



Department of
**Health, Social Services
and Public Safety**

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Physical and Sensory Disability Strategy and Action Plan

2012 – 2015

February 2012

Foreword**Executive Summary**

1.0	Vision and Values	8
2.0	Prevalence and Need.....	18
3.0	Promoting Positive Health, Wellbeing and Early Intervention	37
4.0	Providing Better Services to Support Independent Lives	48
5.0	Supporting Carers and Families.....	70
6.0	Developing an Infrastructure to Implement Change	76
7.0	Health and Social Care Action Plan.....	79

Appendices

- 1. List of Project Team Members**
- 2. References**
- 3. List of Pre-Consultation Events**
- 4. Equality Impact Screening**
- 5. Rural Proofing Screening**
- 6. Wraparound Manifesto – Standards**
- 7. Care / Referral Pathway Diagrams**
- 8. List of Abbreviations**

Alternative Formats

This document is available, on request, in alternative formats - Braille, audio, large print, “easy read”, or as a PDF document. The Department will consider requests to produce this document in other languages. If you require the document in these or other formats please contact the Disability Strategy Team:

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Foreword

One of the key issues identified for urgent action by the NI Executive following devolution was the promotion of social inclusion for all citizens and particularly for those groups or individuals who are, or may feel, marginalised or disadvantaged in society.

As part of the response to that issue, my Department initiated a consultation to support and facilitate the development of a draft Physical and Sensory Disability Strategy and Action Plan. The result and outcome from that work is this Strategy and Action Plan, which I have great pleasure in endorsing.

My Department currently invests approximately £92m annually directly on services for people with physical and/or sensory disabilities. If we add to this to the relevant elements of expenditure on maternity and child health (£127m), family and child care (£190m) and elderly care (£617m), we have a picture of a considerable investment in services for people with physical and sensory disabilities.

In light of this level of investment, we should therefore not be discouraged by the fact that this Strategy has been developed and launched during what is arguably the most challenging financial climate being faced by the NI Executive. In these circumstances the Action Plan realistically assumes that there will be limited additional investment to support its implementation. However, this does not mean that our vision for improving services and support for people with physical and sensory disabilities cannot be achieved. Through more innovative and efficient use of the considerable existing resources invested in this area I believe much can be done.

As Minister for Health and Social Services, I want to do all I can to help create a society in which the obstacles faced by disabled people in their daily lives are removed; a society in which people living with disabilities, and their carers and families, form part of inclusive and engaged communities; a society in which they are able to achieve and fulfil their maximum potential.

The Strategy and Action Plan, which has been developed in accordance with the articles in the United Nations Convention on the Rights of Persons with Disabilities, is intended to improve outcomes, services and support for individuals, regardless of age, who have a physical, sensory or communication disability. It has been developed through a collaborative partnership between service users, families and carers,

many voluntary and community groups and statutory organisations. Whilst the document is predominately written from a health and social care perspective, the importance of cross-governmental working is acknowledged and will be increasingly significant as work on the Strategy's Action Plan progresses.

I want to take this opportunity to thank all those who contributed to its development. Your time, energy and expertise have been greatly appreciated. Case studies bring a document such as this to life, and I am particularly grateful to Chris, Andrea, John and Anita for sharing their experiences with all of us.

EDWIN POOTS MLA

Minister for Health, Social Services and Public Safety

Executive Summary

This strategy (2012 – 2015) confirms the Department's commitment to improving outcomes, services and support for people in Northern Ireland (NI) who have a physical, communication or sensory disability.

It has been developed in accordance with the articles stated in the United Nations Convention on the Rights of Persons with Disabilities and therefore supports the values of dignity, respect, independence, choice, equality and anti-discrimination for disabled people. The principles of family and person-centred care and self directed support are promoted throughout the strategy and recognition is given to the need to adopt a life cycle approach to the provision of services and support. The requirement for integrated working, not just across government departments and health and social care organisations, but also in partnership with the third sector is emphasised throughout the document.

The more detailed sections of the strategy are presented in the five sections which follow this executive summary, with an Infrastructure to Implement Change and an Action Plan attached in sections six and seven respectively.

Section 1 - Vision and Values - sets out the vision, values and objectives of the strategy. It provides a high level summary of the historical and strategic context and presents the policy framework.

Section 2 - Prevalence and Need - outlines the range of data and information currently available in terms of the prevalence of disability in NI.

Section 3 - Promoting Positive Health, Wellbeing and Early Intervention - describes the approach in promoting optimal health and wellbeing, preventing further ill health and achieving recovery where possible.

Section 4 - Providing Better Services to Support Independent Lives – outlines, in some detail, a number of key areas where improving services and support can further promote independence for disabled people, their families and carers. These include personalisation, provision of accessible information, advice, advocacy, equipment such as wheelchairs and prosthetics, rehabilitation, respite, transition planning / support, day opportunities, housing and transport

Section 5 - Supporting Carers and Families - sets out what is current policy for carers and families, describes how that work is being taken forward currently within the HSC and confirms how this strategy supports that ongoing work.

Section 6 - Infrastructure to Implement Change - describes the governance arrangements and implementation structures which will be required to ensure the delivery of the Action Plan.

Section 7 – Health and Social Care Action Plan - presents the detailed action plan for the strategy.

Section One

Vision and Values

1.0 Vision and Values

This strategy has been developed to help achieve improved outcomes, services and support for people in Northern Ireland (NI), regardless of their age, who have a physical, communication or sensory disability.

It has been developed through a process of collaborative partnership and consultative joined-up working between representatives from the Health and Social Care Board (HSCB), Health and Social Care Trusts (HSCTs), Patient and Client Council (PCC), Public Health Agency (PHA), service users, their families and carers and several key community and voluntary organisations and groups. Whilst the strategy is predominately written from a health and social care perspective, engagement has taken place with other government departments.

1.1 Vision for the Strategy

The vision for this strategy is that, by the end of its life (2012-2015), the services commissioned and provided by health and social care organisations for people with disabilities will have developed in such a way that they:

- Support disabled people to become well informed and expert in their own needs;
- Promote health, wellbeing and maximise potential of individuals;
- Encourage the social inclusion of disabled people and work to address the stigma associated with disability;
- Encourage family and person-centred services and the promotion of independent living options;
- Are tailored to meet the changing needs of people over the course of their lifetime; and
- Continue to promote and enable balanced risk taking.

1.2 Objectives

The objectives of the strategy are to:

- Support disabled people to better exercise their rights, choices and life opportunities;
- Support the continuing development of an inclusive and effective range of high quality health and social care services;

- Develop a more integrated approach to the planning and management of services within and across government departments, the HSC and the independent community and voluntary sector;
- Develop clear and achievable recommendations which are capable of being monitored and evaluated; and
- Ensure that an appropriate implementation infrastructure is put in place following the publication of the final strategy.

1.3 Values

The strategy addresses the needs of all age groups, both children and adults, regardless of the cause of the disability. In accordance with the articles and principles stated in the United Nations Convention on the Rights of Persons with Disabilities, it promotes:

- Dignity and respect for individual differences;
- Social inclusion and acceptance of the individual by society;
- Independence and life opportunities;
- Informed choices;
- Anti-discrimination in service provision; and
- Equality of opportunity and access to services and facilities.

The strategy has adopted a life cycle approach to service provision and support, recognising that people living with disabilities will have changing needs throughout their lives. It also recognises that people with a disability, like other members of society, have a range of needs including physical, emotional, psychological and social needs. Therefore, the strategy will address need within the context of a person-centred planning and a life-cycle approach to health and social care services.

1.4 Key Policy Principles

The strategy sets out the Department's policy for the future development and delivery of services for people with disabilities. The Department acknowledges its prime responsibility in this regard which is to set the policy context within which services are to be delivered. This is important as it is crucial that commissioners and providers are given clear guidance on how services are to be developed, prioritised and delivered. This is particularly important in the current challenging financial climate.

The policy principles underpinning the development of this disability strategy are:

- 1. User / Carer Participation** – involvement of users and carers in the planning, delivery and audit of services to ensure the maximisation of control by disabled individuals in all elements of their health and social inclusion. Service commissioners and providers should commit to working with users and carers and this collaboration should be reflected in any service level agreements developed
- 2. Equity** – the greater sharing of resources and expertise between HSC organisations. This will help promote equity of access to informed and skilled health and social care staff for people with disabilities. This will necessitate increased communication and an innovative approach to sharing of scarce resources between organisations.
- 3. Prevention / Early Intervention** – prioritising the commissioning of services that promote prevention and early assessment, diagnosis and intervention with the aim of minimising increased complexity of need in future years.
- 4. Partnership with the Third Sector** – the need to develop more effective and efficient partnerships with the voluntary, community and independent sectors. There are clear advantages to be derived from such partnerships which should be encouraged and which would enable the services provided to be maximised.
- 5. Balanced Risk - Effective Assessment and Management** – the promotion of choice and independence for people with disabilities so that barriers to accessing services are removed and people are encouraged to realise their maximum potential in all aspects of their lives.
- 6. Self Directed Support** – the introduction / further development of Self Directed Support in NI, taking account of best practice models and lessons learned from GB and NI pilot initiatives in SHSCT and in Learning Disability.
- 7. Social Inclusion** – the requirement for interdepartmental collaboration / working in partnership in terms of education, employment, health and social care, housing, leisure and transport so that people with disabilities have access to the same opportunities and choices as everyone else.

The following sections of this strategy have been developed in line with these principles. Recommendations and actions to be taken forward

within the strategy and action plan are produced in accordance with them.

1.5 Definitions of Disability and Impairment

There are a number of definitions and models of 'disability'. These include legislative, medical and social models and definitions.

The Disability Discrimination Act 1995, amended by the Disability Discrimination (NI) Order 2006, defines a person with a disability as:

'Someone with a physical or mental impairment, which has a substantial and long term adverse effect on their ability to carry out normal day-to-day activities'

The social model of disability makes an important distinction between 'impairment' and 'disability'. The key definitions within this model are:

'Impairment – an injury, illness or congenital condition that causes, or is likely to cause, a long term effect on physical appearance and / or limitation of function within the individual that differs from the commonplace'

'Disability – the loss or limitation of opportunities to take part in society on an equal level with others due to social and environmental barriers'

The strategy takes account of the social model of disability which aims to encourage society to consider disability in a different way. It makes the important distinction between 'impairment' and 'disability' in recognising that people with 'impairments' are disabled by the barriers that commonly exist in society. The basis for the social model is that it is not about the disabled person's impairment but how society reacts to it. It requires society to remove the barriers so that all people have equality of opportunity. It has been influential in altering attitudes and causing society to consider that it needs to adapt to the needs of disabled people rather than defining them as the problem.

