from it: a review of service improvements arising from the implementation of Agenda for Change, the Consultant's Contract and the GMS Contract; a review of the role of the occupational health service will be completed and implemented; a new brand identity will be developed resulting in an enhanced and more positive profile amongst key target employee groups including school leavers, students, unemployed people and former HPSS employees; and the development of a health and social care skills report jointly by DHSSPS and DEL.
By 2007 individual workforce plans must have been brought together into an Integrated Workforce Strategy (IWS).	This will include revised projections to allow for the movement of competencies and roles across professions and allowing for a significant shift in focus towards primary and community based care services. Revised plans must also allow for increased capacity to enable the necessary training and development to have been implemented. In the context of this, a series of new professional roles will have been piloted and rolled out across the service by 2010. This development of new working models will be underpinned by pay reform initiatives being set in place currently, which include Agenda for Change, the Consultant contract and the GMS Contract. These will harmonise and modernise the terms and conditions of HPSS staff to promote flexible working and extend the provision of HPSS services through pay modernisation.
By 2007 the development of an Integrated Learning and Development Strategy (ILDS).	The ILDS will be based on an integrated model of learning which will be applicable across all: health and social care workers and professionals; organisations with a role to play in health and social care; and sectors including the statutory, community and voluntary, independent and private sectors. Accordingly, the Strategy will be based on, and informed by, the Integrated Workforce Strategy (IWS). The ILDS will in turn also inform the IWS by specifying the additional capacity which will be required in order to enable staff to participate in Common Learning and integrated training programmes.

8(vi) Objectives for Delivering Quality

8.13 A great deal of action is already underway to promote quality. A new statutory duty of quality has already been placed on Boards and Trusts and this will be underpinned by standards which all providers of health and social care will be expected to meet in the future. The implementation of these standards will be overseen by a new independent, local body - the HPSS Regulation and Improvement Authority which will come into operation on 1 April 2005.

Objective	**Contribution to Vision**
Higher standards	A range of care standards has already been published for public consultation and they will be introduced from 1 April 2005. Further standards will be developed during 2005/06 to ensure the highest quality of treatment and care, and links are being developed with appropriate national bodies. During 2005/06, the new Regulation and Improvement Authority will be phased in, beginning with the transfer of functions and staff from the Board Registration and Inspection Units on 1 April 2005.
Improved safety	A new regional reporting system for serious adverse incidents has been established and, during 2005/06, a range of measures will be taken forward to improve safety, including the establishment of links with the National Patient Safety Agency in the NHS.
Better governance	A range of developmental work is being done in the HPSS to help develop clinical and social care governance.

8(vii) Organised for Delivery

8.14 Our health and social services are coming under increasing pressure to reform and modernise, as are other government services. There are many drivers for reform, some of which are set out in Section 2. The bottom line is, however, that increasingly we will be expected to deliver more with the resources available to us.

8.15 Organisational structure is an important focus within this context, and will continue to be. The extent to which we reform and modernise services will depend on our ability to integrate services across current and future organisational and geographical boundaries. It will also depend on our ability to ensure that resources are directed towards ‘front line’ services.

8.16 The current cross-governmental Review of Public Administration will shape the future structure of the HPSS. The outcome of the Review is yet to be determined, but it is likely that the results will include; a significant reduction in the overall number of organisations within the HPSS; a greater alignment of the geographical boundaries of HPSS organisations with other public bodies to ensure that they service the needs of the same communities or are ‘co-terminous’; and new arrangements for enhancing service user representation. The planning process which we have set out above would support these developments.

8(viii)Resourcing Delivery

8.17 The issue of resources is frequently raised in debates about the future of the HPSS. There is a perception that health and social services are a financial 'black hole', eating up ever-increasing resources for no apparent gain – see also Section 2(ii). This mis-perception must be addressed. The service has had, in common with health and social services internationally, to deal with major increases in demand. Additional resources for our HPSS have allowed the Service to meet these demands.

8.18 Whilst there is always room for improving the use of resources, and there is no room for complacency, the 'black hole' argument needs to be challenged. Many investments in health and wellbeing take time to mature. Health and social care facilities, because of their cost and complexity, take years to design and build and staff take years to educate, train and recruit. Investments made now may be impacting on a very different world in ten years when they have fully matured.

8.19 But that does not reduce the need for accountability. We need to demonstrate how we are using resources and the benefits they are bringing, but we should not be diverted into using limited additional funds to meet short term demands simply because those are more easily measured. In making investments we accept the need to seek short term **outputs**[134] while keeping a close eye on the longer term **outcomes**[135] and remembering that the latter is our priority.

8.20 For example, while accepting the need to tackle waiting lists by improving hospital capacity, we must put resources into measures to reduce demands for hospital services over the longer term.

Objective	**Contribution to Vision**
Promoting the Efficient Use of Resources *By 2008 have achieved significant efficiency gains.*	A key objective will be the release of resources to be deployed flexibly in front line services through efficiency gains and service improvements of at least 2.5 per cent per annum from the 2004/05 baseline. These efficiencies will be achieved by exercises to promote: • productive use of time/productivity; • efficient procurement; • the sharing of back office functions; • avoiding unnecessary hospital admissions and readmissions; • the management of improved performance; • rationalising long stay provision; more effective prescribing and medicines management

8.21 The way in which funding is structured will also have a key impact on our ability to deliver person-centred services. Currently, funding is largely structured around nine Programmes of Care. They provide a common management framework for activity and finance used in planning, managing and monitoring health and social services.

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[134] The immediate impact, such as numbers of people trained, or facilities built, or reductions in waiting lists.
[135] The ultimate aim of our programmes, such as life expectancy.

8.22 Funding needs to be able to move across organisational or sectoral boundaries in order to be deployed flexibly. This is particularly important where effective care depends on a smooth transition between care settings, for example, in cases where people are being discharged from hospital into rehabilitative or 'step down' programmes.

Causeway Orthopaedic Medicine Initiative (COMI): Local Services in Partnership with the Private Sector
Causeway Local Health and Social Care Group funded the innovative COMI project involving a multi-disciplinary team of 2 GP specialists with interests in Musculoskeletal and Sports Medicine, a Senior Musculoskeletal Physiotherapist, a Senior Podiatrist with training in Orthotics and a Secretary. The project was further enhanced by the unique involvement of the private sector (Coleraine Scan Centre), which was commissioned to provide rapid access to MRI scans. The clinic achieved a locally accessible service which: significantly reduced waiting times; facilitated collaborative working; reduced referral rates to hospitals and demonstrated successful partnership working between private and statutory sector.

8(ix) Capital: A Lever for Change

8.23 Capital investment is important in its own right but can also act as a driver for service change: for example by providing facilities for community-based services, taking services out of hospitals or by providing innovative Information and Communications Technology (ICT) solutions.

DCAL Architecture and the Built Environment
Department of Culture Arts and Leisure (DCAL) is engaged with an interdepartmental steering group on the task of delivering a new policy on architecture and the built environment. The policy is intended to be all embracing and research has produced increasing evidence that there are multiple benefits of good building design across a range of building types. For example, "A well-designed hospital will help patients to get better more quickly ". Design matters because our lives are connected through our common built environment. Good design is not just about the aesthetic improvement of our environment, it is as much about improved quality of life, equality of opportunity and economic growth and stability.

8.24 Some £3 billion in total of capital demands and needs have been identified across the HPSS[136]. Over half (56%) of this is in the acute sector, with a further 12% of the demand in Mental Health and Learning Disability services, 9% in local hospitals, 7% in Information and Communications Technology and 6% in Primary Care services (eg. Community Treatment and Care Centres, Health and Wellbeing Centres). It is important to stress that the extent to which these demands can be met will depend on the future availability of resources and that, even if such resources were to be made available now, all of these developments could not be implemented at once. However, the increases in capital investment over recent years are already beginning to impact on the identified demands.

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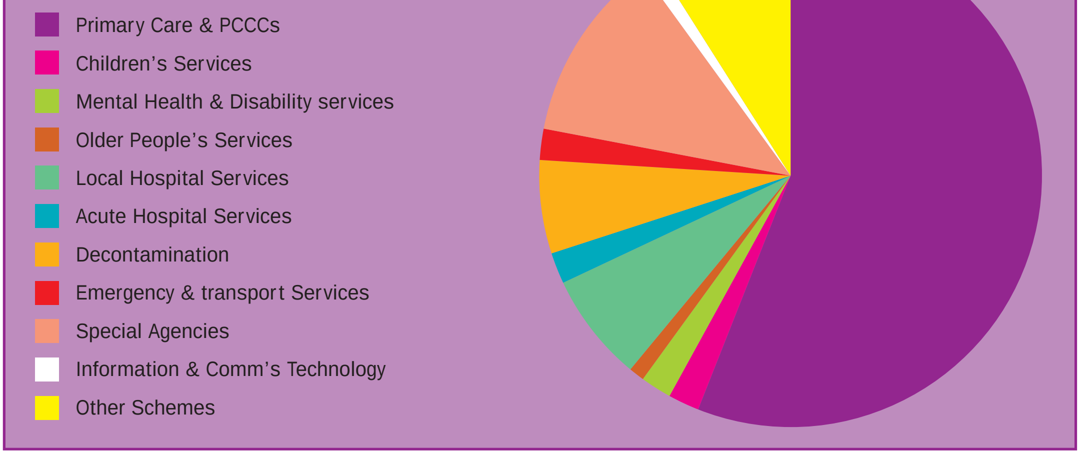
136. Excluding contingency, repair and maintenance costs – otherwise £4.1billion. These figures reflect total demand and differ from the Investment Strategy NI which will set out a plan for the next 10 years.

Figure 8.1
HPSS Capital Needs by Sector



8.25 Around 50% of this relates to projects which are either happening already, for which there are public commitments relating to part or all of the project or for which plans are in a late stage of development and which reflect the major programme of investment announced under *Developing Better Services*. Further priorities are being considered at the time of writing in the context of the cross-Departmental Investment Strategy for Northern Ireland.[137]

Health, Social Services and Public Safety (HSSPS) Investment Strategy
The Investment Strategy for Northern Ireland will set out strategic investment priorities across all areas of Government over the next ten years. The Investment Strategy will be based on Departmental investment proposals, submitted by each of the Northern Ireland Departments, and will seek to bring those proposals together to ensure their effective and joined-up implementation. The DHSSPS proposals represent an investment strategy to support the aims of this regional strategy. The broad approach is to prioritise developments which provide for:

(i) patient and public safety;
(ii) improved community-based facilities to provide services outside of hospitals where appropriate;
(iii) technology to provide for improved and more integrated care;
(iv) sustainable and modern hospital services.

In partnership with the Department for Regional Development we will ensure that the development of the HPSS estate is planned in line with the Regional Development Strategy and Regional Transportation Strategy. In developing specific proposals we will work closely with Planning Service and Roads Service to ensure that the proposals fit with local Development Plans, that suitable infrastructure improvements are included and that as far as possible facilities are sited and designed for easy public transport and pedestrian access.

Under the guidance of the Department of Environment (DOE) and DRD, health and social care services will be delivered in an environmentally sustainable way. Environmental impacts will be reduced by, for example, adopting higher environmental standards for the operation of our facilities, seeking to incorporate sustainable power supplies into these facilities and reducing harmful emissions from HPSS vehicles.

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137. The Investment Strategy for Northern Ireland (ISNI) is being led by the Strategic Investment Board in partnership with all Government Departments.

Through this major investment programme, weighted towards those areas in greatest need, we will work with the Office of the First Minister and Deputy First Minister (OFMDFM), the Department for Social Development (DSD) and the Department of Agriculture and Rural Development (DARD) in support of urban and rural regeneration.

We will also, with local communities, the Northern Ireland Office (NIO) and the Police continue to ensure that all infrastructural developments support community safety by reducing the potential for crime and violence. This will be particularly important in relation to facilities for older people, such as sheltered accommodation, and in Accident and Emergency or out of hours services.

8(x) Modernisation: Using Resources More Effectively & Efficiently

8.26 There is always scope for achieving greater value for money through improvements in productivity. A central part of the implementation of the new strategy will be a rolling modernisation programme to deliver improvements in both efficiency and effectiveness.

8.27 Modernisation will be achieved through changes in working practices which ensure that the 'patient journey' through the system is integrated and person centred. Supported by improved systems, these new working practices will promote a more efficient use of resources. For example unused medicines worth approximately £2 million are returned to community pharmacies each year and studies have estimated that hospital admissions due to medicine-related problems range from 6% to 30%.[138]

8.28 Another area where greater efficiency may be obtained is through greater sharing of "back office" functions between HPSS organisations. One of the criticisms which has been made of the current structure of the HPSS is that some activities which support the core activity of delivering health and social care are being duplicated across every HSS Board, Trust or Agency.

8.29 Adopting a shared services approach to these areas means that functions which have traditionally been provided locally are streamlined and centralised. We will also drive efficiency by benchmarking providers in terms of quality and cost, for example through the use of Healthcare Resource Groups (HRGs).

8(xi) Cross Border Co-operation

8.30 We will promote the most effective use of resources through increased working across borders on the island of Ireland, throughout the UK and across Europe. Globalisation, increased international travel and the increased use and sophistication of information and communications technology (e.g. in the form of telemedicine or telemonitoring) all represent important opportunities for us to use our health and social care resources more effectively through partnership working across borders.

8.31 Existing initiatives on the island of Ireland demonstrate what is possible by sharing resources and expertise across boundaries. Specifically the cross border health and social care initiative, Co-operation and Working Together (CAWT), was established in 1992 by the four Health Boards located along the border between Northern Ireland and the Republic of Ireland to facilitate cross border co-operation. Through CAWT, the Southern and Western Health and Social Services Boards in Northern Ireland and the North Eastern and North Western Health Boards in the Republic of Ireland agreed to co-operate in order to improve the health and social well being of their respective populations.

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138. DHSSPS Drug Induced Hospitalisation: A Northern Ireland Perspective. Internal Paper 1997

Cooperation And Working Together (CAWT)
CAWT implements its activities through cross border sub groups. There are thirteen sub groups in total spanning the complete health and social care spectrum. Comprising senior managers and planners, these sub groups plan practical activities including research, feasibility studies, needs assessment and pilot initiatives to improve cross border services.

Examples of recent developments include projects in the area of emergency planning and pre-hospital emergency care. The recommendations contained within the publication 'Population Health Profile' of the CAWT region, provided the basis for a number of key cross border projects in the areas of health impact assessment, health protection policies and health promotion, shared equipment procurement, joint training initiatives and piloting a GP Out-of-Hours service.

8(xii) The Private Sector

8.32 **Policy Direction 16: We will continue to develop a proactive and responsive relationship with private, community and voluntary sector providers here over the coming years.**

8.33 A recent major review of long term health care trends in the UK[139] concluded that a publicly funded health and social care system free at source represented the most effective and efficient system for funding health and social care. The reasons for this are well documented.

8.34 For the foreseeable future the primary source of funding for the HPSS will be tax-based revenue. Over the coming decades, however, we can expect more people to have the personal resources to purchase services privately. We can also expect greater demands for choice and immediate access to services. These factors have the potential to lead to an enhanced demand for privately funded health and social care services over the coming years, whether through 'out of pocket' payments or health insurance.

8.35 A large volume of our services is already provided through private and voluntary sector organisations. Indeed, we could not cope without private nursing and residential homes.

8.36 In GB the outsourcing of elective surgery through Diagnostic Treatment Centres is being actively pursued. While there are no immediate plans to follow the GB lead in this respect, we will closely monitor developments and seek to learn from the experience.

8.37 In the meantime a number of major capital schemes are currently being implemented or planned for procurement through Public Private Partnerships. These schemes will be implemented responsibly and in ways which protect the rights of workers.

8.38 We will continue to develop a proactive and responsive relationship with private sector providers here over the coming years. We will manage future changes in the funding of health and social services to make the best use of the strengths of all sectors. In particular, we will seek to clarify and define the boundaries of the HPSS so that we focus on what works and what we can achieve.