Throughout the strategy and Action Plan where the terms "disabled people" or "people with disabilities" are referred to, this should be interpreted as including people with a physical, communication, sensory and / or neuro-disability¹ including acquired brain injury. Where the word "disability", is used it should be read as referring to physical,

¹ The term "neuro-disability" includes the range of disabilities such as Acquired Brain Injury, Multiple Sclerosis, Parkinson's Disease and congenital and childhood conditions such as Cerebral Palsy, Muscular Dystrophy and Spina-Bifida and other rare conditions such as Motor Neurone Disease, Huntington's Disease and Progressive Supra-nuclear Palsy. This is not an exhaustive list.

communication, sensory and neuro-disability including acquired brain injury. Where the term “HSC Board” is used in relation to commissioning services, this should be interpreted as including the five Local Commissioning Groups (LCGs).

1.6 Scope of the Document

The scope of the strategy will, regardless of the cause of the disability, impairment or age of the individual, include services and support in relation to:

- Physical disability;
- Sensory disability, including both hearing impairment and sight loss;
- Communication disability; and
- Neuro-disability including Acquired Brain Injury.

The strategy will pay particular attention to:

- Family and person-centred planning and a lifecycle approach to health and social care services and to support, in the context of promoting independence and social inclusion, which takes account of factors such as choice, control, dignity and respect;
- The need for partnership working directly with disabled people, families, carers and across such sectors as health and social care, housing, education, transport, leisure and employment;
- The promotion of health and wellbeing and the prevention of ill health;
- Enhancing access to a range of community, technological and advocacy services, including for example:
 - Adaptations;
 - Advocacy - Self, Peer and Independent;
 - Assistive Technologies;
 - Care in the Community;
 - Direct Payments;
 - Domiciliary Care;
 - Equipment – Prosthetics and Wheelchairs;
 - Individual Personalised Budgets;
 - Rehabilitation;

- Respite / Short Break Care; and
- Transition Planning;
- The provision of an informed and skilled health and social care workforce;
- Appropriate commissioning and service provision to promote efficient and effective care; and
- Ensuring that an appropriate implementation infrastructure is put in place following the publication of the final strategy.

1.7 Historical Context

It is acknowledged that significant changes and positive developments have been achieved over the past two decades in terms of defining and strengthening the rights of disabled people and promoting equality and freedom from discrimination for disabled people. The paragraphs below identify the key changes.

The **Disability Discrimination Act (1995)** was a landmark piece of legislation and the first anti-discrimination legislation which specifically focussed on disabled people. It effectively enshrined, in law, disabled people's rights to participate in civil society by placing duties on employers, service providers, landlords, schools and colleges. As a piece of 'rolling' legislation, the final part came into effect in September 2004.

The Disability Discrimination Act 1995 was further strengthened by the **Disability Discrimination (NI) Order 2006** and required public authorities, when carrying out their statutory functions, to have due regard to the need to:

- Promote positive attitudes towards disabled people; and
- Encourage the participation of disabled people in public life.

The **United Nations Convention on the Rights of Persons with Disabilities** (The Convention) is the first such treaty of the twenty-first century. The Convention does not create new rights for disabled people; rather it helps member countries to have a better understanding of disabled people's human rights. Signatory countries are obliged to "promote, protect and ensure full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity". The UK Government ratified the Convention on 8 June 2009.

In Great Britain (GB), the Welfare Reform Act 2009 reformed the welfare and benefits systems to improve support and incentives for people to move from benefits into work and to provide greater choice and control for people with a disability. The Department for Social Development (DSD) introduced the Welfare Reform Act (NI) 2010 which covers the majority of the GB Act's provisions in respect of social security benefits in NI.

It should be noted that the Welfare Reform Act (NI) 2010 does not take forward the provisions within Part Two of the GB Act which provides disabled people aged 18 or over with greater choice and control in relation to the way in which services are provided to or for them. These are the provisions which would potentially have the biggest impact for this strategy and the Department will need to consider whether and how these provisions would be taken forward in NI. If introduced these provisions could enable disabled people in NI to have more control over the way a range of services are provided to them.

1.8 Strategic Context

Whilst legislation is a key driver for change there are also a number of government policy documents, service frameworks, action plans, reports and guidance which collectively define the responsibilities and obligations placed on the DHSSPS, the HSC Board, the PHA and other HSC organisations. Some of the key legislation and documents referenced and relevant to the development of this strategy are listed below, and a more comprehensive list is contained in Appendix 2.

- The Chronically Sick and Disabled Persons Act 1978;
- The Disability Discrimination Act 1995;
- The Northern Ireland Act 1998;
- The Human Rights Act 1998;
- A Healthier Future 2005 - 2025 (DHSSPS);
- The Disability Discrimination (NI) Order 2006;
- The UN Convention on the Rights of Persons with Disabilities 2008; and
- Report of the Promoting Social Inclusion (PSI) Working Group on Disability (OFMDFM, 2009).²

² This strategy has due regard and strong links with the OFMDFM PSI Working Group Report on Disability and forms a significant part of the DHSSPS response to the OFMDFM PSI Report on Disability.

Policy for people with disabilities has developed to a significant extent elsewhere in the UK and this strategy recognises that it is important that people in NI enjoy similar benefits of strengthened policy. In January 2005, the Prime Minister's Strategy Unit launched the report 'Improving the Life Chances of Disabled People' with a vision that by 2025, disabled people should have full opportunities and choices to improve their quality of life and be respected and included as equal members of society.

In July 2006, the Office for Disability Issues within the Department for Work and Pensions (DWP), established an Independent Living Review with a view to developing a five year strategy for Independent Living. The aims of their strategy were twofold:

- That disabled people (including older disabled people) who need support to go about their daily lives will have greater choice and control over how support is provided; and
- That disabled people (including older disabled people) will have greater access to housing, education, employment, leisure and transport opportunities and to participate in family and community life.

This strategy proposes to adopt a similar approach to independent living but will recognise that we need to look at these issues specifically in light of our own circumstances and take account of what people in NI have been telling us over the consultation phases of this process.

1.9 Consultation to inform Strategy Development

A comprehensive series of early scoping and pre-consultation events were conducted to help inform the remit, themes and key policy principles for this strategy. This involved the DHSSPS departmental core team hosting initial scoping workshops with statutory and voluntary sector representatives and service users, followed by a series of more focussed pre-consultation events with individual community and voluntary organisations and a number of their service users.

Disability Action also hosted a number of workshops to target 'hard to reach' people in order that they were given an opportunity to have their voices heard and to put forward their views regarding the strategy. The information and feedback from these events has played a key part in helping to inform the structure and content of the strategy. Appendix 3 provides a list of the pre-consultation workshops and other events conducted for this strategy.

The pre-consultation events were followed by a full formal three month public consultation. This provided the opportunity for a range of different stakeholders (individuals including persons with disabilities, public authorities and organisations and community and voluntary organisations) to give feedback and comment on the Strategy and Action Plan.

1.10 Equality Impact Assessment - Equality Screening

Section 75 of the NI Act 1998 requires all public bodies in carrying out their functions relating to NI 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;
- Men and women generally;
- Persons with a disability and persons without; and
- Persons with dependants and persons without.

In addition, without prejudice to the above, public bodies must also in carrying out their functions relating to NI have regard to the desirability to promote good relations between persons of a different religious belief, political opinion or racial group.

The DHSSPS has carried out an initial screening of this Strategy and Action Plan and a summary copy of the analysis from that exercise is contained in Appendix 4. The outcome from the exercise demonstrated that there was no evidence to show a disproportionate impact on any of the Section 75 groups. The DHSSPS therefore considers it is reasonable to conclude that in the absence of direct evidence to indicate a discriminatory outcome for any of the Section 75 groups, a full equality impact assessment should not be conducted for the Strategy and Action Plan prior to or at the time of publication.

However, the Department recognises that in the delivery of the Strategy and Action Plan there may be specific more detailed policy areas where consideration of differential impact may have to be revisited and an assessment be conducted.

Section Two

Prevalence and Need

2.0 Prevalence and Need

2.1 Introduction

The aim of this section is to outline the extent of information currently available in relation to the prevalence of disability in NI. This section also seeks to analyse how services will need to be planned and developed in the future, taking into account influencing factors such as the increasing complexity of need and demographic change.

The term disability covers such a wide range and combination of conditions that there is no standard method or single source of information which can provide accurate data about the number of people with a disability in NI. Whilst the creation of a register to provide this information has often been proposed, it is unlikely that all people with disabilities would be in favour of it. The alternative, for researchers and those responsible for planning disability services, has been a reliance on a number of surveys, which provide estimated numbers of people with disabilities and/or on sub groups within the relevant survey.

2.2 Prevalence

Until quite recently the most widely used data source for adults with a disability was the 1992 report produced by the Policy, Planning and Research Unit (PPRU) of the Department of Finance and Personnel (DFP). This report provided information about the estimated numbers of people with a disability, the severity of their condition and who provided their care. It has been the only study which compared prevalence rates of disability in NI with other parts of the UK. In 1992 the prevalence rate for adults in NI was estimated at 17%, higher than any other region of the UK. The national average prevalence rate was estimated at 14%. The differential is often ascribed to a number of factors such as the impact of the 'Troubles', higher rates of conditions such as Multiple Sclerosis, and deprivation.

More recently the Northern Ireland Statistics and Research Agency (NISRA) in its 2007 report, covering both adults and children, provided the following headline estimates:

- **18%** of all people living in private households in NI have some degree of disability. When broken down this means that **21% of adults and 6% of children have a disability;**
- **37%** of NI households include at least one person with a disability; **20%** of these contain more than one person with a disability;

- There is a higher prevalence of disability among adult females with **23% of females** indicating that they had some degree of disability compared with **19% of adult males**;
- Prevalence **increases with age**: ranging from **5% among young adults to 67% among those who are very old (85+)**;
- Male prevalence rates are only higher than female rates amongst the youngest adults (16 to 25): **6% of males compared with 4% of females**;
- **8%** of boys aged 15 and under were found to have a disability, compared with **4%** of girls of the same age.

If one applies these figures to the current population of NI, the estimates are as outlined in Table 1 below.