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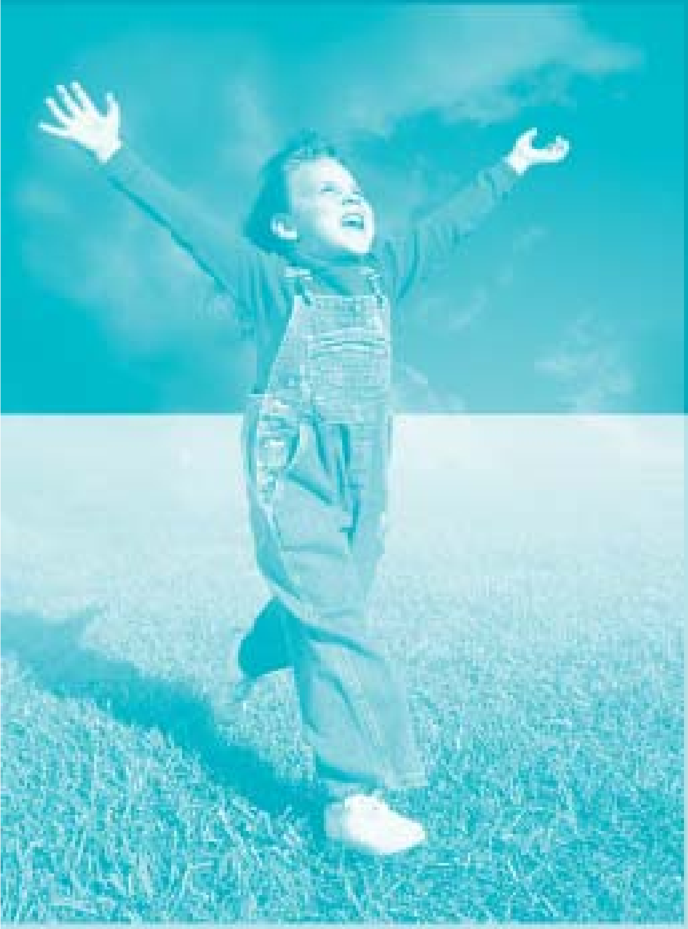
[139] Wanless (2001). Securing our Future: Taking a Long Term View: Interim Report.



CONCLUSION

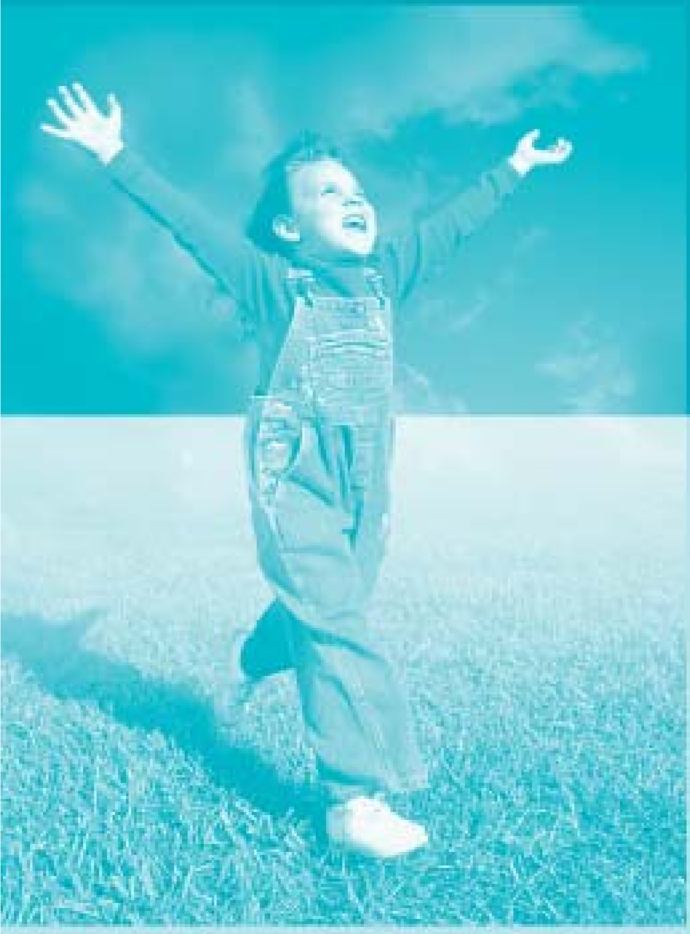
9. CONCLUSION

9.1. In this Regional Strategy we have set out a vision for our future health and wellbeing. There are many challenges ahead, but there are also many opportunities. With concerted effort we can improve the health and wellbeing of everyone in our society. We can provide health and social services which represent the very best public service ethos. But that will take action on the part of the DHSSPS, the health and social services, the private sector and not least the public.

9.2. We believe that people are prepared to accept changes that will bring improvement and we are committed to working in partnership with them to achieve our collective vision for a healthier future.

9.3. This document is being widely circulated to key interest groups and stakeholders. A summary will be provided on request in Irish, Ulster Scots, Cantonese, Urdu, Bengali, Hindi and Punjabi. On request it can be provided on floppy disk or in accessible formats such as large print, Braille and audiotape. It will be accessible on the DHSSPS website at www.dhsspsni.gov.uk. Additional copies may be obtained from the Regional Strategy Team on telephone 028 90 528143 or email regional.strategy@dhsspsni.gov.uk.

Please send your comments to the Regional Strategy Team, DHSSPS, Room C4.22, Castle Buildings, Belfast BT4 3SJ.



APPENDIX

APPENDIX: A

EQUALITY

Integrated Impact Assessment

The Section 75 equality duty

Section 75 of the Northern Ireland Act 1998 requires public authorities, in carrying out their functions in relation to Northern Ireland, to have due regard to the need to promote equality of opportunity:

- between persons of different religious belief, political opinion, racial group, age, marital status or sexual orientation;
- between men and women generally;
- between persons with a disability and persons without, and
- between persons with dependants and persons without.

DHSSPS and all the other HPSS bodies are committed not only to meeting the requirements of Section 75, but also to acting in the spirit of Section 75.

One of the cornerstones of the implementation of Section 75 is Equality Impact Assessments (EQIAs). This is a clearly defined process for identifying adverse impacts on equality of opportunity, as well as new possibilities for promoting equality. EQIAs are carried out on policies as they are being developed, and on existing policies, and are conducted in accordance with detailed guidance produced by the Equality Commission for Northern Ireland.

Integrated Impact Assessment

In addition to EQIAs, the following impact assessment processes have been developed to help policy-makers to identify and avert, or remedy, adverse consequences of policies:

- Community Safety
- Health Impact Assessment
- Human Rights
- New Targeting Social Need
- Public Expenditure and Public Service
- Regional Development Strategy compliance
- Regulatory Impact Assessment
- Rural proofing
- State Aid compliance
- Strategic Environmental Assessment
- Sustainable Development
- Victims

To help policy makers to cover all these aspects, the Office of the First Minister and Deputy First Minister is currently developing the Integrated Impact Assessment (IIA) tool. (www.ofmdfmni.gov.uk/iia) The IIA tool is being piloted by DHSSPS and one other Department. The IIA tool has therefore been applied to the Regional Strategy not only in order to seek to identify adverse impacts and opportunities, but to test the tool itself.

Conclusions

The provisional conclusions which we have drawn from applying the IIA tool are that:

(i) the Strategy will have a range of benefits in terms of equality of opportunity;

(ii) the equality screening part of the IIA has indicated no adverse impacts on equality of opportunity;

(iii) the remaining sections of the IIA indicate that Strategy will be neutral;

(iv) these sections have not indicated any potential adverse impacts.

Potential benefits which have been identified include; a focus on removing health inequalities; an emphasis on more responsive services which can address the complex needs of vulnerable groups; and actions to improve access to, and the quality of, services for the whole population.

We believe that these findings reflect the way in which the Strategy has been developed, in particular the amount and the quality of the engagement which has informed the Strategy, and the fact that within the Department a single Directorate has lead responsibility for both the Strategy and the implementation of the Section 75 duties.

The detailed conclusions of the IIA are available on the DHSSPSNI website at www.dhsspsni.gov.uk

As far as the statutory equality duty is concerned, the equality section of the IIA is a screening exercise, not a full EQIA. A full EQIA necessarily includes consultation with affected groups of people.

Therefore, if having read the Strategy you are concerned that any part of it could have an adverse impact on equality of opportunity in terms of any of the nine Section 75 distinctions (see above), and feel that an EQIA should be considered, the Department will be happy to consider any evidence – qualitative or quantitative – which you may wish to present and will consider the case for an EQIA.

It should be noted that the Regional Strategy is an overarching plan which encompasses a number of more specific strategies. Every element of the Strategy has been or will be subject to equality screening and some elements will be subject to full EQIAs. A region-wide HPSS programme of EQIAs is in progress, and details of this are available on the Department’s website.

APPENDIX: B

CONSULTATION QUESTIONS

A Healthier Future sets out a vision for health and social care in Northern Ireland over the next twenty years. It also identifies a number of key policy directions, actions and outcomes that will contribute to the achievement of the vision.

During the process of developing *A Healthier Future* the Department has sought to hear the views of as many people, organisations and groups as possible, including a telephone survey of 1500 members of the general public. As a result we believe that it offers an inclusive view of the way forward for Health and Social Services in Northern Ireland.

Health and social services affect the whole population, and that is why we now want to invite all those who may have an interest in the service – those who are involved in delivering services, community and voluntary groups and especially the general public – to let us have their views on the vision for the future we have set out in *A Healthier Future.*

We are happy to take views on any aspect of A Healthier Future but you may find it useful to address the following questions when responding:

1. Does the vision adequately describe the health and social services that will meet our future needs and aspirations?

2. A Healthier Future focuses on five major themes: Investing for Health and Wellbeing; Involving People; Responsive Integrated Services; Teams which Deliver; Improving Quality; and Making it Happen. Do you agree that it is appropriate to focus on these themes and are there any others that should be addressed by the regional strategy?

3. A Healthier Future identifies 16 future Policy Directions. Do you believe these are the right Policy Directions to achieve the vision set out in the document?

4. A Healthier Future identifies a number of key actions and outcomes. Do you believe that these are the right actions and outcomes to achieve the vision set out in the document?

5. A Healthier Future identifies the need to reduce smoking as a key element in improving the health of people in Northern Ireland and sets out three main options.
   a. Should restrictions on smoking in public places and in workplaces be a matter for self-regulation and should Government simply act to encourage and support smoking cessation? *or*
   b. Should smoking generally be prohibited in most enclosed public places and workplaces, but allowed in certain settings such as pubs that do not prepare and serve food and in private clubs where the members decide to permit smoking? *or*
   c. Should legislation be introduced to ban smoking in all enclosed public places and workplaces?

6. Are the proposals for taking the strategy forward adequate?

7. Are the equality issues adequately addressed?

On the 21st of December 2004 we are beginning a three month consultation on *A Healthier Future*[140]. The document can be made available in large print, Irish and Chinese (Cantonese), and the Department will consider requests for other formats or translation into other minority ethnic languages. It will also be available from the Departments website at:

http://www.dhsspsni.gov.uk/publications/2004/healthyfuture.asp

Consultation responses and any requests for alternative formats should be sent to:

Regional Strategy Team,
C.4.,
Castle Buildings,
Stormont,
Belfast BT4 3SQ

Telephone: 02890528143,
Fax: 02890520535,
Textphone: 02890527668

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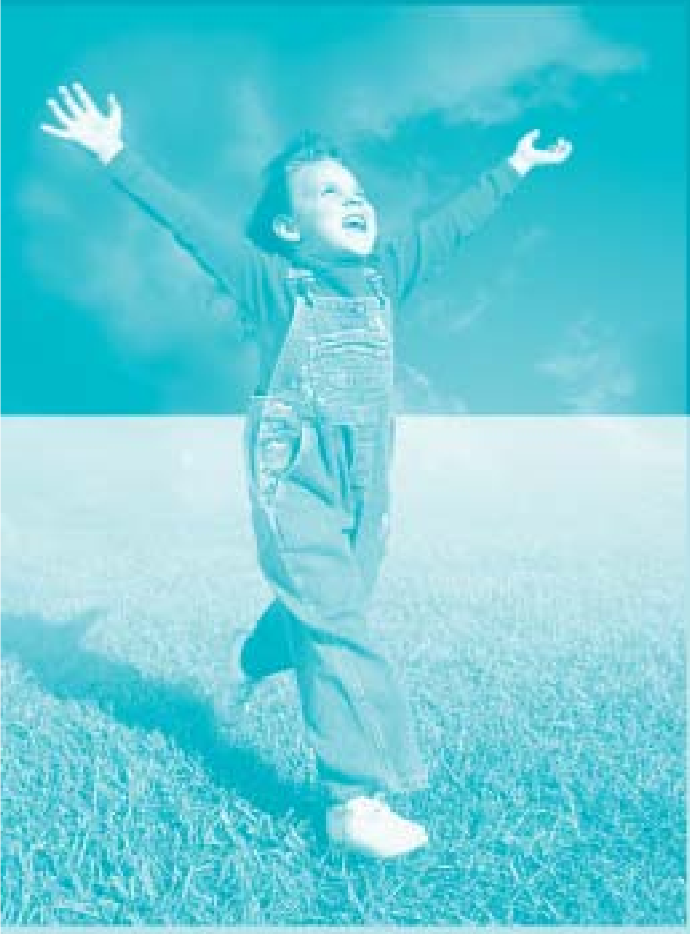
[140] Consultationi responses will be accepted until 5pm on the 25th of March 2005



GLOSSARY

GLOSSARY

Acquired brain injury (ABI)
ABI is an impairment of brain functioning that is physically or psychologically verifiable.

Acute care
Medical or surgical treatment usually provided in an acute hospital.

Ageing Well Networks
Ageing Well UK is Age Concern's major national health promotion programme with and for older people.

Agenda for Change
An agreement for modern pay and conditions for staff HPSS staff.

Care Orders
An interim care order places a child in the care of a designated authority.

Carers
A carer is someone who provides or intends to provide a substantial amount of care on a regular basis.

Childcare Partnerships
A Childcare Partnership is a group of professionals who meet to discuss all aspects of childcare for children aged 14 and under. They make decisions about funding and training for childcare. There are four partnerships in Northern Ireland.

Child Protection Register
Each Trust maintains a list of children resident in its area which are subject to a child protection plan.

Chronic disease
A long term illness or condition.

Chronic condition management programmes
A system of coordinated healthcare interventions and communications for populations with long-term conditions in which patient self-care is significant.

Chronic disease management
See chronic condition management.

CJD (new variant)
Creutzfeldt-Jakob disease -a rare (usually fatal) brain disease (usually in middle age) caused by an unidentified slow virus; characterized by progressive dementia and gradual loss of muscle control.

A new variant of the disease **new variant Creutzfeldt-Jakob Disease (nvCJD)** is distinguished from the classical type by its early onset (usually in the 20s) and a predominance of psychiatric and sensory symptoms.

Clinical and social care governance
A framework within which HPSS organisations are accountable for continuously improving the quality of their services and safeguarding standards of care and treatment.

Community care packages
A HPSS supported placement in residential/nursing home care or a package of support services for someone to remain in their own home.

Community Pharmacy Partnership
A joint initiative between the Community Development and Health Network and the Pharmaceutical Branch of the Department of Health, Social Services and Public Safety funded by the Executive Programme Fund.

Community Sport Programme
Initiatives promoting sport and physical activity in Northern Ireland's most disadvantaged and marginalised communities.

Community Treatment and Care Centres
A building where community health and social care services and information are brought together under one roof, at a location in the heart of the community.

Community care
The network of social and health care designed to help maintain people in the community.

Consultants Contract
The new Consultant's Contract is designed to provide a much more effective system of planning and timetabling of Consultant duties and activities for the HPSS.

DHSSPS Diagnostic Treatment Centres
Diagnostic and Treatment Centres specialise in performing elective care (operations) outside of the usual acute hospital setting.

Evidence based guidelines
Clinical guidelines (in healthcare) are systematically developed statements, which assist in decision making about appropriate healthcare for specific clinical conditions. Evidence-based guidelines are based on good research evidence of clinical effectiveness.

Education Action Zones
These will be child-centred, multi-agency responses based in local schools and working with the local community to improve services.

Executive
The First Minister and Deputy First Minister, together with the 10 Ministers of the legislative Assembly, constitute the Executive.

General Medical Services Contract
A contract for the delivery of general medical services, which came into effect on 1st April 2004; designed to bring about a range of improvements in primary care.

Genetic screening
Testing a group of people to identify individuals at high risk of having or passing on a specific genetic disorder.

Genetic testing
The analysis of an individual's genetic material. Among the purposes of genetic testing could be to gather information on an individual's genetic predisposition to particular health condition, or to confirm a diagnosis of genetic disease.