Table 1 – Estimated Percentage and Numbers of People Living with Disability in NI		
Percentage of Population		Number of People
18% (Children & Adults)	-	322,000
21% (Adults)	-	285,000
6% (Children)	-	26,000

These figures are estimates and are provided for indicative purposes to illustrate the scale of the potential challenge for a strategy such as this.

The Northern Ireland Survey of People with Activity Limitations and Disabilities (NISALD) conducted in 2007 produced the following estimates of different categories of disability within this overall population.

Table 2 – Categories of Disability Prevalence Levels - Mid Year Estimates (2008)			
Category	No	Category	No
Sight	8,782	Chronic Illness	40,982
Hearing	11,709	Breathing	14,636
Communication	2,927	Learning	2,927
Mobility	35,127	Memory	5,855
Dexterity	26,345	Emotional / Psychological	14,636

A range of major voluntary organisations have added their own statistics to enrich our knowledge of the challenges which we face. A number of examples are cited below:

- 230,000 people are affected by arthritis:
- Approximately 35,000 people use wheelchairs:
- Between 3,500 and 4,000 people have Multiple Sclerosis:
- Over 150 people have Huntington’s disease:
- 150,000 people have asthma (35,000 children);
- 1,700 people have prosthetic limbs;
- Approximately 258,000 people are deaf or have a hearing loss
- Approximately 52,000 people are blind or partially sighted;
- An estimated 8,700 people have dual sensory loss; and
- Tinnitus severely affects 8,900 people in NI.

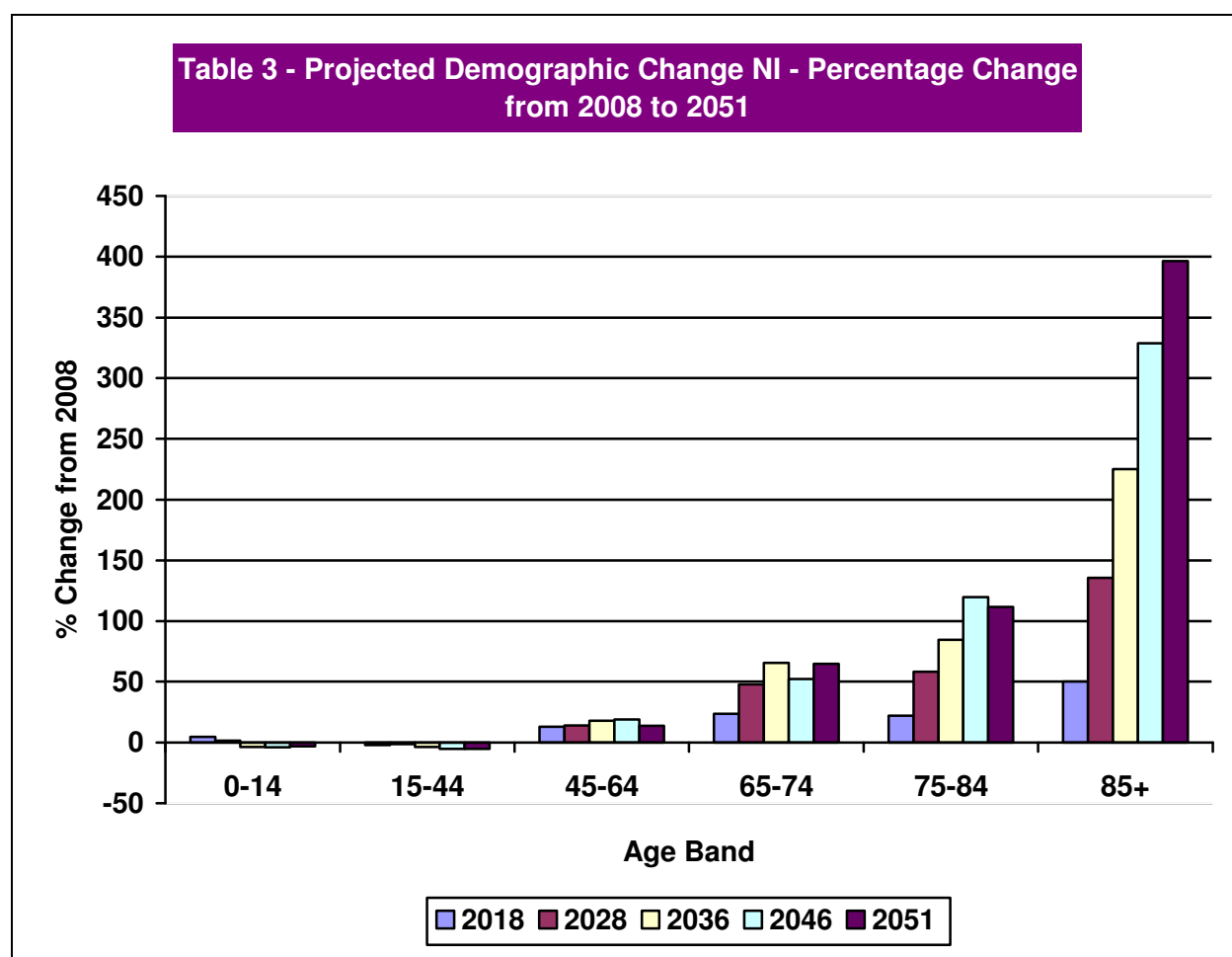
Whilst these figures are helpful in providing some indication of the variety of needs within the population, there are other important considerations which need to be borne in mind when planning services. These considerations include effects such as the impact of demography, geography and socio-economic factors and the variations which they can create.

Arguably, the most significant variable impact on the number of people with a disability is the age profile of our population. Recent estimates show that life expectancy in NI is 75.8 years for men and 80.6 years for women. While the population has been living longer, these extra years

have not necessarily been in good health or free from illness or disability.

NI's over 65 population is set to increase sharply during the next ten years – and more than double in number over the next fifty years. This projected increase will mean that the number of people over 65 could rise by 22% by 2050. An even bigger percentage increase in the number of people aged 90 or over will mean that, fifty years from now there will be nearly ten times the number of people aged 90 or more.

It is widely recognised that disability increases with age and therefore the demand on our services will grow significantly in the next decade and beyond. Although people are living longer, they will experience more years of ill-health, more people will need help with everyday activities and these numbers are likely to double by 2025.³ The chart below shows the projected demographic increase by age band from 2008 – 2051.



Source: 2010 http://www.nisra.gov.uk/archive/demography/publications/annual_reports/2008/Table2.7_2008.xls).

³ Source: Humphries R, Forder J, Fernandez J, (2010) *Securing Good Care for More People: Options for Reform*. London: The Kings Fund.

In terms of using all the available material for planning purposes we need to ensure that best use is made of relevant information emanating from the 2011 census. The census can provide a rich source of data and needs to be analysed and used effectively. It needs to be used more systematically in conjunction with general and more specific surveys and estimates to create a better source of data for planning purposes.

2.3 Addressing Need

This strategy has attempted to illustrate the scale and complexity of strategically addressing the needs of such a significant proportion of our population in a balanced, fair and effective way.

It has already been identified that there are particular difficulties with data within health and social care in terms of quantifying the overall response to need because of the variability in definition and comprehensiveness of information. There is, in fact, very little official disability-specific data available to health and social care planners and the little that is available often needs to be used in conjunction with other sources to provide a more complete picture of presenting need.

The most recent available statistical returns produced by HSC Trusts in relation to people with a disability indicate that approximately 20,000 people had been in contact with them during the year ending 31 March 2010. The table below provides a breakdown of the number of contacts by category of physical or sensory disability and age band.

Table 4 – Number and Category of Disabled People – Social Care Contact with Trusts – Year Ended 31.03.10

Category of Disability	No of Contacts by Age Band			
	Age 0-15	Age 16-64	Age 65-75+	Total
Blind	57	648	1,068	1,773
Partially Sighted	131	649	2,179	2,959
Deaf with Speech	32	175	77	284
Deaf without Speech	25	279	87	391
Hard of Hearing	128	1,037	3,760	4,925
Physical Disability	817	6,710	2,577	10,104
Total	1,190	9,498	9,748	20,436

These figures reveal that a very small proportion of the estimated disabled population access social care services to address these needs, and this may be a reflection of the effectiveness of other options available to them. The more important question is whether those who do need these services can access them and find them to be timely and responsive to their needs.

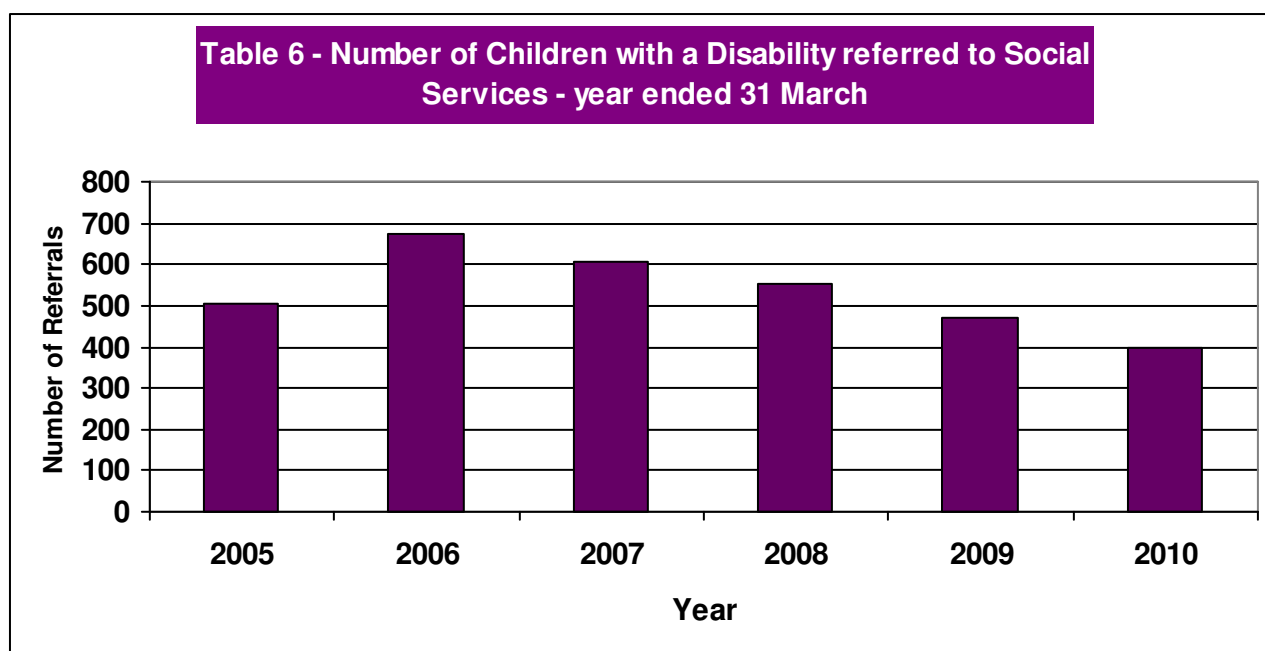
The figures present a very limited, specialist, social work perspective of the HSC system's response. There are, however, few other statistical returns which adequately reflect the contribution which the medical, nursing and allied health professional colleagues make to the disability programme (e.g. occupational therapists, speech and language therapists and physiotherapists).

The chart below illustrates the level of referral to community occupational therapy services, which demonstrates the high level of demand for services over the last decade. The service received a total of 47,363 referrals in 2009.



Note: Data for 2008 is not available. Data for 2010 is not yet available.

The chart below illustrates the level of referral to social services in respect of children with disabilities since 2005.



Source: DHSSPSNI Community Statistics (2005 to 2010)

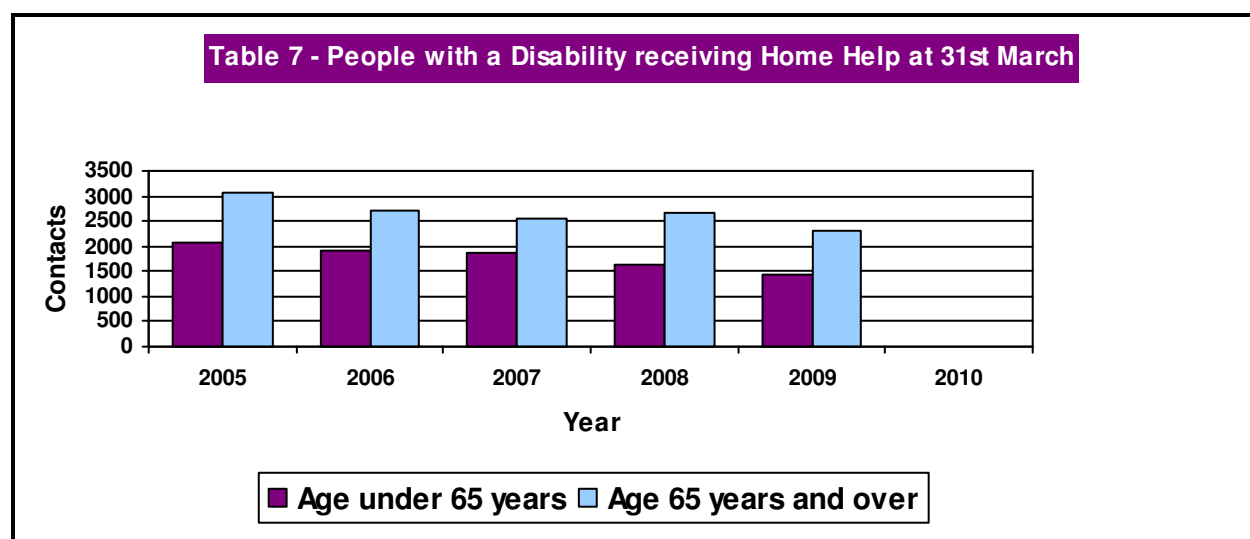
In addition to statutory services there is the very considerable contribution made by the voluntary and community sector to the care and support of people with a disability. This encompasses a range of contributions from well known national and regional organisations to more localised initiatives, and provides a variety of direct services and support to individuals and their carers.

2.4 Service Response

Within the aggregate figures outlined above there is some information about specific services which, once again, focus primarily on social care inputs and the more traditional elements of provision such as institutional, day and domiciliary care.

The information presented in the charts below reveals a stable or reducing reliance on what might be regarded as the more traditional elements of statutory service provision. For example, whilst there has been a drive to ensure as many disabled people as possible are supported at home; the statutory services which do this have seen a reduction in utilisation. The number of people under 65 in receipt of home help has seen a 30% reduction since 2004/5. This may be a reflection of higher thresholds of need/risk to get access to services, and it may reflect more intensive support packages being provided and a more focussed use of domiciliary support.

The chart below provides an illustration of the number of people with a disability under age 65 years who are receiving home help.



Source: DHSSPSNI Community Statistics (2005 to 2010).
Home help data not collected after 2009

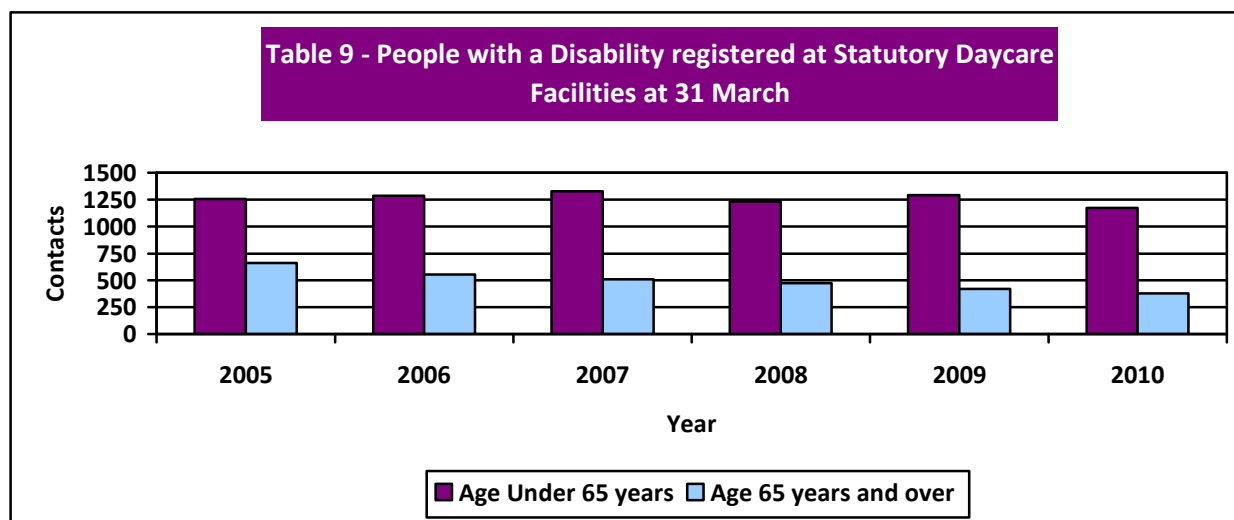
This apparent decline may be due to an increased awareness of the availability of Direct Payments, which may reflect a more assertive and independent constituency of disabled people, or that Home Help provided as part of a domiciliary care package is not included in the above figures.

The figures for the number Direct Payments in effect for the Physical Disability Programme of Care 2008 – 2010 at the end of each quarter are presented in the table below and depict a steady increase each quarter.

Table 8 - Physical Disability Programme of Care - Direct Payments in Effect at the End of Each Quarter 2008 – 2010

HSC Trust	30 Jun 2008	30 Sept 2008	31 Dec 2008	31 Mar 2009	30 Jun 2009	30 Sept 2009	31 Dec 2009	31 Mar 2010	30 Jun 2010	30 Sept 2010
Belfast	102	104	112	133	146	151	165	166	167	170
Northern	77	89	98	126	135	156	136	133	138	150
Southern	67	68	72	82	86	87	111	110	114	114
Western	41	45	45	52	53	54	58	58	56	52
South Eastern	85	86	84	83	88	92	94	93	97	101
Total	372	392	411	476	508	540	564	560	572	587

The numbers of those who use statutory day care as a proportion of those known to the HSC sector has remained consistent over the same period. This is depicted in the chart below and, in 2005, represented 19.8% of the overall number of disabled people who had been in contact with Trusts, rising to 20.4% in 2009.



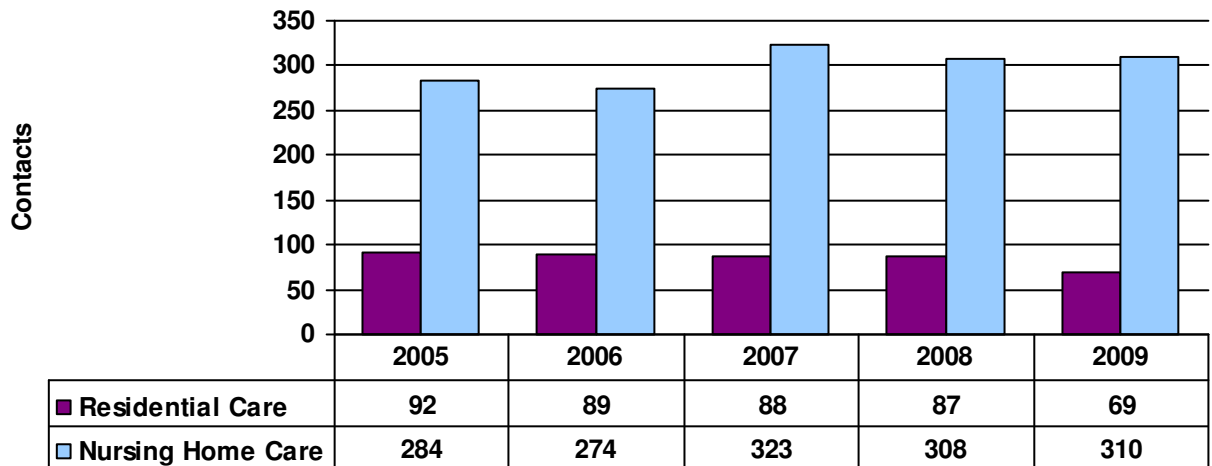
Source: DHSSPSNI Community Statistics (2005 to 2010)

Once again, however, this apparent trend needs to be viewed in the context of a major rethink of the role and function of traditional day care options.

The third example of this trend is in the use of residential and nursing care homes. The use of residential care has gradually declined and the use of beds in nursing homes has slightly increased. This may be due to increasing levels of dependency of people with disabilities and/or the relative shortage of specialist services in the community to respond to those levels of dependency. It also needs to be viewed in the context of the development of supported living for people with disabilities as an alternative to traditional models of care.

The charts below shows the care packages in effect for persons aged under 65 years and 65 years and over with a physical or sensory disability in residential and nursing home care.