Health Action Zones
A designated area where, through joint intervention by public agencies, the community and voluntary and private sector organisations, inequalities in health and social wellbeing will be reduced in order to create a healthier more prosperous and socially included population.

Health and Social Service Councils
Organisations responsible for representing the views of health and social services users, and for providing an independent oversight of the activities of Health and Social Services Boards.

Healthcare Resource Groups (HRG’s)
Groupings of treatment episodes, which are similar in resource use and in clinical response.

Healthy Living Centres
Projects that provide opportunities to improve health and reduce inequalities in health through local community action.

Health Impacts Assessments
A combination of procedures, methods and tools by which a policy, programme or project may be judged as to its potential effects on the health of a population and the distribution of those effects within the population.

Health and Personal Social Services (HPSS)
Includes publicly funded (statutory) hospital services, family and community health services and personal social services.

HPSS Regulation and Improvement Authority
Is the new non departmental public body sponsored by the DHSSPS with overall responsibility for monitoring and inspecting the availability and quality of health and social care services in Northern Ireland.

Health and Social Services (HSS) Boards
There are 4 Health and Social Services Boards. As agents of the DHSSPS they are responsible for planning and commissioning health and social services for their resident populations. They use the resource allocated to them by the DHSSPS to secure the necessary services from Health and Social Service Trusts and other service providers.

HSS Trusts
Organisations responsible for providing health and social services, and for exercising certain statutory functions on behalf of Health and Social Services Boards. There are 19 Trusts.

Inpatient
A person who has been admitted to a hospital or other health facility to receive diagnosis, treatment or other health services.

Investing for Health Partnership
A partnership established at Board area level to develop long term local cross-sectoral health improvement plans to address the identified health and wellbeing needs of their local populations to meet the strategic aims and objectives of Investing for Health.

Integrated Impact Assessment
An approach that assesses the possible impact of proposals (strategies, policies, programmes, projects, plans or other developments) on a range of issues that previously may have been assessed separately - such as economic, environmental, sustainability, equal opportunities, health, wellbeing and quality of life.

Knowledge Transfer Partnerships
Knowledge Transfer Partnerships are designed to help business in developing new products, services and processes by working in partnership with academics or researchers.

Magnetic Resonance Imaging (MRI)
A diagnostic technique that uses magnetic fields and radio waves (instead of X-rays). MRIs produce a three dimensional computer model.

Managed Clinical Network
'Managed Clinical Networks' are defined as linked groups of health professionals and organisations from primary, secondary and tertiary care, working in a co-ordinated manner, unconstrained by existing professional and organisational boundaries, to ensure equitable provision of high quality clinically effective services.

Medicaid
The federal-state program for certain categories of low-income people that covers 36 million Americans, including children, the aged, blind, disabled, and people who are eligible to receive federally assisted income maintenance payments.

Medicare
A U.S. Government program that provides medical expense coverage to people aged 65 and older.

Morbidity
The incidence of a particular disease in a specific locality.

Mortality
The ratio of deaths in an area to the population of that area; expressed per 1000 per year.

Multi-skill networks
Doctors, Nurses and Other Health and Social Care Professionals working together across different facilities and geographical / organisational boundaries, to provide responsive care for service users, delivered from the most suitable location.

Nanotechnology
The science of creating highly miniaturized machines that work on the molecular level.

National Institute for Clinical Excellence
A national body set up by the Department of Health (UK) to oversee standards of clinical practice throughout the country and to pass judgment on the cost-effectiveness and value for money of new drugs.

National Service Framework
Evidence-based standards setting out what patients can expect to receive from the NHS in major care areas or disease groups.

Palliative care
The care of patients with active progressive, advanced disease with a limited prognosis.

Primary care
Includes family and community health services and major components of social care which are delivered outside the hospital setting and which an individual can access on his/her own behalf.

Public Health
The health of the human population as a whole.

Public Private Partnership
A cooperative venture between the public and private sectors, built on the expertise of each partner, that best meets clearly defined public needs through the appropriate allocation of resources, risks and rewards.

Secondary care
Specialist care, typically provided in a hospital setting or following referral from a primary or community health professional.

Social Care Institute
An independent registered charity launched in October 2001 to develop and promote knowledge about good practice in social care.

Social exclusion
This is a term to describe marginalisation from employment, income, social networks such as family, neighbourhood and community, decision making and from an adequate quality of life.

Social harm
A broad term used to describe a range of personal or familial difficulties including family breakdown, delinquency, depression and alcohol and substance abuse.

Standardised Death rate
A death rate that has been standardized for age so different populations can be compared or the same population can be compared over time.

Statutory
decided or controlled by law.

Strategic Investment Board
A company wholly-owned by the Office of the First Minister and Deputy First Minister. It is tasked with the challenges of working across government departments to encourage a joined up approach to for capital investment and infrastructural development.

Telemedicine
The investigation, monitoring, and management of patients, and the education of patients and staff, using systems which allow ready access to expert advice and patient information, no matter where the patient or the relevant information is located. The three main dimensions of telemedicine are health service, telecommunications, and medical computer technology.

Tertiary care
Specialised consultative care usually on referral from primary or secondary medical care personnel, by specialists working in a center that has personnel and facilities for special investigations and treatment.

Travellers
A community of people commonly so called who are identified (by themselves and others) as people with a shared history, culture and traditions, including, historically, a nomadic way on the island of Ireland.

Trust Delivery Plan
The Trusts response to the objectives set out each year by the DHSSPS. These priorities are set out in a document called Priorities for Action.

Unique Personal Identifier
A project will introduce a new Health & Care Number for each citizen and ensure that the number is used in all HPSS Information systems that hold personal care data.

Victims
The surviving physically and psychologically injured of violent, conflict related incidents and those close relatives or partners who care for them, along with the close relatives or partners who mourn their dead. Relating to the conflict in Northern Ireland.

World Health Organisation (WHO)
The World Health Organization is the United Nations specialized agency for health.

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Produced by:
Department of Health, Social Services
and Public Safety,
Castle Buildings, Belfast BT4 3SQ

Telephone (028) 9052 8143

Textphone: (028) 9052 7668.

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DEPARTMENT OF HEALTH, SOCIAL SERVICES AND PUBLIC SAFETY

FRAMEWORK DOCUMENT

Index

1. INTRODUCTION

1.1. The Department has produced this Framework Document to meet the statutory requirement placed upon it by the Health and Social Care (Reform) Act (NI) 2009. The Framework Document describes the roles and functions of the various health and social care bodies and the systems that govern their relationships with each other and the Department.

Background

1.2. The reform of the health and social care system in Northern Ireland has its origins in the Review of Public Administration (RPA) which was initiated by the Northern Ireland Executive in June 2002. The purpose of RPA was to review Northern Ireland's system of public administration with a view to putting in place a modern, citizen-centred, accountable and high quality system of public administration.

1.3. The need to reform the health and social care system at the earliest possible opportunity was widely supported. The new design is more streamlined and accountable and aimed at maximising resources for front-line services and ensuring that people have access to high quality health and social care. Another key feature is that public health and wellbeing is put firmly at the centre of the new system, with a greater emphasis on prevention and support for vulnerable people to live independently in the community for as long as possible.

1.4. The Health and Social Care (Reform) Act (Northern Ireland) 2009 ("the Reform Act") provides the legislative framework within which the new health and social care structures operates. It sets out the high level functions of the various health and social care bodies. It also provides the parameters within which each body must operate, and describes the necessary governance and accountability arrangements to support the effective delivery of health and social care in Northern Ireland.

Framework Document

1.5. The Health and Social Care (Reform) Act (NI) 2009, Section 5(1), requires the Department of Health, Social Services & Public Safety ('the Department') to produce a 'Framework Document' setting out, in relation to each health and social care body:

- i the main priorities and objectives of the body in carrying out its functions and the process by which it is to determine further priorities and objectives;
- ii the matters for which the body is responsible;
- iii the manner in which the body is to discharge its functions and conduct its working relationship with the Department and with any other body specified in the document; and
- iv the arrangements for providing the Department with information to enable it to carry out its functions in relation to the monitoring and holding to account of HSC bodies.

1.6. Section 1 (5) of the Reform Act defines "health and social care bodies" as:

- i Regional Health and Social Care Board (known as Health and Social Care Board);
- ii Regional Agency for Public Health and Social Well-being (known as Public Health Agency);
- iii Regional Business Services Organisation (known as Business Services Organisation);

iv HSC Trusts;

v Special Agencies (i.e. Northern Ireland Blood Transfusion Service, Northern Ireland Medical and Dental Training Agency and Northern Ireland Guardian ad Litem Agency);

vi Patient and Client Council; and

vii Regulation and Quality Improvement Authority

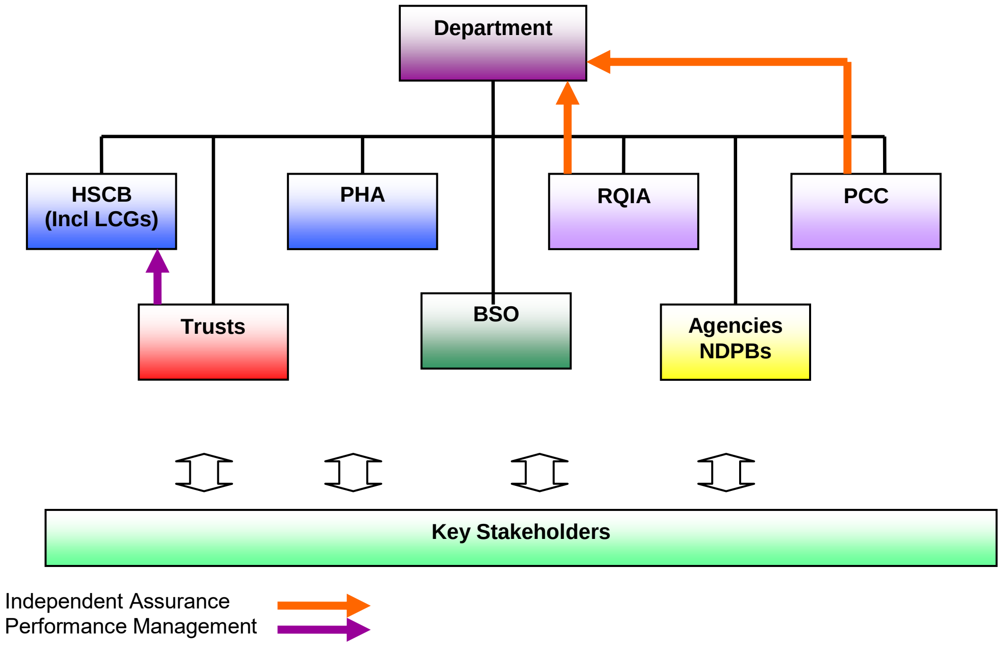
1.7. The focus of the Framework Document is the health and social care system in Northern Ireland and, although not covered by the Reform Act, the Northern Ireland Practice and Education Council and the Northern Ireland Social Care Council are included in the document for completeness. The Northern Ireland Fire and Rescue Service is outside the scope of the Framework Document.

1.8. All of the HSC bodies referred to above remain ultimately accountable to the Department for the discharge of the functions set out in their founding legislation. The changes introduced by the Reform Act augment, but do not detract from, that fundamental accountability.

1.9. Independent family practitioners also play a significant role in the delivery of health and social care. Health and social care objectives can only be achieved with the engagement of a high quality primary care sector that is accessible, accountable and focused on the needs of patients, clients and carers.

2. STRUCTURES, ROLES AND STATUTORY RESPONSIBILITIES

2.1. This section outlines the roles, responsibilities and relationships between the Department and health and social care (HSC) bodies. The diagram below shows the structure of the health and social care system.



Key: HSCB = Health and Social Care Board
LCGs = Local Commissioning Groups
PHA= Public Health Agency
BSO = Business Services Organisation
RQIA = Regulation and Quality Improvement Authority
PCC = Patient and Client Council
Agencies = Special Agencies (Northern Ireland Blood Transfusion Service, Northern Ireland Medical and Dental Training Agency and Northern Ireland Guardian ad Litem Agency)

Department of Health, Social Services & Public Safety

2.2. Section 2 of the Reform Act places on the Department a general duty to promote an integrated system of:

i health care designed to secure improvement:

- in the physical and mental health of people in Northern Ireland, and
- in the prevention, diagnosis and treatment of illness; and

ii social care designed to secure improvement in the social well-being of people in Northern Ireland.

2.3. In terms of service commissioning and provision, the Department discharges this duty primarily by delegating the exercise of its statutory functions to the Health and Social Care Board (HSCB) and the Public Health Agency (PHA) and to a number of other HSC bodies created to exercise specific functions on its behalf. All these HSC bodies are accountable to the Department which in turn is accountable, through the Minister, to the Assembly for the manner in which this duty is performed.

2.4. In addition, the Department retains the normal authority and responsibilities of a parent Department as regards direction and control of an arm's length body. The main principles, procedures etc are set out in the DFP guidance *Managing Public Money Northern Ireland* and are reflected in each body's management statement/financial memorandum (MSFM), in the letter appointing its chief executive as accounting officer for the body, and in the letters appointing its chair and other non-executive board members. The functioning of the bodies covered by this Framework Document is to be viewed in the context of, and without prejudice to, the Department's overriding authority and overall accountability.

Health & Social Care Board

2.5. The HSCB, which is established as the Regional Health & Social Care Board, under Section 7(1) of the Health & Social Care (Reform) Act

(Northern Ireland) 2009, has a range of functions that can be summarised under three broad headings.

2.6. **Commissioning** – this is the process of securing the provision of health and social care and other related interventions that is organised around a “commissioning cycle” from assessment of need, strategic planning, priority setting and resource acquisition, to addressing need by agreeing with providers the delivery of appropriate services, monitoring delivery to ensure that it meets established safety and quality standards, and evaluating the impact and feeding back into a new baseline position in terms of how needs have changed. The discharge of this function and the HSCB’s relationship with the PHA are set out in sections three and four.

2.7. **Performance management and service improvement** – this is a process of developing a culture of continuous improvement in the interests of patients, clients and carers by monitoring health and social care performance against relevant objectives, targets and standards, promptly and effectively addressing poor performance through appropriate interventions, service development and, where necessary, the application of sanctions and identifying and promulgating best practice. Working with the PHA, the HSCB has an important role to play in providing professional leadership to the HSC.

2.8. **Resource management** – this is a process of ensuring the best possible use of the resources of the health and social care system, both in terms of quality accessible services for users and value for money for the taxpayer.

2.9. The HSCB is required by the Reform Act to establish five committees, known as Local Commissioning Groups (LCGs), each focusing on the planning and resourcing of health and social care services to meet the needs of its local population. LCGs are co-terminus with the five HSC Trusts.

Public Health Agency

2.10. The PHA, which is established as the Regional Agency for Public Health & Social Well-being under Section 12(1) of the Health & Social Care (Reform) Act (Northern Ireland) 2009 incorporates and builds on the work previously carried out by the Health Promotion Agency, the former Health and Social Services Boards and the Research and Development Office of the former Central Services Agency. Its primary functions can be summarised under three broad headings.

2.11. **Improvement in health and social well-being** – with the aim of influencing wider service commissioning, securing the provision of specific programmes and supporting research and development initiatives designed to secure the improvement of the health and social well-being of, and reduce health inequalities between, people in Northern Ireland;

2.12. **Health protection** – with the aim of protecting the community (or any part of the community) against communicable disease and other dangers to health and social well-being, including dangers arising on environmental or public health grounds or arising out of emergencies;

2.13. **Service development** – working with the HSCB with the aim of providing professional input to the commissioning of health and social care services that meet established safety and quality standards and support innovation. Working with the HSCB, the PHA has an important role to play in providing professional leadership to the HSC.

2.14. In exercise of these functions, the PHA also has a general responsibility for promoting improved partnership between the HSC sector and local government, other public sector organisations and the voluntary and community sectors to bring about improvements in public health and social well-being and for anticipating the new opportunities offered by community planning.