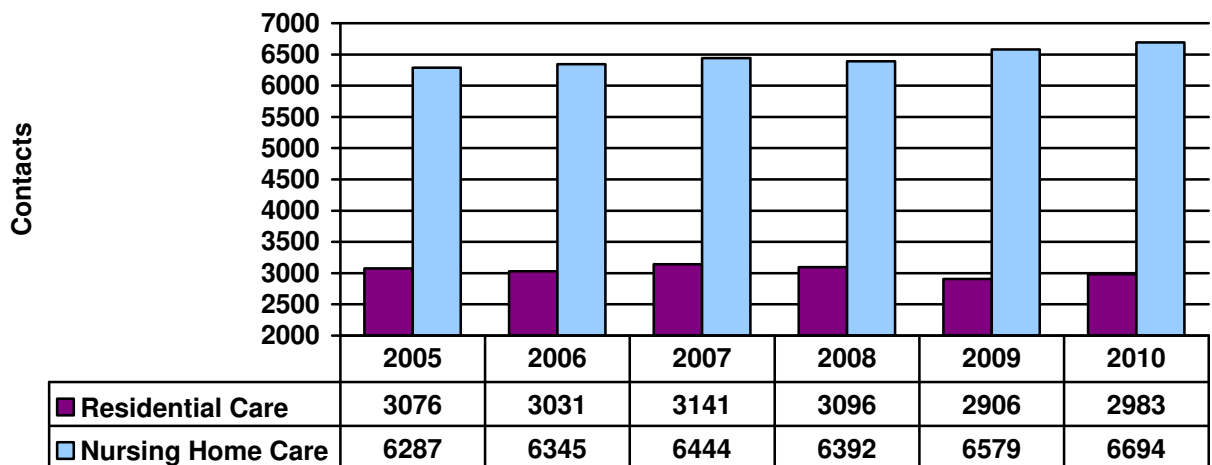
Table 10A - Care Packages in Effect for People with a Disability (0-64 yrs) in Residential and Nursing Home only at 31 March



Source: DHSSPSNI Community Statistics (2005 to 2010)

Note: Includes Statutory, Voluntary and Private Sectors

Table 10B - Care Packages in Effect for People with a Disability (65 years and over) in Residential and Nursing Home only at 31 March



Source: DHSSPSNI Community Statistics (2005 to 2010)

Note: Includes Statutory, Voluntary and Private Sectors

All of the above points to a reduced reliance on some of the more traditional models of care, which is likely to be influenced by the growing demands of people with disabilities to have a greater degree of control over the services they require and for them to be more innovative and person-centred. It is worth noting that there have been many examples of innovation in day opportunities across NI, underpinned by a desire to

move away from high volume statutory services to more tailored, responsive provision.

An example of this has been the recent investment in respite / short break care, which is a highly valued support by both service users and their carers. Whilst some of this has been delivered within some of the more traditional service models referred to above, there have been promising developments in terms of low and high intensity domiciliary respite.

Table 11 below shows the most recent figures for both the overall volume of input in terms of hours and expenditure on respite / short break care in the physical disability Programme of Care in 2008/09.

Table 11 – Respite / Short Break – Volume of Hours and Expenditure by Trust – 2008/09					
HSC Trust	Belfast	South Eastern	Southern	Northern	Western
Volume of Hours	80,366	91,891	101,627	94,030	105,207
Expenditure	£482,107	£764,067	£565,559	£284,179	£583,903

These trends should be viewed positively as a move by people with disabilities away from traditional models of care. This may present an opportunity to promote concepts such as personalisation and self directed support to a greater degree than was possible previously. It is anticipated that there will be an increased focus on the further development of short break and respite care in terms of service improvement, innovation and modernisation.

The success of Direct Payments, after a slow start, has made a major contribution to promoting greater independence, control and choice. The number of recipients and resources committed has increased steadily as outlined in the table below.

Table 12 – Direct Payments in Effect – 2007 – 2010

All Programmes of Care				
Quarter Ended	30 Sept '07	30 Sept '08	30 Sept '09	30 Sept '10
No of recipients	762	1029	1511	1773
Amount Paid	£1,395,683	£1,782,291	£2,572,603	£3,101,705
Physical Disability Programmes of Care				
Quarter Ended	30 Sept '07	30 Sept '08	30 Sept '09	30 Sept '10
No of Recipients	312	392	540	587
Amount Paid	£532,574	£636,368	£864,763	£1,046,534

2.5 Children and Young People

In light of the above analysis, which relates mostly to adults, and the absence of a comprehensive set of data in respect of children and young people with disabilities, the following paragraphs set out the approach to the planning and delivery of children's services in NI.

The key strategic drivers for children's services are the OFMDFM Ten Year Children's Strategy 'Our Children and Young People: Our Pledge' and the DHSSPS 'Families Matter Family Support Strategy,' which draw heavily upon the **UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities**. The policy principles and proposals in this Strategy and Action Plan, relating to children and young people have been developed, in accordance with the articles and principles of both of these Conventions

The Children (NI) Order 1995 is the primary piece of legislation in respect of children in NI. Article 17 states that a child shall be taken to be in need if "he is disabled." Article 18 determines the statutory responsibilities of HSC Trusts to provide for 'children in need' in their area, including disabled children. In addition, Article 19 provides for support for 'children in need' within early years, which also includes children with disabilities. The Order requires HSC Trusts to take account of the child's individual circumstances and to engage with parents when assessing needs of children with disabilities.

2.6 Children's Services Planning

Schedule 2 of the Children (NI) Order 1995 places a statutory responsibility on the HSC Board to review services for 'children in need' and their families and publish an annual children's services plan in consultation with a range of agencies. This will be done through the Children and Young People's Strategic Partnership (CYPSP) which has regional responsibility for the integrated planning of services for children and young people. The CYPSP is a multi-agency, strategic partnership consisting of the leadership of all key organisations that have responsibility for improving outcomes for all children and young people in Northern Ireland including health, social services, education, policing and housing as well as representatives from the voluntary and community sectors.

Community and voluntary sector involvement is being facilitated through a selection process run by Children in NI (CiNI) together with the NI Councils for Voluntary Action (NICVA) and Ethnic Minorities (NICEM). The HSC Board are also proposing to use the CYPSP as a platform to contribute to the implementation of other strategies including the OFMDFM Strategy and the Families Matter Strategy and the Partnership will oversee a number of groups which will take forward integrated planning for children and young people. These groups will include one relating to children and young people with disability and one relating to transition which will address transitions for young disabled people. The participation of children and young people and their parents will be facilitated to ensure that all plans made are appropriate. The task of both these groups will be to ensure that integrated plans are made which improve the planning and delivery of six identified high level outcomes for children, which focus on the need for them to be:

- Healthy;
- Enjoying learning and achieving;
- Living in safety and with stability;
- Experiencing economic and environmental well-being;
- Contributing positively to community and society; and
- Living in a society which respects their rights.

For example developments in relation to children with disabilities benefitted from the Children and Young People Funding Package, which has provided a dedicated and ring-fenced resource to enable a collaborative engagement between health and educational services in supporting children with a range of additional needs through early

identification and intervention. Each HSC Trust has established multi-disciplinary teams with a focus on collaborative working with educational settings in pursuit of these objectives. This has included:

- The enhanced recruitment of allied health professionals especially speech and language therapists to provide greater support to after school and early years' settings;
- Extra funding for services around prosthetics and digital hearing aids;
- The enhancement of services for children and young people following the Regional Wheelchair Review; and
- Support for young people with additional needs through transition with an emphasis on the provision of alternatives to traditional day care settings for these young people as they transition to adult services.

2.7 Families Matter - The Family Support Strategy

The DHSSPS “Families Matter” Strategy 2009 focuses on the need for integrated planning but with the fundamental perspective of the child/young person and their carers at the centre of the process and participating fully in the decision making. It adopts the Whole Child Model and provides the following definition:

The Whole Child Model, which is supported by international best practice, suggests that improving outcomes for children and young people can only be achieved effectively through integration at the following three levels:

- Integrated planning of services for children, young people and families.
- Integrated services for children, young people and families – across agencies and sectors.
- Integrated direct work with children, young people and their families – through approaches with multi-agency teams and services based together, so as to address the range of the child and family needs in a holistic way.

2.8 Children’s Services Pathways and Service Frameworks

The Wraparound Project, which was introduced in August 2003 by the then Southern Health and Social Services Board (SHSSB), provides a good example of best practice in terms of an integrated and multi-

agency, multi-disciplinary team approach to planning and providing services for children, young people, their families and carers. Appendix 6 contains a copy of the Wraparound Manifesto Standards. This strategy recommends that an approach similar to the Wraparound Initiative, which takes account of the Whole Child Model and UNOCINI, should be implemented in all HSC Trust areas in NI for children and young people's services.

It is vital also to highlight the complexity of multiple disabilities and/or dual diagnoses often prevalent in children with disabilities, and to address these needs based on the Whole Child Model. As part of these service pathways, the same minimum level of service should be available across all HSC Trusts on an equal basis.

2.9 Understanding the Needs Of Children In NI (UNOCINI)

The regional work undertaken by the DHSSPS Reform Implementation Team (RIT), in partnership with key agencies, has implemented the service improvement programme within children's services. This reform has been underpinned by the introduction of the Understanding the Needs Of Children In Northern Ireland (UNOCINI) model of assessment and service planning. The key pathways as outlined within the UNOCINI framework are cross-disciplinary and cross-agency and are centred upon the needs of the individual child.

The UNOCINI framework has been agreed as the primary service pathway for children's services within the HSC and for key agencies involved with children and young people. UNOCINI has applicability to all situations where 'children in need' assessments are required and where the outcome of such assessment of needs requires services to be provided. The framework, which is needs-led, includes a 'child in need' pathway which can accommodate children and young people with disability. The UNOCINI framework also allows for the undertaking of specialist assessment in cases where, for example, there may be complex physical healthcare needs and where a more in-depth and specifically focused assessment is required given the needs of the child and their carers.

2.10 Children and Young People with Complex Physical Healthcare Needs

Current guidance relating to children and young people with complex physical healthcare needs is contained in the document "*Developing Services for Children with Complex Physical Healthcare Needs*" – DHSSPS 2009. This document sets out proposals for the improvements

required to health and social care provision for these children and young people and their families. The areas for improvement comprise three elements: These are

- An Integrated Care Pathway for Community Services (ICP).
- A Regional Nursing Assessment Tool.
- The Development of Short-Break Services.

These proposed service developments are being taken forward under the auspices of a Regional Inter-agency Implementation Group. Although the implementation proposals are presented separately, there is a great deal of overlap among them not least because the same personnel in HSC services and the non-statutory sector will have an involvement in all three areas.

The proposals reflect the complexity of care and support services that is required to be provided to children and young people with exceptional needs. To a degree they reflect the examples of good practice that can be found in parts of Northern Ireland and can be reproduced regionally at comparatively little expense as follows.

- A detailed Integrated Care Pathway has been developed that can overcome many of the inefficiencies, duplication and communication failures in existing provision
- A Nursing Assessment Tool has been developed that has the potential to delineate the specialised interventions required by these children and families.
- Proposals for an incremental increase in the type and quantity of short break provision have been developed.
- Specific workforce improvements have been identified which would cost a relatively small proportion of the overall budget of child and family services.

The document acknowledges that the research and development undertaken for this work places Northern Ireland to the forefront of service developments for this client group within these islands and possibly beyond. It argues that the greatest lesson to emerge is a reinforcement of what can be achieved when families and practitioners from all sectors cross the boundaries of precedent and roles and together join forces in pursuit of the common objective of providing better lives for children and young people in our society.

2.11 Links to Education

The links to education for children and young people with disabilities are vital and the involvement of a child, young person and parent is imperative to ensure the appropriate action is taken to address their educational needs. The Education (NI) Order 1996 identifies a child as having 'special educational needs' (SEN) if he/she has a learning difficulty which calls for special educational provision to be made for him/her. A child has a 'learning difficulty' if he/she has:

- a significantly greater difficulty in learning than the majority of children of his/her age;
- a disability which either prevents or hinders him/her from making use of educational facilities of a kind generally provided for children of his/her age in ordinary schools; or
- Not attained the lower limit of compulsory school age and is, or would be if special educational provision were not made for him/her, likely to fall within either of the previous two paragraphs when he/she is of compulsory school age.

More recently, provisions introduced in the Special Educational Needs and Disability (NI) Order (SENDO) 2005 strengthen the right of a child with SEN to be educated in mainstream schools where parents want this and the interests of the other children can be protected.

Statutory responsibility for securing provision for pupils with SEN rests with both schools and the five Education and Library Boards (ELBs), which are responsible under special education legislation for identifying, assessing and, in appropriate cases, making provision for children with SEN in their areas. Under this legislation the five Education and Library Boards have a statutory duty to place children with SEN within the grant-aided sector, be that mainstream or special school. When considering appropriate placement of the child, the education board and schools must consult and work in partnership with the parents of the child to ensure the child's needs are fully met.

The 2009/10 school census has recorded 63,100 children on the SEN register:

- 33,451 children within the primary school sector;
- 1,672 children within pre-school and nursery schools;
- 23,535 in post primary education 11-19 years of age;
- 4,443 within special schools sector.

The total represents 19.2% of the overall number of children who have been enrolled in school within NI. The number of children on the SEN register has been steadily increasing over the last 5 years.

The most relevant information pertaining to pupils with SEN leaving education and going on to further education, higher education, employment or unemployment is taken from the 2007/08 Census. 24,091 pupils left school this year with 3,505 of them being on the SEN register as having a “special educational need”:

- 373 pupils went on to higher education = 10.6%
- 1,235 pupils went on to further education = 35.2%
- 423 pupils taking up employment = 12.1%
- 1,136 pupils going to some form of training = 32.4%
- 226 pupils unemployed = 6.5%
- 112 pupils who have left school and have not been recorded against any of the above = 3.2%.

Section Three

Promoting Positive Health, Wellbeing and Early Intervention

3.0 Promoting Positive Health, Wellbeing and Early Intervention

3.1 Introduction

There is growing recognition of a need to place greater emphasis on the promotion of health and wellbeing and the reduction of health inequalities for all people, including those with a disability. Although people in NI are living longer and their health has improved greatly over the past century, too many still die prematurely or experience serious illness or disability which could have been prevented. There are unacceptable inequalities in health, with the poorest more likely to be sick or disabled and to die prematurely. It is generally accepted that poverty is one of the greatest determinants of health.

People with disabilities are susceptible to the same chronic conditions experienced by the general population (e.g. cardiovascular disease, respiratory disease and poor mental health). This is very often in addition to conditions secondary to their disability (e.g. people with spinal cord injury are more susceptible to developing pressure sores and kidney infections).

Compared with the non-disabled population, disabled people are also more likely to experience disadvantage in their daily lives. This is evidenced⁴ in the fact that they are:

- Less likely to reach their maximum educational potential;
- More likely to be unemployed;
- More likely to experience poverty;
- More likely to experience discrimination in relation to housing, employment, transport and leisure services.

These factors can have a significant and lifelong impact on the health and wellbeing of people with a disability.

This section aims to promote optimal health and wellbeing within the disabled person's unique circumstances, whereby health is not simply viewed as the absence of disability, but rather, is regarded as the ability to function effectively in given environments, to fulfil individual needs and to adapt to major stresses.

⁴ Sources: i) Report of the Promoting Social Inclusion Working Group on Disability - OFMDFM 2009; ii) Improving the life chances of disabled people OFMDFM Jan 2005).

The promotion of positive health and wellbeing and early intervention for people with disabilities needs to address three key areas:

- I. Supporting individual lifestyle choices;
- II. Primary, secondary and tertiary action to address the specific and individual needs of those experiencing a disability;
- III. Reducing the effects of the wider social determinants of health and social exclusion.

In bringing forward this Strategy and Action Plan, the Department will consider what opportunities there are to promote positive attitudes towards disabled people and encourage their participation in public life, pursuant to the disability duties under the DDA 1995. For example the opportunity to promote positive attitudes and encourage the participation of disabled people in public life will be taken. In addition when bringing forward health promotion initiatives the HSC sector will have an opportunity to depict people with disabilities in a positive light.

3.1.1 Supporting Individual Lifestyle Choices

Creating equality of choice and opportunity for people with a disability to adopt healthy lifestyle choices is a key factor in promoting improved health and wellbeing. As with non-disabled people, there are significant health benefits to be realised through individuals adopting healthy lifestyles and behaviours related to factors such as:

- Increasing levels of physical activity;
- Improving diet;
- Improving oral health;
- Stopping smoking;
- Managing the use of alcohol and drugs;
- Reducing stress and the factors that affect mental and emotional wellbeing;
- Adopting healthy sexual lifestyles.

Policies, strategies, programmes and services should encourage and support individuals to adopt healthy lifestyles. These need to embrace the needs of people with a disability and ensure equality of access and opportunity for all. Service providers need to consider the specific needs of the individual in terms of access, environment and support to ensure they can take full advantage of the opportunities to adopt healthier lifestyles.

3.1.2 Primary, Secondary and Tertiary Action

In maximising the individual's potential to enjoy a healthy and fulfilled life experience, it is essential to promote effective disability prevention strategies.

- Primary prevention is focussed on action to prevent the occurrence of some disabilities via a number of strategies, which include the availability of pre-conceptual counselling, including genetic counselling, the promotion of positive health behaviours in all aspects of daily living such as hearing, vision, communication, skin care, mobility and activity and sexual health.
- Secondary prevention is focussed on early identification and detection of disability followed by appropriate intervention. Secondary prevention strategies include the provision of maternity care, antenatal and neonatal screening and the universal child health promotion (e.g. Healthy Child, Healthy Futures) programme. Secondary prevention strategies also include specialist support from multi-disciplinary teams to prevent the progress of the disability (e.g. speech and language therapy services for children with communication disabilities).
- Tertiary prevention is focussed on reducing the impact of the disability and improving quality of life through e.g. active rehabilitation. Tertiary prevention strategies include the provision of Expert Patient Programmes and Specialist Rehabilitation Programmes (e.g. Respiratory and Cardiac Rehabilitation).

3.1.3 Reducing the Effects of the Wider Social Determinants

Improving health and wellbeing requires coordinated and concerted action across organisations and communities to address the wider social determinants of health, such as income, housing, employment, relationships, personal safety, security, environment, educational opportunity and access to services. All of these factors combine to create a situation in which people with a disability experience higher levels of social exclusion and as a result poorer health and quality of life than those without a disability.

Addressing the health and wellbeing needs of disabled people requires an approach that supports the individual to lead in identifying not only their needs but in finding the right solutions to these by taking into account personal choice. These solutions and the response of those involved in providing the solutions needs to be dynamic and responsive

to the changing needs, experiences and situations of individuals over the course of their lives. Solutions need to be multi-faceted and focussed on making a real and lasting difference. HSC commissioners and providers, planners, educators, employers, those involved in providing housing, transport, leisure and recreation services, providers of goods and services and local communities themselves are key in ensuring that the health and wellbeing of disabled people is the best it can be.

Removing or lowering the barriers that often limit the life experiences of people with a disability and marginalises them within our society is central to improving their health and wellbeing. Action to address these barriers needs to focus on:

- Creating positive attitudes towards people with a disability that challenge many current negative stereotypes;
- Ensuring the policies and practices of organisations provide equality of access and opportunity;
- Environments (e.g. home, workplace, transport systems, leisure and recreation services) that embrace the specific needs of people with a disability;
- Empowerment that ensures disabled people are fully involved in identifying their needs, designing services and solutions to address these and in being part of the response.

3.2 Promoting Mental Health and Wellbeing

In keeping with the Bamford Review, the NI Mental Health Promotion Strategy and the “Protect Life” Suicide Prevention Strategy demonstrate that there is a need to ensure that the factors affecting the mental health and wellbeing of people with a disability are effectively addressed.

The Mental Health Promotion Strategy which is currently under review has highlighted that the following factors contribute to positive mental health and wellbeing:

- A nurturing childhood – the early years (particularly from conception to 3 years old) are of unique importance in terms of intellectual, emotional and social development;
- Education – making use of the capacity to learn, grow and develop;
- Being in employment – having good working conditions;
- Having good physical health and being active;
- Being socially engaged – taking part in community activities.

- Having strong personal relationships;
- Living in a healthy environment – having access to urban green spaces, warm housing, affordable and accessible transport; and
- Being in a safe community free from the threat of violence and crime.

At an individual level there is a need to promote positive mental health and build resilience by addressing factors such as family and personal relationships, social engagement, physical health, childhood experiences, educational attainment and personal development.