Health and Social Care Trusts

2.15. HSC Trusts, which are established under Article 10 of the Health and Personal Social Services (Northern Ireland) Order 1991, are the main providers of health and social care services to the public, as commissioned by the HSCB. There are now six HSC Trusts operating in Northern Ireland:

- Belfast Health and Social Care Trust (covering local council areas of Belfast and Castlereagh);

- South Eastern Health and Social Care Trust (covering local council areas of Newtownards, Down, North Down and Lisburn);

- Northern Health and Social Care Trust (covering local council areas of Coleraine, Moyle, Larne, Antrim, Carrickfergus, Newtownabbey, Ballymoney, Ballymena, Magherafelt and Cookstown);

- Southern Health and Social Care Trust (covering local council areas of Dungannon, Armagh, Craigavon, Banbridge and Newry and Mourne);

- Western Health and Social Care Trust (covering local council areas of Derry, Limavady, Strabane, Omagh, and Fermanagh)

- Northern Ireland Ambulance Service Trust (covering all of Northern Ireland)

2.16. The six HSC Trusts are established to provide goods and services for the purposes of health and social care and, with the exception of the Ambulance Trust, are also responsible for exercising on behalf of the HSCB certain statutory functions which are delegated to them by virtue of authorisations made under the Health and Personal Social Services (Northern Ireland) Order 1994. Each HSC Trust also has a statutory obligation to put and keep in place arrangements for monitoring and improving the quality of health and social care which it provides to individuals and the environment in which it provides them (Health and Personal Social Services (Quality, Improvement and Regulation) (NI) Order 2003).

2.17. Section 21 of the Reform Act places a specific duty on each Trust to exercise its functions with the aim of improving the health and social wellbeing of, and reducing the health inequalities between, those for whom it provides, or may provide, health and social care.

Business Services Organisation

2.18. The BSO, which is established as the Regional Business Services Organisation under Section 14 (1) of the Health & Social Care (Reform) Act (Northern Ireland) 2009, contributes to health and social care in Northern Ireland by taking responsibility for the provision of a range of business support and specialist professional services to other health and social care bodies, as directed by the Department in accordance with Section 15 of the Reform Act.

2.19. The BSO incorporates the majority of services previously provided by Central Services Agency. The BSO, however, provides a broader range of support functions for the health and social care service, bringing together services which are common to bodies or persons engaged in providing health or social care. These include: administrative support, advice and assistance; financial services; human resource, personnel and corporate services; training; estates; information technology and information management; procurement of goods and services; legal services; internal audit and fraud prevention. Such support services may be provided directly by the BSO or through a third party.

Patient and Client Council

2.20. The PCC, which is established under Section 16 (1) of the Health & Social Care (Reform) Act (Northern Ireland) 2009, is a regional body supported by five local offices operating within the same geographical areas covered by the five HSC Trusts and LCGs. The overarching objective of the PCC is to provide a powerful, independent voice for patients, clients, carers, and communities on health and social care issues through the exercise of the following functions:

- to represent the interests of the public by engaging with the public to obtain their views on services and engaging with Health and Social Care (HSC) organisations to ensure that the needs and expectations of the public are addressed in the planning, commissioning and delivery of health and social care services;
- to promote the involvement of patients, clients, carers and the public in the design, planning, commissioning and delivery of health and social care;
- to provide assistance to individuals making or intending to make a complaint relating to health and social care; and
- to promote the provision of advice and information to the public by the HSC about the design, commissioning and delivery of health and social care services.

Regulation and Quality Improvement Authority (RQIA)

2.21. The RQIA was established under Article 3 of the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003. Although accountable to the Department, it is an independent health and social care regulatory body, whose functions include:

i Keeping the Department informed about the provision, availability and quality of health and social care services;

ii Promoting improvement in the quality of health and social car services by, for example, disseminating advice on good practice and standards;

iii Reviewing and reporting on clinical and social care governance in the HSC - the RQIA also undertakes a programme of planned thematic and governance reviews across a range of subject areas, reporting to the Department and the Health and Social Care and making recommendations to take account of good practice and service improvements. Such reviews may be instigated by RQIA or commissioned by the Department;

iv Regulating (registering and inspecting) a wide range of health and social care services. Inspections are based on a new set of minimum care standards which ensures that both the public and service providers know what quality of services is expected. Establishments and agencies regulated by the RQIA include nursing and residential care homes; children's homes; independent hospitals; clinics; nursing agencies; day care settings for adults; residential family centres; adult placement agencies and voluntary adoption agencies. The Reform Act also transferred the functions of the former Mental Health Commission to the RQIA with effect from 1 April 2009. The RQIA now has a specific responsibility for keeping under review the care and treatment of patients and clients with a mental disorder or learning disability.

2.22. The RQIA is also the enforcement authority under the Ionising Radiation and Medical Exposure (Amendment) Regulations (N.I.) 2010 [IRMER] and is one of the four designated National Preventive Mechanisms under the United Nations Optional Protocol for the Convention against Torture [OPCAT] with a responsibility to visit individuals in places of detention and to prevent inhumane or degrading treatment. RQIA also conducts a rolling programme of hygiene inspections in HSC hospitals.

2.23. The Department can ask the RQIA to provide advice, reports or information on such matters relating to the provision of services or the exercise of its functions as may be specified in the Department's request. The RQIA may also advise the Department about any changes which it considers should be made in the standards set by the Department.

Special Agencies

2.24. Special Agencies are established under the Health and Personal Social Services (Special Agencies) (Northern Ireland) Order 1990 to provide specific functions on behalf of the Department.

2.26. **Northern Ireland Blood Transfusion Service (NIBTS)** - The NIBTS is responsible for the collection, testing and distribution of blood donations each year. The main aim of the NIBTS is to fully supply the needs of all hospitals and clinical units in Northern Ireland with safe and effective blood, blood products and other related services. The discharge of this function includes a commitment to the care and welfare of blood donors.

2.27. **Northern Ireland Medical and Dental Training Agency (NIMDTA)** – The NIMDTA was established to ensure that doctors and dentists are effectively trained to provide the highest standards of patient care. The NIMDTA is responsible for funding, managing and supporting postgraduate medical and dental education. It provides a wide range of functions in the organisation, development and quality assurance of postgraduate medical and dental education and in the delivery and quality assurance of continuing professional development for general, medical and dental practitioners.

2.28. **Northern Ireland Guardian ad Litem Agency (NIGALA)** – The NIGALA is responsible for maintaining a register of Guardians ad Litem who are independent officers of the court experienced in working with children and families. Under the Children (NI) Order 1995, a Guardian ad Litem is appointed to safeguard the interests of children who are subject to family and adoption court proceedings and to ensure that their feelings and wishes are made clear to the court. The NIGALA also has a pivotal role in ensuring that the Children (Northern Ireland) Order is implemented as intended. The provision of an effective and efficient Guardian ad Litem Service is vital if the Children Order is to operate satisfactorily. It occupies a similar role under the Adoption (Northern Ireland) Order 1987 in that it brings an independence and objectivity to the task of safeguarding the interests of the child.

Non Departmental Public Bodies (NDPBs)

2.29. **The Northern Ireland Practice and Education Council for Nursing and Midwifery (NIPEC) -** The NIPEC was established under the Health and Personal Social Services Act (Northern Ireland) 2002 as a non-departmental public body to support the development of nurses and midwives by promoting high standards of practice, education and professional development. The NIPEC also provides advice and guidance on best practice and matters relating to nursing and midwifery.

2.30. **The Northern Ireland Social Care Council (NISCC)** - The NISCC was established under the Health and Personal Social Services Act (Northern Ireland) 2001 as a non-departmental public body to protect the public, specifically those who use social care services, and to promote confidence and competence in the social care workforce. It achieves this aim by registering and regulating the social care workforce, setting and monitoring the standards for professional social work training and promoting training within the broader social care workforce.

Summary of working relationships

2.31. In common with all Arms Length Bodies (ALBs), on issues of governance and assurance, all the HSC bodies are directly accountable to the Department. Detailed accountability arrangements are set out in section 6 of this Framework Document.

2.32. Article 67 of the Health and Personal Social Services (Northern Ireland) Order 1972 as amended by the Health and Social Care (Reform) Act (Northern Ireland) 2009 provides that "In exercising their respective functions, health and social care bodies, district councils, Education and Library Boards and the Northern Ireland Housing Executive shall co-operate with one another in order to secure and advance the health and social welfare of Northern Ireland."

2.33. Under the Reform Act, the Department has an overall duty to promote an integrated system of health and social care designed to improve the health and social well-being of the people in Northern Ireland. All health and social care bodies must work closely and co-operatively with the Department, with each other and with organisations outside the Department, in the manner best calculated to further that overall duty. Whilst this general duty of co-operation is paramount, there are a number of specific areas where co-operative working needs to be highlighted and these are dealt with in the following paragraphs.

2.34. The Department sets the strategic context for the commissioning of health and social care services through a Commissioning Direction to the HSCB. It may also direct the HSCB as to the performance indicators it should employ in improving the performance of HSC Trusts.

The Health and Social Care Board and the Public Health Agency

2.35. Under Section 8 of the Reform Act, the HSCB is required to produce an annual commissioning plan in response to the Commissioning Direction, in full consultation and agreement with the PHA. The form and content of the commissioning plan is directed by the Department in accordance with Section 8 of the Reform Act. This requirement is at the core of the key working relationship that translates the strategic objectives, priorities and standards set by the Department into a range of high quality, accessible health and social care services and general improvement in public health and wellbeing. In practice, the employees of the HSCB and PHA work in fully integrated teams to support the commissioning process at local and regional levels.

2.36. Developing, securing approval for and implementing the annual commissioning plan and associated Service and Budget Agreements with providers is the responsibility of the HSCB. The HSCB is, however, statutorily required to have regard to advice and information provided by the PHA and cannot publish the plan unless it has been approved by the PHA. In the unlikely event that the HSCB and the PHA cannot agree on the commissioning plan, the matter is referred to the Department for resolution. The HSCB and the PHA must also work together in a fully integrated way to support providers to improve performance and deliver desired outcomes.

2.37. Given the Department's retained responsibilities in areas such as human resources and estate management, strategic planning for health and social services must take place in a spirit of co-operation between the Department, the HSCB, the PHA and other HSC stakeholders, notwithstanding the formal accountability arrangements described elsewhere in this Framework Document.

Health and Social Care Board and HSC Trusts

2.38. Trusts must provide services in response to the commissioning plan, and must meet the standards and targets set by the Minister. Service and Budget Agreements (SBAs) are the administrative vehicle for demonstrating that these obligations will be met. SBAs are established between the HSCB and Trusts setting out the services to be provided and linking volumes and outcomes to cost.

2.39. Working with the PHA as appropriate, the HSCB is responsible for managing and monitoring the achievement by Trusts of agreed objectives and targets, including financial breakeven. At the same time, the HSCB and PHA also work together closely in supporting Trusts to improve performance and achieve the desired outcomes.

2.40. Section 10 of the Reform Act gives the HSCB power, subject to the approval of the Department, to give guidance or direction to a Trust on carrying out a Trust function. Before giving direction, the HSCB is required to consult with the Trust concerned except when the urgency of the matter may preclude consultation. The HSCB must not however give any direction or guidance to a Trust that is inconsistent with this Framework Document or inconsistent with any other direction or guidance already given to the Trust by the Department.

Health and Social Care Board and Family Practitioner Services

2.41. Primary care in general and family practitioner services (FPS) in particular are central to the health and social care system. Family practitioners and those who work with them in extended primary care teams act as the first point of contact and as a gateway to a wider variety of services across the HSC. The HSCB has a key role to play in managing contracts with family practitioners, not only in terms of pay and performance monitoring but also in terms of quality improvement, adherence to standards and delivery of departmental policy. The HSCB is accountable to the Department for the proper management of FPS budgets.

Business Services Organisation and the Wider HSC

2.42. The role of BSO is to provide support services on behalf of HSC bodies as directed by the Department. The relationships between the BSO and HSC bodies are governed by the development of SLAs between the BSO and the relevant organisation setting out the range, quantity, quality and costs of the services to be provided. These SLAs will develop in accordance with the phased expansion of the range of services provided by the BSO.

Patient and Client Council and Wider HSC

2.43. In addition to the overall requirement on HSC bodies to co-operate with each other to secure and advance the health and social welfare of Northern Ireland, Section 18 of the Reform Act places a specific duty on certain HSC bodies, as defined in the Act, to co-operate with the PCC in the exercise of its functions. This means that HSC bodies must consult the PCC on matters relevant to the latter's functions and must furnish the PCC with the information necessary for the discharge of its functions. Furthermore, HSC bodies must have regard to advice provided by the PCC about best methods and practices for consulting and involving the public in health and social care matters.

2.44. The PCC's relationship with the other HSC bodies is therefore characterised by, on the one hand, its independence from these bodies in representing the interests and promoting the involvement of the public in health and social care and, on the other, the need to engage with the wider HSC in a positive and constructive manner to ensure that it is able to efficiently and effectively discharge its statutory functions on behalf of patients, clients and carers. It also has considerable influence over the manner in which consultations are conducted by the HSC.

2.45. The PCC's functions do not include a duty to consult on behalf of the HSC. Each HSC body is required to put in place its own arrangements for engagement and consultation.

Regulation and Quality Improvement Authority, the Department and Wider HSC

2.46. The RQIA's relationship with the Department and other HSC bodies is driven by its independent role in keeping the Department informed about the availability and quality of services, drawing on its regulatory functions, and its wider statutory responsibility to encourage improvement in the quality of services. HSC bodies look to the RQIA for independent validation of their internal arrangements for clinical and social care governance. Examples of RQIA's work in this respect can be seen within its rolling programme of special and thematic reviews within the HSC. The RQIA must also work closely with HSC Trusts in the discharge of its functions relating to regulation of independent sector providers, particularly in terms of safeguarding the interests of vulnerable people.

Special Agencies and the Department

2.47. Special Agencies carry out a range of discrete functions as set out above. Their primary relationship is with the Department, on behalf of which they discharge their functions. The services they deliver are largely in support of the wider health and social care system and they must therefore develop appropriate working relationships with other health and social care bodies.

The Northern Ireland Practice and Education Council, the Department and the HSC

2.48. The NIPEC's primary relationship is with the Department on behalf of which it discharges its functions. NIPEC also works closely with key stakeholders in the HSC system to support registered nurses, midwives and specialist community public health nurses to provide a safe and effective nursing and midwifery service to the population of Northern Ireland.

The Northern Ireland Social Care Council (NISCC), the Department and the Wider HSC

2.49. The NISCC's primary relationship is with the Department, on behalf of which it discharges its functions. The NISCC provides a framework for commissioners and providers to promote consistency in standards of conduct and practice throughout the social care system. The NISCC also works closely with its registrants and other key stakeholders to achieve its aims of raising the quality of social care practice.

3. SETTING THE AGENDA

Establishing the Priorities

3.1. In terms of setting the strategic agenda for the Health and Social Care system, Section 2 of the Reform Act requires the Department to:

i develop policies to secure the improvement of the health and social wellbeing of, and to reduce health inequalities between, people in Northern Ireland;

ii determine priorities and objectives for the provision of health and social care;

iii allocate financial resources available for health and social care, having regard to the need to use such resources in the most economic, efficient and effective way;

iv set standards for the provision of health and social care;

v formulate the general policy and principles by reference to which particular functions are to be exercised.

3.2. The Department sets the strategic vision and priorities for Health and Social Care. The strategic vision provides an overarching direction of travel for the HSC that reflects already well-established policies and strategies. The strategic vision underpins the Department's contribution to budget process and Programme for Government (PfG) and, flowing from this, provides the context for the development of an annual Commissioning Direction, Priorities for Action (PfA), Commissioning Plan and Trust Delivery Plans (TDPs).

3.3. The Programme for Government (PfG) and a framework of Public Service Agreements (PSAs) express the Executive's strategic aims and policies in measurable objectives and targets.

3.4. The Department publishes annually Priorities for Action (PfA), which translates the PfG and other ministerial priorities into an achievable and challenging agenda for Health and Social Care.

3.5. The Department sets out the Minister's instructions to the commissioners in the annual Commissioning Direction under Section 8 (3) of the Reform Act. This reflects the priorities in the PfA as revised annually, and the relevant standards and obligations that apply every year. Hence this makes clear the framework within which the HSCB (including its LCGs) and the PHA commission health and social care.

3.6. Every year the HSCB is responsible for producing a commissioning plan in full consultation and with the approval of the PHA. The plan must outline how they plan to deliver on the key priorities standards or targets set in PfA. This plan provides the framework for each HSC Trust to develop its annual Trust Delivery Plan (TDP) detailing the Trust's response to the annual commissioning priorities and targets set out in the commissioning plan.

Allocating the resources

3.7. Section 2 of the Reform Act requires the Department to allocate financial resources available for health and social care, having regard to the need to use such resources in the most economic, efficient and effective way.

3.8. Resources available to the Northern Ireland Block are largely determined at the outcome of the HM Treasury Spending Review on the basis of the population based Barnett formula. This sets the overall Departmental Expenditure Limit (DEL) for Northern Ireland. The funding levels are normally set for three or more financial years and may be reviewed every two years or so. Within the constraints of the NI DEL, gross spending power available to the Executive can be increased, currently through revenue generated from the Regional Rate and borrowing power within the Reinvestment and Reform Initiative. Within the overall Block limits set by Treasury (i.e the NI DEL), the NI Executive establishes, in the light of local priorities, the three or four year resource allocations for all NI Departments, which cover both current expenditure and capital investment. The PfG specifies the Executive's plans and priorities for the years covered by the relevant budget period, while a separate Investment Strategy establishes capital priorities over a 10-year period.

3.9. It is the Department's responsibility to secure, as part of the Budget process, resources that enable the health and social care system to satisfy the population's need for high quality, accessible services.

3.10. In allocating current expenditure to HSC bodies, the Department must strike a balance between facilitating full and timely deployment of resources to the frontline and the need to ensure that appropriate control of funds is retained centrally by the Department. The aim is to channel the maximum resources to the point of service delivery at the earliest possible stage, with appropriate controls in place to ensure that they are deployed in accordance with Government priorities.

3.11. A Capitation Formula informs the Department (and, in turn, the HSCB) as to the most fair and equitable allocation of revenue funding for LCG areas. It does this by taking into account the number of people living within an area, with suitable adjustments relating to the age, sex and additional needs (largely due to deprivation) of the populations in question. The HSCB is required annually to provide the Department with an assessment of equity gaps, including the potential for re-distribution of resources across LCG populations and to demonstrate that resources have in fact benefited the populations for which they were intended. Allocation of capital expenditure to HSC Trusts is managed by the Department, with input from commissioners on the associated current expenditure funding required. The capital allocation and reporting process in described in more detail later in this section.

Funding the Health and Social Care Board and the Public Health Agency

3.12. The HSCB is responsible and accountable for commissioning of services, resource allocation and performance management, whilst the primary objective of PHA is to protect and improve the health and social well-being of the Northern Ireland population.

3.13. Section 8 of the Reform Act requires the HSCB, in respect of each financial year, to prepare and publish a commissioning plan in full consultation with and approved by the PHA. Each organisation holds the administrative and programme resources appropriate to their respective roles and responsibilities. Where such resources are deployed outside the context of the commissioning plan, the HSCB and the PHA submit, for Departmental approval, separate business plans in respect of those resources.

3.14. The following principles apply in relation to the funding arrangements for the HSCB and the PHA:

i Each of the bodies receives the bulk of its funding directly from the Department and each organisation remains separately accountable for all of the funds allocated to it;

ii In accordance with the detailed commissioning arrangements set out in section four, the funds allocated to the HSCB are:

- Committed to secure the provision of health and social care services for local populations from the six HSC Trusts, Family Health Services and other providers, consistent with the approved Commissioning Plan; and
- used for staffing, goods and services associated with the discharge of its functions;

iii The PHA directly funds initiatives related to its core roles of health improvement, screening or health protection activity, partnership working with local government, staffing and goods and services. Plans for use of the PHA's funding are incorporated within the Commissioning Plan, developed by the HSCB in consultation with and the agreement of the PHA. Similarly, services commissioned by the PHA from HSC Trusts and independent practitioners are reflected the Commissioning Plan as appropriate. Whilst the payment of funds for these services is administered by the HSCB on behalf of the PHA through the Service and Budget Agreements with HSC Trusts, the PHA remains accountable to the Department for the deployment of the resources. In the case of services commissioned from Family Health Service contractors, such as GPs, the HSCB takes primary responsibility for contract management, taking input from the PHA as appropriate.

Funding the Patient and Client Council

3.15. The Department directly meets the operating costs of the Patient and Client Council (PCC) to ensure that it operates independently from the service. The PCC produces, for Departmental approval, an annual business plan demonstrating how these resources will be used.

Funding the Business Services Organisation

3.16. Funding for the Business Services Organisation's (BSO) operating costs will flow through Service and Budget Agreements (SBAs) with its customers, the other HSC bodies. The SBAs determine the range, quality and costs of services to be provided. Movement towards the position of the BSO as an organisation fully financed from its service agreements with customers is being staged over a transitional period from April 2009.

3.17. The Health and Social Care (Reform) Act requires BSO to ensure that the arrangements which it puts in place for securing support services for its customers are the most economic, efficient and effective way of providing such services. It is required to have these arrangements approved by the Department before they are put in place. The Department approves the BSO's annual corporate business plan.

Funding Health and Social Care Trusts

3.18. HSC Trusts access funds by means of Service and Budget Agreements (SBAs) with their commissioners. Trusts are required to submit annual delivery plans (TDPs) to the HSCB for approval. TDPs must address both the content of the agreed SBAs with commissioners and the wider range of other corporate responsibilities. The HSCB provides assurance to the Department about the service and financial viability of TDPs.

Funding the Regulation and Quality Improvement Authority

3.19. The RQIA is funded directly by the Department on the basis of the priorities and objectives set out in its annual business plan and 3- year corporate strategy, which are approved by the Department. RQIA generates the balance of income through statutory fee charges for regulation of establishments and agencies.

Funding the Northern Ireland Guardian ad Litem Agency

3.20. NIGALA is funded directly by the Department on the basis of priorities and objectives set out in its annual corporate business plan, which is approved by the Department.

Funding the Northern Ireland Medical and Dental Training Agency

3.21. NIMDTA is funded directly by the Department on the basis of priorities and objectives set out in its annual corporate business plan, which is approved by the Department.

Funding the Northern Ireland Blood Transfusion Service

3.22. Resources are allocated initially to the HSCB and are then channelled to Trusts through their Service and Budget Agreements (SBAs). NIBTS accesses the funds through the SBAs it has with Trusts for its services.

Funding the Northern Ireland Practice and Education Council

3.23. The NIPEC is funded directly by the Department on the basis of priorities and objectives set out in its annual corporate business plan, which is approved by the Department.

Funding the Northern Ireland Social Care Council

3.24. The NISCC is funded substantially by the Department on the basis of priorities and objectives set out in its annual corporate business plan, which is approved by the Department. It also receives income from registration fees, Skills for Care and Development and in respect of student placements in the criminal justice sector (funded by the Department of Justice).

The Capital Allocation and Reporting Process

3.25. The strategic capital planning function, together with responsibility for overseeing procurement and performance management of capital programme delivery, rests with the Department. The Investment Strategy for Northern Ireland (ISNI), managed by the Strategic Investment Board (SIB) in conjunction with OFMDFM provides an indicative 10-year funding envelope for the Department. The Department contributes to the development of the ISNI, which is approved by the NI Executive.

3.26. Resources available to the Northern Ireland are largely determined at the outcome of the HM Treasury Spending Review on the basis of the population based Barnett formula. The NI Executive establishes, on the basis of its own priorities, the spending plans for all NI departments. In parallel, the Executive's infrastructure plans are set out in a separate 10-year Investment Strategy for Northern Ireland. The current Strategy covers the period 2008-2018.

3.27. To inform ministerial decisions on capital allocation, the Department conducts a biennial Capital Priorities Review, with input from a Policy Infrastructure Forum comprising representatives from the Department, the HSCB and the PHA. A 10-year rolling capital plan is produced as the output of these regular reviews.

3.28. The HSCB and the PHA are responsible for identifying and quantifying the services required to meet assessed needs and for commissioner endorsement of the associated current expenditure costs subject to considerations of affordability.

3.29. The Trusts and the HSCB (for ICT), are responsible for preparing and obtaining approval for business cases for the capital requirements needed to deliver the service. These business cases must have commissioner support before approval.

3.30. The Department has overall responsibility for the capital investment programme and also acts as a Centre of Specialist Expertise (COSE) and a Centre of Procurement Expertise (COPE) for capital infrastructure and undertakes a performance management role in relation to the estate.

3.31. The HSCB, taking account of professional advice from the PHA, is responsible for confirming the appropriate models of care to deliver health and social care across Northern Ireland and the associated indicative infrastructure requirements.

3.32. BSO is the responsible Centre of Procurement Expertise for the procurement of services, supplies and IT equipment.

4. COMMISSIONING

Introduction

4.1. The purpose of HSC commissioning is to improve and protect the health and social well-being of the people of Northern Ireland and reduce differences in access to good health and quality of life. Commissioning aims to achieve a progressive improvement in services through investment based on evidence of effectiveness, compliance with quality and efficiency standards and a focus on addressing the determinants of poor health and wellbeing. The involvement of patients, clients, carers and communities and engagement with other partners has a central role in the commissioning process.

4.2. The Department sets the policy and legislative context for health and social care in Northern Ireland. It also determines the standards and targets by which quality, access and outcomes should be measured and provides the strategic direction for the health and social care professions. The commissioning process, which includes resource and performance management and is led by the HSCB, translates the agenda set by the Department into a comprehensive, integrated commissioning plan for health and social care services. Commissioning must maintain a strong focus on identifying and prioritising the needs of patients, clients, carers and communities. In doing so, it is the driver for continuous service improvement and provides assurance that resources are delivering the maximum benefits for users and taxpayers alike. In management terms, the separation of commissioners and providers is designed to promote a patient and client-centred system.

The Commissioning Cycle

4.3. Commissioning includes the following activities:

i Assessing the health and social well-being needs of groups, populations and communities of interest;

ii Prioritising needs within available resources;

iii Building the capacity of the population to improve their own health and social well-being by partnership working on the determinants of health and social well-being in local areas;

iv Engaging with patients/clients/carers/families and other key stakeholders and service providers at local level in planning health and social care services to meet current and emerging needs;

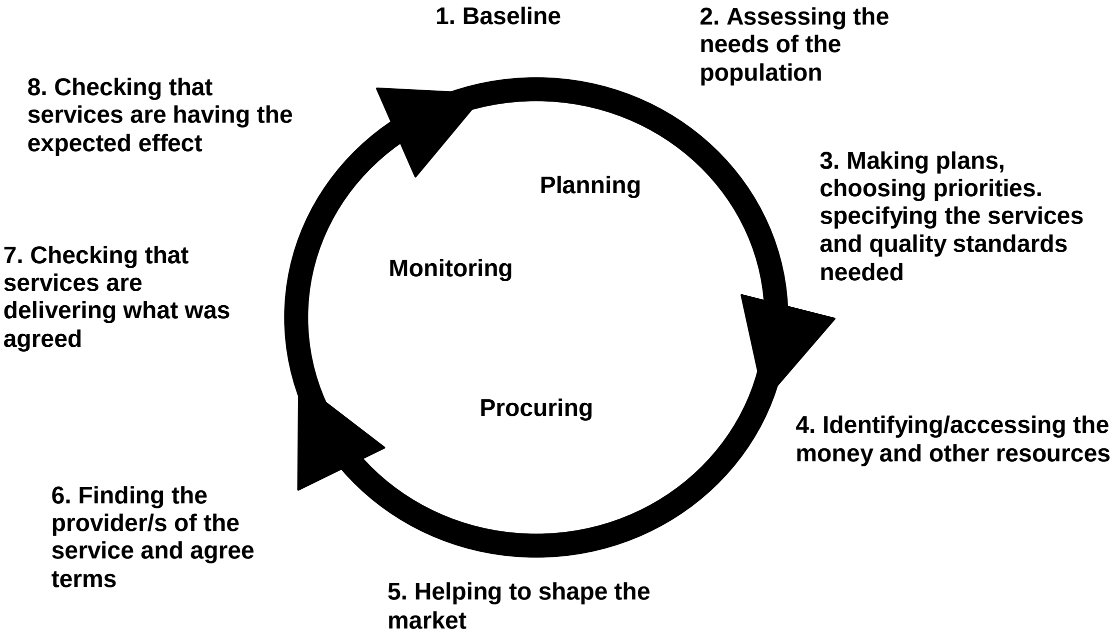
v Securing, through Service and Budget Agreements, the delivery of value for money services that meet standards and service frameworks for safe, effective, high quality care;

vi Safeguarding the vulnerable; and

vii Using investment, performance management and other initiatives to develop and reform services.

4.4. In the context of the integrated health and social care system in Northern Ireland, commissioning should be seen as an ‘end to end’ process. It organises activities around a commissioning cycle that moves through from assessing needs, strategic planning, priority setting, securing resources to address needs, agreeing with providers the delivery of appropriate services, monitoring that delivery, evaluating impact and feeding back that assessment into the new baseline position in terms of how needs have changed. Throughout the cycle, the HSCB and its LCGs engage with stakeholders, including service providers, at regional and local level.

4.5. Commissioners will facilitate a more integrated provider system by managing the interfaces between providers (statutory, independent and voluntary), developing provider networks and acting as ‘guardians’ of the care pathway.



The Commissioning Plan Direction

4.6. In exercising the powers conferred on it by Section 8 (3) of the Reform Act, the Department sets out the Minister’s instructions to commissioners in an annual commissioning plan direction. The commissioning plan direction sets the framework within which the HSCB (including its LCGs) and the PHA commission health and social care.

The Commissioning Plan

4.7. Section 8 of the Reform Act requires the HSCB, in respect of each financial year, to prepare and publish a commissioning plan in full consultation with and approved by the PHA. The commissioning direction specifies the form and content of the commissioning plan in terms of the services to be commissioned and the resources to be deployed. The plan may not be published unless approved by the PHA. In the unlikely event of failure to agree the commissioning plan, the matter is referred to the Department for resolution.

Local Commissioning

4.8. The reformed system of commissioning introduced from 1 April 2009 established five geographically based Local Commissioning Groups (LCGs) that are co-terminus with the boundaries of the five Health and Social Care Trusts. The status of LCGs as committees of the HSCB is established in primary legislation.

4.9. LCGs have a lead role in the strategic commissioning process, in particular, having helped to shape strategic thinking, to apply it locally on behalf of their populations. They have responsibility for assessing health and social care needs in their areas, planning to meet current and emerging needs and securing the delivery of a comprehensive range of services to meet the needs of their populations. They have full delegated authority to discharge these responsibilities, including a significant ability to direct resources. The capitation formula identifies funds for the populations of each LCG area, and the HSCB is accountable for ensuring that they are used for that purpose. LCGs identify local priorities taking account of the views of patients, clients, carers, wider communities and service providers. They forge partnerships and involve a range of stakeholders in designing and reshaping services to better meet the needs of their local communities. The resources for each LCG population may be used to secure services for that population from any appropriate provider.

4.10. For the most part, the HSCB’s Commissioning Plan reflects the decisions and recommendations of the LCGs in relation to the use of the capitation-based shares of the budget for their populations at local level. However, it is recognised that some services, by virtue of their specialist nature, restricted volume or statutory accountability, must be commissioned collaboratively on a regional basis, and hence the LCGs’ decisions and recommendation will include contributions to the commissioning of regional services. The HSCB is responsible for establishing appropriate mechanisms for this process, which will ensure that fair shares from the capitation-based budgets are committed to regionally commissioned services.

4.11. As committees of the HSCB, LCGs work within strategic priorities set by the Department, the HSCB, regional policy frameworks, available resources and performance targets. Section 9 (4) of the Reform Act requires LCGs to work in collaboration with the PHA and have due regard to any advice or information provided by it. To ensure a joint approach to commissioning, LCGs are supported by fully integrated, locally based, multi-disciplinary commissioning support teams made up of staff from the PHA and HSCB. Professional staff from both the HSCB and PHA are included in the membership of LCGs.

4.12. Each year the HSCB determines, in consultation with LCGs, the range of services to be commissioned locally and regionally and identifies the budgets from which such services are to be commissioned. LCGs prepare local commissioning plans, in keeping with the priorities and objectives of the HSCB. LCG commissioning plans are incorporated within the overall commissioning plan, which must be approved by the HSCB and the PHA.

Link between Commissioning and Performance Management

4.13. Monitoring performance of providers against the agreements they make in relation to service delivery is a key part of the commissioning cycle, and commissioners continue to ensure that this role remains core to how they work with providers. The HSCB and PHA must maintain appropriate monitoring arrangements in respect of provider performance in relation to agreed objectives, targets, quality and contract volumes.