At a broader level there is a need to address the social determinants of health and wellbeing, such as access to employment and training, leisure and recreation, income, healthy living and working environments, safety, security and social involvement. Programmes, services and support mechanisms need to be developed to reflect the particular needs and circumstances of individuals with a disability and, as a result, ensure they promote positive mental health, build resilience and reduce the factors that negatively impact on mental health and wellbeing.

3.3 Balanced Risk Taking

The governing principles behind good approaches to choice and risk are that:

- People have the right to live their lives to the full so long as that does not stop others from doing the same;
- People should be enabled to make independent choices about their health and wellbeing;
- People should be helped to manage identified risks in everyday living; and
- Positive risk taking should be promoted where possible with the aim of empowering children and adults with disabilities to fulfil their goals and ambitions to the maximum potential.

3.4 Promoting Good Hearing Health

Hearing loss is becoming increasingly prevalent in a society where the population is ageing and where young people are facing potentially dangerous levels of exposure to noise in their social lives.

Taking action to encourage the public to value their hearing and address hearing loss includes the need to identify treatable hearing loss as early

as possible and then to act on it. Preventing unnecessary hearing loss can be achieved through education and promotion of public health messages, and people with existing hearing loss can be encouraged to take action by raising awareness of hearing loss and tackling the stigma surrounding hearing loss.

3.4.1 Prevention

Action on Hearing Loss research shows that 90% of young people have experienced the signs of hearing damage after a night out, and two thirds listen to their MP3 players at dangerously loud volumes, but most are not aware of the potential damage this could cause to their hearing. A programme of awareness-raising among the public about the dangers of over exposure to loud noise and to encourage them to take steps to protect themselves could have a positive impact on levels of hearing loss in the future.

3.4.2 Early intervention

Untreated hearing loss can lead to isolation for an individual with a negative impact on personal relationships, employment, social life, and ultimately mental health. More than half of people over the age of sixty have some degree of noticeable hearing loss.

On average a person with hearing loss takes 15 years to address it. Action on Hearing Loss evidence shows that people who take up hearing aids earlier not only enjoy an improved quality of life, but also use the technology more easily, adapt more quickly and experience more gains. Research also shows indicates that people who wear hearing aids participate more regularly in social activities, have lower levels of depression, and experience less stress in their family lives than those who did not address their hearing loss.

More information needs to be provided to the public on interventions and support available for hearing loss.

Early intervention is crucial in meeting the health needs of deaf children and in particular the promotion of their wellbeing. Deaf children are often identified from as early as five weeks old as a result of newborn hearing screening programmes. The benefits of such programmes in assisting with earlier diagnosis allows for early referral and intervention with enhanced outcomes for children and their families.

3.5 Promoting Good Visual Health

The UK Vision Strategy, which was launched in April 2008, was developed in response to the World Health Assembly resolution to reduce avoidable blindness by the year 2020, and improve support and services for blind and partially sighted people. The DHSSPS is committed to playing a full role in ensuring that these aims are met.

The implementation of the NI Vision Strategy is being led by RNIB through the Vision Strategy Implementation Group, aiming for major transformation in eye health, eye care and sight services through a united cross-sectoral approach. It builds on the work of the Regional Steering Group for Sensory Impairment.

The Vision Strategy has three key outcomes:

1. Improving the eye health of the people;
2. Eliminating avoidable sight loss and delivering excellent support to people with sight loss;
3. Inclusion, participation and independence for people with sight loss.

For many people visual impairment is associated with a reduced quality of life and is linked to such health issues as injury from falls in older people and increased incidence of depression. It also has an economic impact and is associated with socioeconomic deprivation. Age is a risk factor for visual impairment, signalling the potential for an increasing burden on eye care services in the future.⁵

The aims, objectives and priorities of the Vision Strategy are consistent with this strategy and should be regarded as the approach to addressing the needs of people with visual impairment during the strategy period.

The Department of Health, Social Services and Public Safety is currently developing an eyecare strategy "Developing Eyecare Partnerships, Improving Eyecare Provision in NI". This strategy recognises the aims of Vision 2020 and the successful multi-disciplinary models of care already in development in Northern Ireland and operating in other parts of the UK, and will make a number of recommendations with the aim of developing a new way of partnership working across primary and secondary care sectors and across disciplines within each sector.

⁵ Reference: Visual Loss in N. Ireland: The Picture in 2009. Julie Ann Little

3.6 Early Intervention for Children with Communication Disabilities

It is vital that a child or young person with a communication disability receives the appropriate help and support in an early and ongoing timely manner; otherwise the risk of that disability having a long-term effect on their future lives is greatly increased. Speech, language and communication needs can, if left untreated, lead to lower educational attainment, behavioural problems, emotional and psychological difficulties, poorer employment prospects, challenges to mental health, and in some cases, a descent into criminality.

A Speech, Language and Communication Therapy Action Plan was developed by the DHSSPS and launched on 22 March 2011. The Action Plan is providing the strategic direction for the further development of HSC speech and language therapy services over the next two years. Key elements of the plan include:

- Commissioning and service redesign to maximise outcomes;
- Supporting and empowering children, parents and carers;
- Enabling HSC staff to promote early recognition, assessment, intervention, treatment, care and support; and
- Collaboration between speech and language therapists and teachers and education professionals to enable them to promote early recognition, assessment, intervention and support.

The following is a pen picture of a 22 year old who told us about how he has been able to access services throughout his childhood up to the present time.

Chris is 22 years old and lives in Belfast. This is what Chris told us about his day to day life and how he is able to access services which enable him to live a healthy active life.



I was born with diplegic cerebral palsy which basically means that my legs don't work very well. I can use crutches but usually get around in a wheelchair.

I attended Fleming Fulton Special School from age 2½ (nursery) and left in 2006 with 8 GCSEs. After this, I went to Belfast Metropolitan Collage to do a double award A-level in ICT.

After leaving school I worked in a call centre for a year and also did some voluntary work in Fleming Fulton School. I am now in paid employment working part time for the School.

I got my own house a few months ago and, despite the challenges, I really enjoy living on my own. I have been learning to cook and can do my own ironing, vacuuming and washing - my mum is very proud of me and I can now properly appreciate all the hard work she did for me as I was growing up. I have some difficulty with certain household / domestic tasks and I am hoping to get help with this.

During the summer months I play basketball and tennis. My dad and cousin both play basketball and although neither of them is disabled we very often play wheelchair basketball – those are the games which give me the edge. I am a big cinema goer and like to go clubbing once a week. I passed my driving test about a year ago and have my own car, but I often use public transport when I am going out. Having the options around transport makes a big difference in terms of enabling me to access services and pursue leisure and social activities.

Having diplegic cerebral palsy means that I have no sense of balance. The health service provide very good wheelchair training which taught me how to balance my chair when navigating ramps or kerbs. It's a pity the health service did not provide a better choice of wheelchairs. In England they have a voucher scheme which contributes towards the costs of a wheelchair if you do not like anything on offer from social services. It would be great if there was a similar scheme here.

I would say that my main difficulty in living life as a disabled person is accessing services, particularly services like physiotherapy which I need to maintain my mobility. When I was at Fleming Fulton School, all my health needs were met through the school. It has been difficult to adjust to having to access them myself.

There are some very good websites which help signpost people to services. I would recommend the BBC "Ouch" website <http://www.bbc.co.uk/ouch/> as a very good source of information and discussion forum for disabled people. I warn you though it's not for the easily offended but it provides an up-beat if slightly irreverent analysis and account of real issues and experiences from disabled people's perspective. This is where I learned about the wheelchair voucher scheme.

3.7 Safeguarding Adults – Preventing and Protecting Against Harm in Partnership

The Strategy recognises the considerable progress made, to date, in relation to adult safeguarding in NI. There has been an increased recognition in recent years that a range of adults, for a variety of reasons, are open to harm through abuse, exploitation or neglect. It is crucial that, throughout the implementation phase of this Strategy and Action Plan, there is compliance with the effective safeguarding requirements and standards of best practice which are set out in the current frameworks and guidance⁶. These require individuals, professionals and agencies across both the statutory, community, voluntary and independent sectors to work in partnership to prevent harm, or, where harm occurs or is likely to occur, to build protective measures around the person at risk.

⁶ Relevant documents are referenced in Appendix 2

Section Four

Providing Better Services to Support Independent Lives

4.0 Providing Better Services to Support Independent Lives

4.1 Introduction

This section describes how the HSC can contribute to the provision of better services and support to help disabled people live independent lives.

4.2 Improving Services and Support

The key areas in terms of improving services to support and further promote independent living options for disabled people as identified during the pre-consultation events for this strategy include:

- Personalisation:
 - choice and control;
 - family / person-centred planning; and
 - self-directed support;
- Information, advice and advocacy, especially around long term conditions and rare diseases;
- Provision of a skilled workforce;
- Equipment;
- Rehabilitation;
- Short breaks / respite;
- Service re-design;
- Transition support / planning;
- Day opportunities, including:
 - Inclusive lifestyle support;
 - Vocational and employment opportunities; and
 - Increased opportunities for people with complexities of need;
- Housing; and
- Transport.

The following is a pen picture of a 23 year old who told us about how she has been able to establish her independent lifestyle and make her own decisions and choices.

Andrea is 23 years old and comes from Pomeroy in Co Tyrone. She now lives in Belfast. This is what Andrea told us about how she is able to live an independent life making her own lifestyle choices



I began developing sight problems at the age of eight as a result of juvenile arthritis. Prior to this, my vision had been pretty good and I was already in P3 in St Mary's Primary School, Pomeroy when I began to notice my sight deteriorating. Despite this I continued my education through St Mary's Primary School and St Patrick's Academy, Dungannon with the support of a classroom assistant.

I would say that my experience in mainstream education was largely positive and generally I received the support I needed throughout my time at school. In the main teachers were aware of my visual impairment and made reasonable adjustments to ensure that I was able to access the class and study material. The fact that I had access to the school's Special Educational Needs Co-ordinating Officer and Liaison Officer meant that, through a series of regular reviews involving my parents, my teachers and myself, reasonable adjustments continued to be made as my needs evolved.

I got to know my Community Vision Co-ordinator (Jackie) when I was in my early teens. Jackie helped me with social activities such as shopping and meeting up with other young people. My rehabilitation worker (Mark) helps me with social care activities such as cooking, mobility etc. Mark also provides me with assistive technology and equipment which help promote my independence.