4.14. The HSCB incorporating its LCGs must have appropriate monitoring arrangements to confirm that commissioned services are delivered, to benchmark comparative performance, and to ensure that quality outcomes, including positive user experience, are delivered.

4.15. Providers must have appropriate monitoring arrangements to ensure that they are meeting the requirements of commissioners and performing efficiently, effectively and economically.

4.16. The Department maintains appropriate monitoring arrangements in relation to the HSCB and the PHA to ensure that resources are used to best effect in the achievement of agreed strategic objectives and targets.

4.17. The HSCB and PHA also work together closely in supporting providers, through professional leadership and management collaboration, to improve performance and achieve desired outcomes. The HSCB is the lead organisation for supporting providers in relation to the delivery of a wide range of health and social care services and outcomes, with support provided by PHA professional staff. PHA is the lead organisation for supporting providers in the areas of health improvement, screening and health protection, with support provided by the performance, commissioning, finance, primary and social care staff of the HSCB.

Procurement by HSC Trusts

4.18. At the present time, it is not practical or desirable for the HSCB to contract directly with the full range of providers involved in the HSC system. The services involved are numerous, diverse, need to be provided flexibly and often need to be arranged at short notice, to meet the needs of individuals. Therefore a wide range of services commissioned by the HSCB are sub-contracted by Trusts to independent sector providers.

5 PERSONAL AND PUBLIC INVOLVEMENT

5.1 Patients, clients, carers and communities must be put at the centre of decision making in health and social care. This means that they must be properly involved in the planning, delivery and evaluation of their services. HSC bodies are accountable to people and communities for the quality, accessibility and responsiveness of the services they plan and provide.

5.2 Section 19 of the Reform Act places a statutory requirement on each organisation involved in the commissioning and delivery of health and social care to provide information about the services for which it is responsible; to gather information about care needs and the efficacy of care; and to support people in accessing that care and maintaining their own health and wellbeing.

5.3 This statutory requirement extends to the development of a consultation scheme, which must set out how the organisation involves and consults with patients, clients, carers and the Patient Client Council (PCC) about the health and social care for which it is responsible. Consultation schemes must be submitted to the Department for approval. The Department may approve a consultation scheme, with or without amendments, after consulting with the PCC.

5.4 Section 20 of the Reform Act specifies the form that consultation schemes should take, but this is supplemented by detailed policy guidelines for the HSC on personal and public involvement and the development and approval of consultation schemes.

Roles in Personal and Public Involvement (PPI)

5.5 In respect of Personal and Public Involvement (PPI), the Reform Act places a specific responsibility on the PCC to promote best practice in involvement and in the provision of information about health and social care services. HSC bodies are required by the Reform Act to co-operate fully with the PCC in the discharge of these statutory responsibilities. The Department may consult the PCC in respect of specific consultation schemes before approving them.

5.6 The Department sets the policy and standards for Personal and Public Involvement (PPI). Working through the HSCB, the PHA has responsibility for ensuring that Trusts meet their PPI statutory and policy responsibilities and leading the implementation of policy on PPI across the HSC. A PPI Forum, chaired by the PHA and involving representatives from all HSC organisations, has been established for that purpose. This in no way detracts from the individual statutory responsibilities of organisations with regard to PPI.

5.7 The HSCB is responsible for ensuring that its LCGs establish arrangements for effective PPI which will allow the views of stakeholders to inform the development of commissioning plans. The HSCB should also ensure that Family Practitioner Services are meeting the requirements laid down in Departmental guidance on PPI.

5.8 HSC Trusts are responsible for establishing individual organisational governance arrangements, and for implementing their PPI consultation schemes, to meet their statutory duty of involvement, as well as any requirements laid down in Departmental guidance on PPI.

5.9 Special agencies also have responsibilities in respect of PPI. The NI Blood Transfusion Service (NIBTS), the NI Guardian Ad Litem Agency (NIGALA) and the NI Medical and Dental Training Agency (NIMDTA) should establish arrangements to ensure they meet their statutory duty of involvement and any requirements laid down in Departmental guidance. Each of these three special agencies will be accountable directly to the Department for the discharge of these functions.

5.10 The PCC will undertake research and conduct investigations into the most effective methods and practices for involving the public and provide advice on these to HSC organisations. The PCC also has an important challenge role for those HSC bodies prescribed in the Reform Act in respect of PPI, and will accordingly be expected to comment upon and scrutinise the actions and decisions of these bodies as they relate to PPI.

5.11 RQIA will continue to provide independent assurance to the Minister, via the Department, of the effectiveness of PPI structures in HSC organisations by continuing to monitor these as part of its programme of review of clinical and social care governance arrangements against the Quality Standards.

6 HOLDING THE SYSTEM TO ACCOUNT

Introduction

6.1. Ultimate accountability for the exercise of proper control of financial, corporate and clinical and social care governance in the HSC system rests with the Department and the Minister. Within a system of such magnitude and complexity, assurance about the rigour of control mechanisms can only be derived from the development and operation of robust systems and processes at all levels of decision making.

Performance and Assurance Dimensions

6.2. This section of the Framework Document describes the various lines of accountability and how they are exercised at different levels within the HSC system. The key performance and assurance roles and responsibilities are encompassed in the four dimensions of:

i Corporate Control – the arrangements by which the individual HSC bodies direct and control their functions and relate to stakeholders;

ii Safety and Quality – the arrangements for ensuring that health and social care services are safe and effective and meet patients' and clients' needs, including appropriate involvement;

iii Finance – the arrangements for ensuring the financial stability of the HSC system, for ensuring value for money and for ensuring that allocated resources are deployed fully in achievement of agreed outcomes in compliance with the requirements of the public expenditure control framework;

iv Operational Performance and Service Improvement – the arrangements for ensuring the delivery of Departmental targets and required service improvements.

Key Principles

6.3. The requirements in relation to performance and assurance roles may differ from body to body but some key principles underpin the overall approach to holding the HSC system to account:

i the Department has ultimate accountability for the effective functioning of the HSC across the four dimensions;

ii the Department will provide clear guidance across each of the four dimensions, specifying outputs and outcomes that are appropriate, affordable and achievable. This guidance will be developed with the involvement of the HSC bodies, consistent with their roles and responsibilities;

iii each HSC body is locally accountable for its organisational performance across the four dimensions and for ensuring that appropriate assurance arrangements are in place. This obligation rests wholly with the body's board of directors. It is the responsibility of boards to manage local performance and to manage emerging issues in the first instance;

iv the standard assurance arrangements and associated information streams within individual HSC organisations will, as far as possible, be used to meet the assurance requirements of the HSCB and PHA, and those of the Department, subject to such additional independent verification as may be deemed necessary;

v the Department, and in turn the HSCB and PHA (where they have a performance and assurance role in relation to one or more of the other bodies), will maintain a relationship with other HSC bodies based on openness and the sharing of information, adopting an informal, supportive approach to clarify and resolve issues as they arise, and thereby minimising the need for formal intervention.

Corporate Control Dimension

6.4. Corporate control encompasses the policies, procedures, practices and internal structures which are designed to give assurance that the HSC body is fulfilling its essential obligations as a public body. Most of the requirements reflect those in place across the public sector, but a few have been instituted for reasons peculiar to the field of health and social care – notably the statutory duty of quality created by Article 34 of the HPSS (Quality, Improvement and Regulation) (NI) Order 2003. In addition to that obligation, the controls relate to: the existence of appropriate board roles, structures and capacity; corporate and business planning arrangements; risk management and internal controls; and monitoring and assurance of those processes.

6.5. All HSC bodies shall:

i adhere to the terms of the Accounting Officer appointment letter issued by the Department. This letter specifies the governance responsibilities and duties which the body owes to the Departmental Accounting Officer;

ii comply, in full, with the control framework requirements set out in the Management Statement/Financial Memorandum issued by the Department, in a form agreed by the Department of Finance and Personnel;

iii submit to the Department an annual Statement on Internal Control, signed by the Accounting Officer of the body, covering the range of issues in the standard form prescribed by the Department of Finance and Personnel, augmented by the additional health and social care-specific requirements set by the Department;

iv submit to the Department a mid-year assurance statement on control issues covering the same areas as the annual Statement on Internal Control;

v report as required on compliance with controls assurance and quality standards set by the Department including compliance with the Department's requirements for implementation of a risk management strategy and evidence that guidance on an assurance framework is being followed;

vi ensure that the appointment processes carried out by the body are demonstrably independent and free from external conflicts of interest;

vii adopt an Assurance Framework to strengthen board-level control and assurance in general, the Statement on Internal Control, and the mid-year assurance statement;

viii operate a board-approved scheme of delegated decision-making within the body based on systems of good practice updated by the Department;

ix ensure compliance with accepted or prescribed standards of public administration set by the Department – for example, in relation to equality of opportunity, equality legislation, complaints, etc;

x ensure compliance with the checklist of actions required of sponsor branches in the Department in obtaining assurance from their respective body's covering: roles and responsibilities; business planning and risk management; governance; and internal audit;

xi ensure compliance with procurement policy securing value for money, economically advantageous outcomes, equality of opportunity, sustainable development, etc., in accordance with the policy framework set by the Executive and the Department of Finance and Personnel, key performance indicators set by the Department, the procurement strategy led by Regional Procurement Group (supported by BSO) and procurement under the Department's Infrastructure Strategy;

xii ensure that an Internal Audit function within each body operates to HM Treasury standards, including the requirement for external assessments, adhering to the professional qualifications, conduct and remit set out by the Department, and giving a comprehensive professional opinion from the chief internal auditor on the adequacy and effectiveness of the body's system of internal control;

xiii ensure implementation of agreed Northern Ireland Audit Office and Public Accounts Committee recommendations; and

xiv comply with the NI Executive's pay policy for the HSC e.g. arrangements for senior executive pay.

6.6. Compliance with the requirements at (i) – (x) are the subject of ongoing monitoring by the Department, and issues for resolution are resolved at bi-annual accountability reviews or through ad hoc action, if deemed appropriate by the Department.

6.7. In relation to the requirement at (xi) the Regional Procurement Group, supported by BSO, as a centre of procurement expertise, promotes and oversees implementation of the overall procurement strategy and monitors compliance with procurement policy, while the Department secures assurance on adherence to policy rules and achievement of key performance indicators. All capital infrastructure is procured in conjunction with the centre of procurement expertise within the Department.

6.8. Adherence to the requirement at with (xii) is subject to ad hoc scrutiny by the Department's Head of Internal Audit, with issues resolved at bi-annual accountability reviews or through ad hoc action if deemed appropriate by the Department.

6.9. Compliance with (xiii) is the subject of ongoing monitoring by the Department (or HSCB or PHA as determined by the Department), with issues for resolution will be resolved at bi-annual accountability reviews or through ad hoc action, if deemed appropriate by the Department. Progress in relation to the recommendations is reported by the Department to the Northern Ireland Audit Office, Public Accounts Committee and the Department of Finance and Personnel.

6.10. Compliance at (xiv) is monitored by the Department, with issues for resolution addressed at bi-annual accountability reviews or through ad hoc action, if deemed appropriate by the Department.

Safety and Quality Dimension

6.11. Safety and quality covers a broad agenda, overlapping with many areas of operational performance and, to some extent, with financial performance and corporate control. It also applies to all programmes of care, including health improvement and health protection, and to infrastructure. This section describes assurance arrangements for specified elements of safety and quality, in particular, the arrangements for ensuring that HSC services are:

i safe - doing no harm to patients or clients and provided in an environment that is safe and clean;

ii effective - achieving agreed clinical and social care outcomes, which reflect high quality care and treatment and have a proven impact on health and wellbeing, especially prevention of poor health and wellbeing;

iii personalised - centred on the needs of individual patients clients and carers through their involvement in planning, delivery and evaluation.

6.12. Assurance to the Department and the Minister about the safety and quality of services is provided from a number of different sources. Each health and social body has clearly defined roles and responsibilities in this regard, which are summarised below.

6.13. The HSCB, working with the PHA on (i) to (viii) and (xii) below, is responsible for monitoring and reporting to the Department on:

i Compliance with Priorities for Action safety and quality requirements at least quarterly e.g. quality improvement plans;

ii Implementation of the RQIA and other independent safety and quality review recommendations in accordance with agreed plans;

iii Implementation of National Institute for Health and Clinical Excellence (NICE) technology appraisals endorsed by the Department;

iv Application by Trusts of lessons from adverse incidents and near misses (including those to be recorded on the PHA-managed RAIL system) and communicating, acting upon and reporting action taken in relation to safety information issued through the Northern Ireland Adverse Incident Centre Safety Alert Broadcast System (SABS);

v Evidence of provider-initiated action to improve safety and quality;

vi Family Practitioner Services' compliance with accepted standards e.g. clinical and social care governance arrangements, evidence of quality improvement, professional regulation and training and development etc;

vii Trusts' compliance with accepted standards e.g. professional regulation and training and development (excluding those covered in para 6.14 (i) below);

viii Independent sector contracts related to waiting lists initiatives regarding for example conformity with clinical and social care governance arrangements and their performance on specified quality measures;

ix Independent sector contracts related to the provision of social care, regarding compliance with clinical and social care governance arrangements and specific quality standards;

x Implementation of statutory functions under agreed Schemes of Delegation;

xi Trust compliance with accepted standards for social care professionals e.g. professional regulation and training and development; and

xii Safety and quality aspects of HSCB contracts with independent sector providers.

6.14. The PHA is responsible for monitoring and reporting to the Department on:

i Trust compliance with accepted standards for medical, nursing and allied health professionals e.g. professional regulation and training and development; and

ii Compliance with statutory midwifery supervision requirements;

iii The identification and effective promulgation of learning from investigation of adverse incidents through the Regional Adverse Incident and Learning (RAIL) system and support for the development of quality improvement plans; and

iv Safety and quality aspects of PHA contracts with independent sector providers.

6.15. Joint Commissioning Teams led by the HSCB or PHA, as appropriate, are responsible for monitoring:

i Implementation of Service Frameworks;

ii Implementation of mandatory policy or guidance issued by the Department, which are not subject to formal performance arrangements, e.g. pandemic ‘flu plans, quality of screening programmes, etc

iii Compliance with safety and quality and clinical and social care governance requirements specified by the commissioners of HSC services.

6.16. Trusts are responsible for monitoring independent sector contracts for health and social care to ensure compliance with relevant Departmental, HSCB or Trust guidance, including clinical and social care governance, relevant quality standards and arrangements to duly safeguard children and vulnerable adults.

6.17. The HSCB, working with the PHA, is responsible for monitoring Trust compliance with policies, standards and specific targets for the patient and client environment and support services including laundry and linen, catering, cleaning, portering and car parking.

6.18. The Department is responsible for monitoring:

i Compliance with policy, legislation and standards in respect of reusable medical devices;

ii Compliance with policy, legislation, standards and guidance in respect of the safe operation of life-critical healthcare-specific systems and processes.

6.19. In addition to assurance processes outlined above, the RQIA has an overall responsibility to encourage continuous improvement in the quality of health and social care across the public and independent health and social care sectors, against standards set by the Department, and to provide independent assurance on the quality of that care. When asked to do so by the Department it provides advice, reports or information on such matters relating to the provision of services or the exercise of its functions as may be specified in the Department's request. It may also, at any time, advise the Department on any changes which it thinks should be made in the minimum standards set by the Department. RQIA also undertakes a programme of planned thematic and governance reviews across a range of subject areas, examining services provided, and highlighting areas of good practice, and making recommendations for improvement and reporting lessons learned to the Department and the wider HSC. Such reviews may be conducted as part of RQIA's ongoing independent assessment of quality, safety and availability of HSC services or may be commissioned by the Department.

Finance Dimension

6.20. Appropriate financial accountability mechanisms are necessary to:

i Ensure that the optimum resources are secured from the Executive for health and social care;

ii Ensure the resources allocated by Minister/Department deliver the agreed outcomes and represent value for money;

iii Deliver and maintain financial stability, through effective operation of the financial accountability of Trusts via the HSCB to the Department;

iv Ensure that the commissioners can be assured that financing of services is managed on the agreed and approved basis set by the HSCB, its LCGs and the PHA;

v Facilitate the delivery of economic, effective and efficient services by rewarding planned activity that maximises effectiveness and quality and minimises cost; and

vi Facilitate the development of innovative and effective models of care.

6.21. All financial resources delegated by the Department to HSC bodies remain subject to the same standards of probity and accountability irrespective of where day-to-day management and control is vested.

6.22. All organisations are ultimately accountable to the Department for the achievement of overall financial balance. The Department monitors on a monthly basis the break-even performance of each organisation and, exceptionally, bids for unanticipated and inescapable in-year pressures. The HSCB monitors the performance and financial breakeven of Trusts, measuring against Service and Budget Agreements and delivery of service targets, reporting on its monitoring to the Department;

6.23. To guard against over-spending and minimise under-spending, the Department undertakes monthly monitoring of the overall HSC (and Departmental) financial position, reporting the evolving position to the Department of Finance and Personnel. The Department is also responsible for the strategic capital planning process and oversight of procurement and programme management, taking action where slippage or potential overspends become apparent. HSC Trusts are required to report on capital expenditure on a monthly basis and detailed liaison on projects is undertaken through quarterly Strategic Investment Group meetings.

6.24. The Department undertakes monitoring of the efficiency savings obligations contained in the Executive's Budget settlement. Each HSC body is required to provide such information in order to satisfy itself, and the Executive, that the conditions attached to the efficiencies are being met.

6.25. Trust Financial Returns and Strategic Resource Framework-related data, which provide essential information on expenditure on HSC services and contain cost comparisons across providers, continue to be produced under Departmental guidance. Responsibility for collation, analysis etc lies with HSCB.

6.26. The Department is responsible for keeping the counter-fraud strategy under review, and for the development and issuing of related guidance. It also approves publication of the annual fraud report and addresses performance issues relating to the counter-fraud assurance arrangements in each HSC body. It is for the BSO to maintain and provide to the Department all monitoring information that it, DFP or the NIAO may require. Each HSC body is required to comply with prescribed fraud prevention, fraud reporting, fraud investigation and other operational counter-fraud processes, availing itself of BSO support as appropriate.

6.27. The Department, informed by Department of Finance and Personnel, is the focal point for developing and cascading financial guidance, circulars and memoranda. This includes the specification of statutory and other reporting requirements.

Operational Performance and Service Improvement

6.28. Performance management and service improvement arrangements are those that are necessary to ensure the achievement of Government and ministerial objectives, standards and targets.

6.29. Section 8 of the Reform Act requires that the HSCB exercise its functions with the aim of improving the performance of HSC Trusts, by reference to such indicators as the Department may direct. In determining responsibilities for performance management and service improvement, the overriding principle is that, unless there is good reason to the contrary, as in the case of capital expenditure, estate management and Human Resources, all such functions should be undertaken by the HSCB because: this is a core function of the HSCB; it minimises the lines of accountability for providers; it maximises the ‘breadth of sight’ for the HSCB, allowing it to adopt a holistic view of performance taking account of all relevant factors.

6.30. Possible exceptions to this principle are areas for which the HSCB does not have lead responsibility, or where there is likely to be significant formal interaction with other Government departments, e.g. joint responsibility for the delivery of Public Service Agreement (PSA) targets (in which case the Department would take the lead on behalf of the HSC sector).

6.31. The HSCB is in the lead for monitoring and supporting providers in relation to the delivery of a wide range of HSC services and outcomes, with support from PHA professional staff. The PHA is in the lead for monitoring and supporting providers in the areas of health improvement, screening and health protection, with relevant support provided by the HSCB. The organisations are, therefore to establish and maintain a number of joint programme teams, consisting of relevant staff from each organisation.

6.32. In relation to the monitoring of provider performance, the resolution of any performance issues is a matter for the HSCB, in close co-operation with the PHA, escalating to the Department only if required.

6.33. With the approval of the Department, the HSCB and the PHA (where appropriate) produce detailed practical definitions for the application of targets. They also put in place arrangements to: monitor progress against targets, assess risks to achievement; hold regular performance meetings with providers; and escalate risks as appropriate. The HSCB reports on this process to the Department to enable it to maintain an overview of performance in these areas. The HSCB also resolves performance issues, escalating to the Department only where such resolution cannot be achieved. Capital, estate management and human resource targets are performance managed by Department.

6.34. The HSCB is responsible for the collection of all routine information from HSC Trusts for performance monitoring or statistical publication purposes at agreed intervals and to agreed standards, and for providing this to the Department. This will minimise the potential for duplication and establish a clear, single channel for submission and validation of information

6.35. In pursuit of service improvements in their respective areas of responsibility, the HSCB and the PHA must:

i identify evidenced-based good practice and develop an annual programme of action;

ii take account of patient, client and carer experience, including lessons learnt from complaints;

iii lead regional reform programmes, issuing guidance and specifying required actions;

iv provide training and support;

v review Trust action plans;

vi provide support to individual providers to address specific issues and manage provider-provider interfaces;

vii review implementation of reforms and make available any reports on progress;

viii make regular reports to the Department, as required, on their activities in this field.

6.36. Regarding Public Service Agreement targets, the Department is responsible for their development and agreement, and for reporting progress against them to the Office of the First Minister and Deputy First Minister and the Department of Finance and Personnel.

6.37. The Department sets HSC productivity and other HR-related targets and reports to Office of the First Minister and Deputy First Minister and the Department of Finance and Personnel on progress towards their achievement. The HSCB is responsible for the regular ongoing monitoring of progress by providers, addressing issues of under-performance where they arise, escalating to the Department only where necessary;

6.38. The European Working Time Directive has put in place compliance arrangements, for which the Department sets targets for the medical workforce. The HSCB monitors progress, addresses issues of under-performance and reports to Department on compliance and progress. It is for the HSCB to resolve any compliance etc issues, escalating matters to the Department’s attention only where necessary.

6.39. The Department is responsible for setting targets and monitoring HSC Trust performance in relation to the level of compliance with policy, legislation, standards and guidance in respect of the management of the HSC estate. HSC Trusts are accountable for the practical application of such guidance etc, for the effective management of the associated operational risks, and for providing appropriate assurance as to the discharge of these responsibilities. The Department has in place an appropriate review process to allow Trusts to report to the Department on a regular basis as to their overall management of the HSC estate.

Independent Challenge

6.40. In considering how the HSC system is held to account, special mention should be made of the Regulation and Quality Improvement Authority and the Patient and Client Council, both of which have a particular role to play. They each provide an independent perspective on the performance of the HSC system, one which validates and challenges the system's own performance management arrangements.

6.41. The RQIA focuses on the quality and safety of services, using statutory and other standards agreed by the Department to benchmark not only the services but also the governance frameworks within which they are provided. PCC focuses on the interests of patients, clients and carers in HSC services. This goes beyond a straightforward information or advocacy role; it includes working with HSC bodies to promote the active involvement of patients, clients, carers and communities in the design, delivery and evaluation of services. The RQIA and the PCC also have the power to look into specific aspects of health and social care and report their findings publicly to the Department.

6.42. Both of these organisations provide important independent assurance to the wider public about the quality, efficacy and accessibility of health and social care services and the extent to which they are focused on user needs.

7 Conclusion

7.1 This Framework Document is a summary of the structures, functions and processes that underpin the planning, delivery and evaluation of health and social care services in Northern Ireland. It will be kept under continuous review in the light of emerging policy and legislation.

7.2 If you have any enquiries about the content of the Framework Document, please contact:

Office of Permanent Secretary
DHSSPS
Permanent.Secretary@dhsspsni.gov.uk

FROM THE MINISTER OF HEALTH

Department of
Health
An Roinn Sláinte
Männystrie O Poustie
www.health-ni.gov.uk

Castle Buildings
Stormont Estate
Belfast BT4 3SQ
Telephone: 028 9052 0638
email: private.office@health-ni.gov.uk

MEMORANDUM

SUB/1378/2016

FROM: MICHELLE O'NEILL MLA
Minister of Health

DATE: 14 December 2016

TO: MINISTERS (TEO, DFC, DE, DFE, DFI, DOJ)

BAMFORD EVALUATION

I am pleased to attach the draft Bamford evaluation report for your consideration.

The report indicates that much has been achieved to improve services for people with mental ill-health or a learning disability. They also highlight a number of areas where development is required so that collectively we can continue to improve the lives of these people within our community.

In terms of the way forward, the report concludes that there is little benefit in creating another Bamford Action Plan, and that the identified needs are included in the new population-based, outcomes-focussed Programme for Government.

With regard to the Bamford structures, the report recognises the important role played by the Ministerial Group, the Inter-Department Senior Officials Group and the Bamford Monitoring Group, but recommends that the time has come to stand these structures down and mainstream the continued development of mental health and learning disability services.

I would be grateful if you could review the documents, and respond by Wednesday 11 January on your areas of interest, filling in any gaps in information which still exist. I will then send the final drafts to the Executive for formal approval.

I want to thank all colleagues and their officials for the valuable contributions to this extensive exercise, and for your continued support in making the lives of people with mental ill-health or a learning disability better.

Is mise le meas

Michelle O'Neill

MICHELLE O'NEILL MLA
Minister of Health

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

SERVICE FRAMEWORK FOR LEARNING DISABILITY

Working for a Healthier People

INVESTOR IN 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 Service Framework for Learning Disability 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 Service Framework for Learning Disability 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

SERVICE FRAMEWORK FOR LEARNING DISABILITY

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.	Establish baseline March 2014. Performance level to be determined once baseline established March 2015.
	2. All HSC organisations and organisations providing services on behalf of the HSC have **Safeguarding Plans** in place.	Establish baseline March 2014. Performance level to be determined once baseline established March 2015.
	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 March 2014. Performance level to be determined once baseline established March 2015.

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 March 2015. Performance levels to be determined once baseline established. March 2016.
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. Percentage of job descriptions containing PPI as responsibility March 2015: senior and middle management March 2016: designated PPI leads at all levels of HSC organisations March 2017: all new job descriptions	Establish baseline and set target March 2014. Monitor progress March 2015. 100% in all new job descriptions March 2016.
	2. Percentage of patients and clients expressing satisfaction	Establish baseline and set target March 2014. Report percentage increase of patient and client satisfaction March 2015.

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 3 (Generic): (continued)		Report percentage increase of patient and client satisfaction March 2016.
	3. Percentage of staff who have gained PPI training (details to be agreed for 2015/2016)	Conduct training needs assessment for PPI, commission design of PPI training programme March 2014. Establish baseline and set target March 2015. Monitor percentage of staff trained at different levels in PPI March 2016.
Standard 4: Adults with a learning disability should be helped by HSC professionals to develop their capacity to give or refuse informed consent.	1. Develop and agree a regional training plan that ensures that relevant HSC staff are trained in consent and capacity issues.	All HSC organisations March 2016.
	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	Development and implementation of SAAT March 2015. Performance level to be determined based on outcomes of SAAT March 2016.
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. Percentage of patients and clients expressing satisfaction with communication	Establish baseline March 2014. Report percentage increase of patient and client satisfaction with communications March 2015.

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 5 (Generic): (continued)		Report percentage increase of patient and client satisfaction with communication March 2016.
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.	Develop and implement SAAT March 2015. Performance levels to be determined based on outcomes of SAAT March 2016.
	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.	Regional Training Plan in place. March 2015. Training is delivered in accordance with Regional Training Plan. March 2016.
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.	Development and implementation of SAAT March 2015. Performance levels to be determined once baseline established March 2016.
	2. Each person with a learning disability can access a named person who can signpost them to relevant services.	Establish baseline of information provided March 2016. 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 March 2015. Establish performance levels based on outcomes from SAAT March 2016.
	2 Percentage of requests for Direct Payments from people with a learning disability that were approved.	Develop and implement SAAT March 2015. Establish performance levels based on outcomes from SAAT March 2016.
	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 March 2017.
Standard 9 (Generic): Service users and their carers should have access to independent advocacy as required.	1. To be determined	To be determined.

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 March 2016. Performance levels to be determined once baseline established March 2017.
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 annual assessment either under the Family Health Needs Assessment or UNOCINI Assessments.	Establish baseline March 2016. Performance levels to be determined once baseline established March 2017.
	2 Percentage of children and young people who have an agreed care plan detailing a pathway to receiving appropriate care and support	Establish baseline March 2016. Performance levels to be determined once baseline established March 2017.

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 supports 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.	Scope requirements and produce audit plan March 2015. Audit 50% of information available March 2016. 100% March 2017.
	2 Percentage of children and young people with complex physical health needs who have effective transition arrangements in place between hospital and community.	Develop and implement SAAT March 2015. Performance level to be determined based on SAAT outcomes March 2016. Fast Track arrangements for access to hospital/community services to be audited following establishment of baseline.
	3 Percentage of children with a learning disability and complex physical health needs who have received a multi-professional assessment as per regional integrated care pathway.	90% March 2015. 95% March 2016. 98% March 2017.

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.	Establish baseline March 2015. Performance levels to be determined once baseline established March 2016.

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.	Develop and implement SAAT March 2016. Performance levels to be determined based on SAAT outcomes March 2017.
	2. Evidence of transfer to DES, where appropriate, for health checks for children on transition to adult services.	90% March 2015. 95% March 2016. 98% March 2017.

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.	HSC Board policy developed and agreed March 2015.
	2. Trusts to facilitate appropriate training for staff.	40% March 2016. 80% March 2017.
	3. Trusts to facilitate appropriate training for service users and family carers.	Level to be established pending development of regional policy March 2017.
	4. Increase in the number of people with a learning disability accessing sexual health and reproductive healthcare services.	Develop and implement SAAT March 2015. Performance levels to be determined based on SAAT outcomes March 2016.

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).	Establish baseline March 2015. Performance levels to be determined once baseline established March 2016.
	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 March 2015. Performance levels to be determined once baseline established March 2016.

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, outside of their building based service.	Develop and implement SAAT March 2015. Performance levels to be determined based on SAAT outcomes March 2016.
	2. Percentage of adults with a severe or profound learning disability receiving support in a building based service, who express satisfaction with the opportunity to experience day opportunities.	Develop and implement SAAT March 2015. Performance levels to be determined based on SAAT outcomes March 2016.
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.	HSC Board in collaboration with all Trusts March 2015.
	2. Percentage of parents with a learning disability who have a multi-professional/agency competence based assessment.	Establish baseline March 2016. Performance levels to be determined once baseline established March 2017.
	3. Percentage of parents with a learning disability involved in child protection or judicial processes who have received locally based skills training.	85% March 2015. 90% March 2016. 95% March 2017.
	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.	Establish baseline March 2015. Performance levels to be determined once baseline established March 2016.

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.	All HSC Trusts establish baseline March 2015. Performance levels to be determined once baseline established March 2016.
	2. Percentage of GPs who have a system for identifying people with a learning disability on their register.	Baseline as per learning disability DES March 2015. Performance levels to be determined once baseline established March 2016.
	3. Each GP practice has a designated link professional within local learning disability services.	Establish baseline March 2015. Performance levels to be determined once baseline established March 2016.
	4. Evidence of reasonable adjustments by health service providers.	Establish baseline March 2015. Performance levels to be determined once baseline established March 2016.

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
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. Number of people who are accessing Stop Smoking Services	Baseline 2011/12 = 39204. - 4 % year on year increase March 2014 – March 2016.
	2. Proportion of the smoking population who are accessing Stop Smoking Services.	Baseline 2011/12 =10.8%. NICE guidance and the ten year tobacco strategy call for a target of over 5% of the smoking population to be reached, hence target to maintain at >/= 5% March 2014 – March 2016.
	3. Number of people using stop smoking services who have quit at 4 weeks and 52 weeks.	Baseline 2011/12 = 20,299 for those quit at 4 weeks and 5,889 for those quit at 52 weeks. Target 4% increase in respective numbers year on year March 2014 – March 2016.
Standard 21: All people with a learning disability should be supported to achieve optimum physical and mental health.	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.	All Trusts have in place a health improvement strategy for people with a learning disability March 2015.
	2. Percentage of adults with a learning disability who have an annual health check.	Establish baseline March 2015. Performance levels to be determined once baseline established March 2016.
	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 March 2015. Performance levels to be determined once baseline established March 2016.

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
Standard 21:(continued)	4. Percentage of people with a learning disability who have been examined by a dentist in the past year.	Establish baseline March 2015. Performance levels to be determined once baseline established March 2016.
	5. Percentage of females with a learning disability who access cervical and breast screening services.	Establish baseline March 2015. Performance levels to be determined once baseline established March 2016.
	6. Percentage of people with a learning disability who have a sight test with an optometrist in the past year.	Establish baseline March 2015. Performance levels to be determined once baseline established March 2016.
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.	Protocol in place March 2015.
	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.	Establish baseline March 2016. Performance levels to be determined once baseline established March 2017.
	3. Percentage of Health Action Plans and health checks which include mental health assessment and mental health promotion.	Establish baseline. March 2015. Performance levels to be determined once baseline established March 2016.

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
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.	Baseline for 2011/12 = 32% overall, 26% for males and 36% for females. Target: maintain or at best increase percentage by 1% year on year March 2014 – March 2016.
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.	New physical activity guidelines were launched in 2011 and as such a new suite of questions to establish the percentage of people meeting the recommended level of physical activity per week has been integrated within the 2012/13 Northern Ireland Health Survey. It is anticipated these new baseline results will be available in Nov / Dec 2013 March 2014. Performance level to be agreed thereafter.
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 primary care settings in relation to their alcohol consumption.	Establish baseline March 2014. Performance level to be determined once baseline established March 2015.

Meeting Complex Physical and Mental Health Needs

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
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.	Develop and implement SAAT March 2015. Performance level to be determined based on SAAT outcome March 2016.
	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.	Develop and implement SAAT March 2015. Performance level to be determined based on SAAT outcome March 2016.
	3. Where challenging behaviours present a significant risk to the individual, a Management Plan has been developed and implemented within 48 hours.	Develop and implement SAAT March 2015. Performance level to be determined based on SAAT outcome March 2016.
	4. Evidence that HSC has engaged with other relevant delivery partners in developing and implementing consistent approaches in individual cases.	All HSC Trusts March 2016.
	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.	Develop and implement SAAT March 2017. Performance level to be determined based on SAAT outcomes.

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
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 March 2015.

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.	Develop and implement SAAT March 2015. Performance levels to be determined based on SAAT outcomes March 2016.
	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.	Develop and implement SAAT March 2015. Performance levels to be determined based on SAAT outcomes March 2016.
	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 March 2015. Performance levels to be determined based on SAAT outcomes March 2016.
	4. Percentage of people leaving learning disability hospital within one week after treatment has been completed.	95% March 2015 97% March 2016 100% March 2017.

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
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 front line staff in a range of settings participating in Carer Awareness Training Programmes	20% March 2015. 50% March 2016.
	2. The number of carers who are offered Carers Assessments	Improvement targets set by HSC Board in conjunction with Carers Strategy. Implementation Group. Reviewed annually.
	3. The percentage of carers who participate in Carers Assessments	Improvement targets set by HSC 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.	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 March 2015. Performance levels to be determined once baseline established March 2016.

Ageing Well

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.	Develop and implement SAAT March 2015. Performance levels to be determined based on SAAT outcomes March 2016.
	2. Percentage of carers aged 65 years and over receiving domiciliary or short break support services.	Develop and implement SAAT March 2015 Performance levels to be determined based on SAAT outcomes March 2016.

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
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.	Establish baseline March 2015. Performance levels to be determined once baseline established March 2016.
	2. Percentage of people with a learning disability and dementia who have received additional supports following a dementia diagnosis.	Develop and implement SAAT March 2016. Performance levels to be determined based on SAAT outcomes March 2017.
	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 March 2015. Performance levels to be determined once baseline established March 2016.

Palliative and End of Life Care

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.	Establish baseline March 2014. Performance levels to be determined once baseline established March 2015.
	2. Percentage of population with an understanding of advance care planning	Establish baseline March 2014. Performance levels to be determined once baseline established March 2015.

STANDARD	KEY PERFORMANCE INDICATORS	ANTICIPATED PERFORMANCE LEVEL
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.	Develop and implement SAAT March 2015. Performance levels to be determined based on SAAT outcomes March 2016.
	2. Evidence of specific actions in service delivery that make reasonable adjustment for their learning disability.	Develop and implement SAAT March 2015. Performance levels to be determined based on SAAT outcomes March 2016.

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

SECTION 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[1]. 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.

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[1] Generic Standards updated following CMO letter of 29 May 2013

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[2], 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

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[2] 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"[3], 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,

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[3] 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 Service Framework for Learning Disability 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.

SECTION 2: SERVICE FRAMEWORK FOR LEARNING DISABILITY

Introduction

The aim of the Service Framework for Learning Disability 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 Service Framework for Learning Disability 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 Service Framework for Learning Disability 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 Service Framework for Learning Disability

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 Service Framework for Learning Disability 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 Service Framework for Learning Disability. 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 Service Framework for Learning Disability 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 Service Framework for Learning Disability 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 Service Framework for Learning Disability 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[4] (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:[5]

- non-discrimination;

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[4] UNCRPD http://www.un.org/disabilities/default.asp?id=150

[5] 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 Service Framework for Learning Disability 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

<table>
<tr><td colspan="4">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</td></tr>
<tr><td colspan="4">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.</td></tr>
<tr><td colspan="4">Responsibility for delivery/implementation</td></tr>
<tr><td colspan="4">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.</td></tr>
<tr><td colspan="4">Quality Dimensions</td></tr>
<tr><td colspan="4">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</td></tr>
<tr><td>Performance Indicator

This information will be monitored to show if the standard is being delivered.</td><td>Data Source

This identifies where the information will be derived from.</td><td>Anticipated Performance Level
This describes how well the service must perform against this indicator.</td><td>Date to be achieved by

This specifies when the anticipated performance level should be reached.</td></tr>
</table>

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 Sections:

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

SECTION 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	6,432	1,718	8,150
20-34	2,504	1,047	3,551
35-49	1,489	949	2,438
50+	1,473	753	2,226
Totals	**11,898**	**4,467**	**16,365**

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 Service Framework for Learning Disability to other Service Frameworks

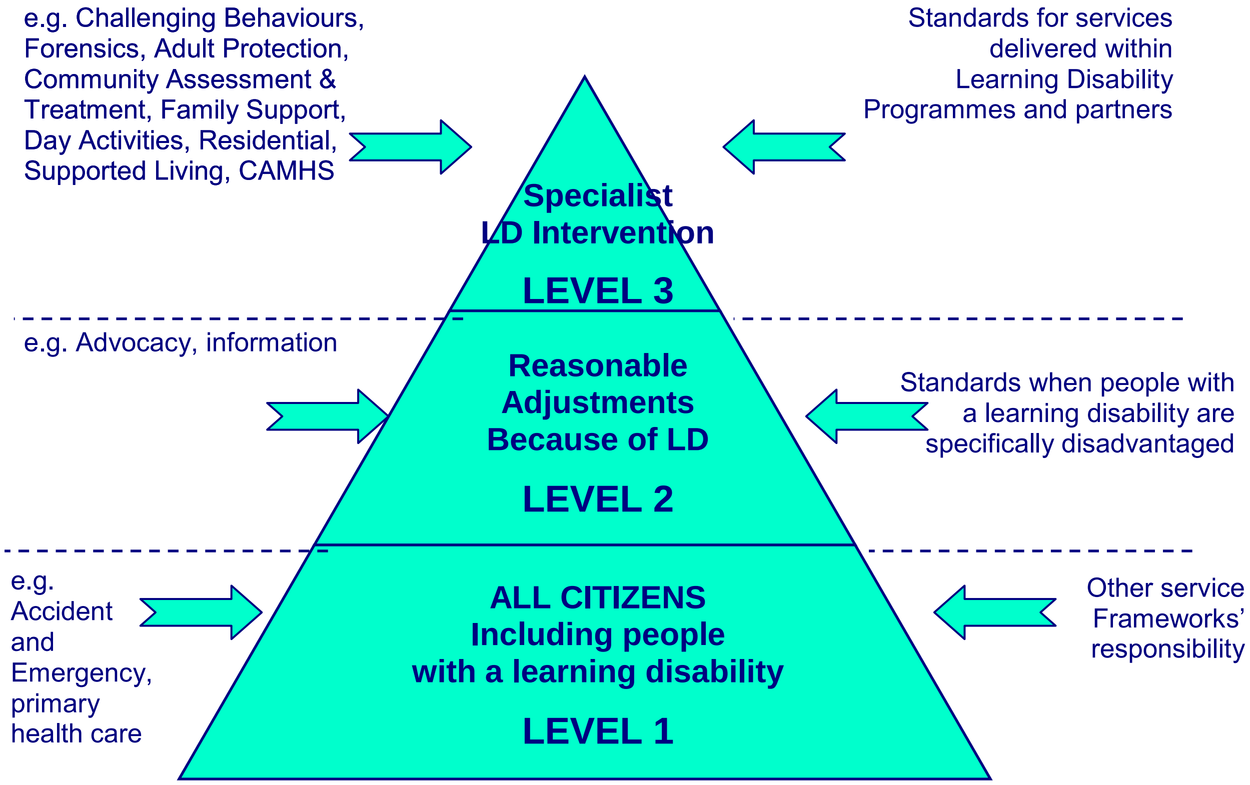

Figure 2

Figure 2 above describes the relationship between the Service Framework for Learning Disability 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 Service Framework for Learning Disability 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 Service Framework for Learning Disability 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 Service Framework for Learning Disability 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.

SECTION 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 level to be determined once baseline established	March 2014 March 2015

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 level to be determined once baseline established	March 2014 March 2015
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	March 2014 March 2015

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	March 2015 March 2016

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**
1. Percentage of job descriptions containing PPI as responsibility March 2014: senior and middle management March 2015: designated PPI leads at all levels of HSC organisations March 2016: all new job descriptions	Audit sample of job descriptions	Establish baseline and set target Monitor progress 100% - in all new job descriptions	March 2014 March 2015 March 2016
2.Percentage of patients and clients expressing	Patient & Client Experience monitoring	Establish baseline and set target	March 2014

satisfaction		Report percentage increase of patient and client satisfaction	March 2015
	Annual Accountability Report	Report percentage increase of patient and client satisfaction	March 2016
3. Percentage of staff who have gained PPI training (details to be agreed for 2014/2015)	Annual Accountability Report Training Report	Conduct training needs assessment for PPI, commission design of PPI training programme	March 2014
		Establish baseline and set target	March 2015
		Monitor percentage of staff trained at different levels in PPI	March 2016

Standard 4:
Adults with a learning disability should be 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	March 2016
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	March 2015 March 2016

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 (2013) Good Medical Practice
http://www.gmc-uk.org/guidance/good_medical_practice.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
Percentage of patients and clients expressing satisfaction with communication	Patient & Client Experience monitoring report Annual Accountability Report	Establish baseline and set target Report percentage increase of patient and client satisfaction with communication Report percentage increase of patient and client satisfaction with communication	March 2014 March 2015 March 2016

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	March 2015 March 2016

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.	March 2015 March 2016

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	March 2015 March 2016
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	March 2016

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 Service Framework for Learning Disability 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 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 (Section 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	March 2015 March 2016
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	March 2015 March 2016
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	March 2017

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 determined			To be determined

SECTION 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 Section 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 Section 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 Service Framework for Learning Disability 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	March 2016 March 2017

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 annual assessment either under the Family Health Needs Assessment or UNOCINI assessments.	Audit/Sampling	Establish baseline Performance levels to be determined once baseline established	March 2016 March 2017
2 Percentage of children and young people who have an agreed care 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	March 2016 March 2017

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.	March 2015
		Audit 50% of information available	March 2016
		100%	March 2017

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	March 2015 March 2016
3 Percentage of children with a learning disability and complex physical health needs who have received a multi-professional assessment as per regional integrated care pathway.	Trust Reports	90% 95% 98%	March 2015 March 2016 March 2017

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	March 2015 March 2016

SECTION 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	March 2016 March 2017
2 Evidence of transfer to DES, where appropriate, for health checks for children on transition to adult services	DES	90% 95% 98%	March 2015 March 2016 March 2017

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-__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	March 2015

2 Trusts to facilitate appropriate training for staff.	Trust Reports	40% 80%	March 2016 March 2017
3 Trusts to facilitate appropriate training for service users and family carers.	Trust Reports	Level to be established pending development of regional policy	March 2017
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	March 2015 March 2016

SECTION 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	March 2015 March 2016
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	March 2015 March 2016

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, outside of their building based service.	SAAT	Develop and implement SAAT Performance levels to be determined based on SAAT outcomes	March 2015 March 2016
2 Percentage of adults with a severe or profound learning disability receiving support in a building based service, who express satisfaction with the opportunity to experience day opportunities.	SAAT	Develop and implement SAAT Performance levels to be determined based on SAAT outcomes	March 2015 March 2016

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	March 2015

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	March 2016 March 2017
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%	March 2015 March 2016 March 2017
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	March 2015 March 2016

SECTION 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	March 2015 March 2016
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	March 2015 March 2016
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	March 2015 March 2016
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	March 2015 March 2016

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
Number of people who are accessing Stop Smoking Services	ELITE (PHA Stop Smoking Services Performance Report)	Baseline 2011/12 = 39204 4 % year on year increase	March 2014 March 2015 March 2016
Proportion of the smoking population who are accessing Stop Smoking Services.	ELITE (PHA Stop Smoking Services Performance Report)	Baseline 2011/12 =10.8%. NICE guidance and the ten year tobacco strategy call for a target of over 5% of the smoking population to be reached, hence target to maintain at >/= 5%	March 2014 March 2015 March 2016
Number of people using stop smoking services who have quit at 4 weeks and 52 weeks.	ELITE (PHA Stop Smoking Services Performance Report)	Baseline 2011/12 = 20,299 for those quit at 4 weeks and 5,889 for those quit at 52 weeks. Target 4% increase in respective numbers year on year	March 2014 March 2015 March 2016

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.	March 2015
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	March 2015 March 2016
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	March 2015 March 2016
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	March 2015 March 2016

5 Percentage of females with a learning disability who access cervical and breast screening services.	GP records Health facilitators	Establish Baseline Performance levels to be determined once baseline established	March 2015 March 2016
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	March 2015 March 2016

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	March 2015
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	March 2016 March 2017

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	March 2015 March 2016

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.	To be determined	Baseline for 2011/12 = 32% overall, 26% for males and 36% for females Target: maintain or at best increase percentage by 1% year on year	March 2014 March 2015 March 2016

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	New physical activity guidelines were launched in 2011 and as such a new suite of questions to establish the percentage of people meeting the recommended level of physical activity per week has been integrated within the 2012/13 Northern Ireland Health Survey. It is anticipated these new baseline results will be available in Nov / Dec 2013. Performance level to be agreed thereafter.	March 2014

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 primary care settings in relation to their alcohol consumption.	Northern Ireland Local Enhanced Service	Establish baseline Performance level to be determined once baseline established	March 2014 March 2015

SECTION 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	March 2015 March 2016

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	March 2015 March 2016
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	March 2015 March 2016
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	March 2016
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	March 2017

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	March 2015

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

SECTION 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 Section 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	March 2015 March 2016
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	March 2015 March 2016
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	March 2015 March 2016
4 Percentage of people leaving learning disability hospital within one week after treatment has been completed	PfA monitoring	95% 97% 100%	March 2015 March 2016 March 2017

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

Earley L *et al* (2007) Children's perceptions and experiences of care giving: A focus group study. *Counselling Psychology Quarterly.* 20. 1. pp.69–80

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

Olsen R (1996) Young Carers: challenging the facts and politics of research into children and caring. Disability and Society, 11 (1), 41-54

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 front line staff in a range of settings participating in Carer Awareness Training Programmes	Trust Training Report (including Induction programmes)	20% 50%	March 2015 March 2016
2. The number of carers who are offered Carers Assessments	HSC Board/ DHSSPS returns	Improvement targets set by HSC Board in conjunction with Carers Strategy Implementation Group	Reviewed annually
3. The percentage of carers who participate in Carers Assessments	HSC Board/ DHSSPS returns	Improvement targets set by HSC 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	March 2015 March 2016

SECTION 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	March 2015 March 2016

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	March 2015 March 2016

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-__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	March 2015 March 2016
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	March 2016 March 2017
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	March 2015 March 2016

SECTION 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	March 2014 March 2015
2. Percentage of the population with an understanding of advance care planning	NISRA survey for baseline levels	Establish baseline Performance indicator to be determined when baseline established	March 2014 March 2015

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 (e.g. 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.	March 2015 March 2016

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.	March 2015 March 2016

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 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 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	Western HSC Trust
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 life 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