I attended Queen's University Belfast where I completed my degree in law and politics. I graduated in June 2008 and began work in the NICS in November 2008. While in college I did some volunteering for RNIB in order to get some work experience but would have liked to have been able to explore / access a wider range of options and opportunities for paid work during my time at university.

I enjoy working in the NICS and although always busy, the fact that my work environment is largely electronic makes it easier to carry out my day to day tasks. My personal computer has 'Job Access With Speech' or JAWS software and a scanner which helps me deal with a wide range of matters including correspondence for the Minister's Private Office.

I found the 'Access to Work' initiative run by DEL very helpful in ensuring that my workplace adjustments were assessed and met and the assistance I am provided with to travel to work make this a lot easier than it would otherwise be.

I enjoy singing and recently was successful in a citybeat competition and I am currently learning to play the guitar. Like a lot of other girls I enjoy shopping (building up my collection of designer shoes has been the basis of many a Saturday afternoon shopping expedition). I also enjoy cycling – I have a tandem and I enlist either my dad or my boyfriend as the sighted front cyclist on my cycle rides.

4.3 Personalisation

The objective of this section is to ensure that services promote independent living by ensuring that disabled people have choice and are supported to empower themselves regarding the assistance they need.

4.3.1 Choice and Control

The Disability Rights Commission has defined independent living as “all disabled people having the same choice, control and freedom as any other citizen at home, at work and as members of the community. This does not necessarily mean disabled people ‘*doing everything for themselves*’ but that any practical assistance people need should be based on their own choices and aspirations.”

It has been argued that too often the needs of people with disability have been met in ways that do not give people choice and control, and that the traditional service-led approach has often meant that people have not received the right help at the right time and have been unable to shape the kind of support they need. This strategy promotes the view that all services should be delivered within a “personalised” framework, and that therefore there is a need to vigorously promote this approach in an attempt to reshape and modernise services.

Personalisation is about giving people much more choice and control, and the focus is on timely, preventative and high quality personally tailored services with everyone having maximum possible control and power over the support services they receive.

Personalisation encourages a new, more flexible approach to service provision. It is one that focuses on the person using the services and their carers and that is able to adapt to innovative support offering broader opportunities, which include the scope for people to take appropriate risks.

4.3.2 Family / Person-Centred Planning

Given the variety and complexity of disabilities, there is a need to develop and provide support and access to services in a range of ways that are suitable to the needs of the family in the case of a child, and the individual in the case of an adult. In order to respect people’s dignity and right to privacy while promoting social inclusion and independence, it is vital that the planning process is family and / or person-centred as appropriate and recognises the unique impact of each disabled child and / or adult’s circumstances.

This strategy has already recognised that each person or child with a disability is different and has needs which are unique to them which will evolve and change over time. Services must therefore be designed and delivered in a flexible way to allow the people who need them to make informed choices about the care and support they wish to receive.

There must be a partnership approach, where people with a disability are not merely passive recipients of services but active participants, along with their family and carers. In order to achieve this it is vital for health and social care professionals to be able to take every reasonable step to include the individual or the family who will be receiving the services in the planning process. An essential starting point in the process of family and person-centred planning is therefore to involve the individual, the family and their carer/s.

A further essential element which is key to the success of this approach is effective interagency working and partnership with community, voluntary and private sectors to commission services appropriate to the needs of individuals. Appendix 7 contains generic care and referral pathway diagrams, which attempt to capture and encompass the range of services which may be required throughout a disabled child or adult's life.

For children, early intervention, effective transition, succession planning and support throughout their lives is critical to family centred planning. The Wraparound Initiative, as initiated by the then SHSSB in August 2003, is an example of a good practice model. "Wraparound" provides for a multi-agency, multi-disciplinary approach to providing health and social care services for children with a disability and their families. It is, in effect, a "one stop shop" for families of children with a disability, whether in a community or hospital setting. It is recommended that an approach similar to Wraparound is adopted in all HSC Trust areas in NI for providing services for children with disabilities.

4.3.3 Self-Directed Support

This strategy supports the aim of providing support packages which are based around the person's individual circumstances and which are chosen and controlled by them. It also acknowledges that there are lessons to be learned from the implementation of self directed support and individualised / personalised budgets in other parts of the UK and from pilot projects in NI.

A project, recently initiated within the Southern HSC Trust, which is of particular interest for this strategy is the 'Living Your Life to the Full'

project. The initial overall aim of this project had been to improve the quality and impact of community services delivered by the Southern HSC Trust's Older People and Primary Care Directorate (OPPCD) for older people living in their own homes. Since its initiation the scope of the project has been broadened to incorporate all adult PoCs.

The project will design, develop and introduce a new service model which will provide a stronger platform not only for continuous improvement and efficiency but more importantly to help ensure the Trust is in a better position to respond to future demand given the anticipated future demographic trends and resource constraints. The Project will have three key strands:

1. Care Bureau
2. Access and Information
3. Re-ablement

The following are some of the key issues and challenges which, along with lessons learned from other projects and initiatives, need to be taken into account in order for self-directed and personalised support to be successfully introduced in NI:

- Assessment and advice from a specialist in the management and control of the person's disability;
- Assistance from professionals who listen to the individual's views in order to understand the impact of their disability on their life and help them to plan the support;
- Sufficient resources, whether in the form of Direct Payment or a budget, to support people's needs effectively; and
- Where the person wishes to manage the budget themselves, support to broker services to meet needs.

4.3.4 Long Term Conditions

The DHSSPS has developed a Policy Framework for the care and treatment of adults in Northern Ireland with one or more long term conditions. The Policy Framework has been developed in partnership with key stakeholders including the Long Term Conditions Alliance in Northern Ireland.

The overall aim of the policy framework is to help HSC Commissioners, Trusts, the Public Health Agency, the voluntary & community sectors and independent care providers plan and develop more effective

services to support people with long term conditions and their carers, enabling them to get the best from the health and social care system. The policy framework will be a strategic driver in the reform and modernisation of services to support better health and social care outcomes. It is expected that, subject to Minister's approval, the Policy Framework will be published in March 2012.

4.3.5 Rare Diseases

At the time of publication, a draft National Plan for Rare Diseases in the UK is under development. The draft Plan will include input from expert stakeholders from research, patients and patient organisations, clinicians, the pharmaceutical industry, commissioners and wider government and health and social care organisations.

It is proposed that the draft Plan will include commitments to:

- Ensure clear healthcare pathways are developed for people with rare diseases with cooperation, contribution and input from all relevant experts;
- Provide co-ordinated care for people with rare diseases within a multidisciplinary team approach to help counter fragmentation across organisational boundaries – this is important because many rare diseases affect a number of systems within the body, so very often patients need to see healthcare professionals from several different specialities during their lifetime; and
- Improve the availability and provision of information about services and support for rare diseases.

4.4 Information and Advice

Information can hold the key to feeling empowered and being independent and is crucial to inclusion, yet many disabled people indicate that they are often unaware of what services are available to them. Having access to information at the right time can help people stay independent and in control of their lives. However, information of itself is not enough for all disabled people: getting advice and advocacy in order to use it to best effect is needed by many.

Disabled people should not be disadvantaged in accessing information or services, and appropriate information should be available in a choice of formats, for example, audiotape, Braille, easy read or large print, on request. Information should reach everybody who might benefit from it in a form they can readily absorb. For this to be achieved, the right

decisions have to be taken at the earliest stages of planning and budgeting. Accessible formats should never be an afterthought. Websites should be designed and maintained to the highest levels of accessibility and usability.

People using different forms of communication such as British or Irish Sign Language (BSL / ISL) and those who are deaf or hard of hearing or are blind or visually impaired need support to help them access information about health and social care services. This may range from interpreting services to Braille tuition, to dedicated courses in the use of everyday ICT, as well as requiring equipment such as low vision aids or high specification audio equipment. Other forms of communication support for hard of hearing people and those with acquired/sudden hearing loss, including electronic note taking and lip speaking, may also be required.

The strategic significance of providing good quality information is understood by all stakeholders and it is generally recognised that there is a wide availability of information from a diverse range of statutory and voluntary providers. However, evidence shows that ensuring access to information, and the support to make effective use of it, is a very difficult task. A critical issue going forward is to look at how existing information systems can be made more user friendly, efficient and effective. The challenge is to improve co-ordination and signposting between information providers across professional / governmental boundaries, and remove unhelpful barriers to information provision.

For example, a “one stop shop” is often suggested as a solution, and while this can be helpful to some it can have limited value for others because it relies on individuals finding the one-stop. Recent research by the Joseph Rowntree Foundation indicates that a more productive approach is to focus on a “no wrong door”, which aims to ensure that wherever disabled people make contact with the system, they receive the information and advice that they need or, at least, are directed to sources of such support.

4.5 Family Support Website

The HSC Board has developed the NI Family Support website which gives details of a wide range of services provided by statutory, voluntary and community organisations. The website is a publicly available free resource (www.familysupportni.gov.uk).

The information provided relates to family support services that are available locally and the website maps family support services at local

and regional levels across NI It provides full profile details for the services including contact details, access and referral arrangements.

The website is aimed at members of the public wishing to access a specific family support service, help or advice or frontline staff to help them get up to date information on the location of family support services. It can also be used by organisations/partnerships as a planning tool that can be linked to outcomes for children and young people.

4.6 Advocacy

Advocacy is a vital service that can empower and support people including those with disabilities who need it to access opportunities, make choices, and encourage inclusion in services and communities.

The need to develop advocacy services in Northern Ireland was highlighted in the Bamford Review and, following a workshop held by the Advocacy NI Network in January 2010, the DHSSPS set up a working group chaired by PCC to develop principles and standards for the future commissioning and delivery of advocacy services. Informed by the outcomes of stakeholder workshops in September 2010 and May 2011, a draft policy guide for commissioners was published for consultation on 27 June 2011. The Department is currently considering the outcomes of the consultation and it is intended that the final policy guide will be published in late Spring 2012.

Further more detailed guidance for commissioners will also be prepared once the detail of the new statutory right to an independent advocate in the proposed Mental Capacity Bill which the Department is currently working on has been fully developed

4.7 Provision of a Skilled Workforce

A trained and skilled workforce is essential to the delivery of a modern and responsive health and social care service for disabled people. The workforce should be continually developed to provide specialist services for people with complex needs and steps should be taken to ensure that staff are adequately informed and skilled to respond appropriately to the needs of disabled people whilst respecting their rights to privacy, dignity and equality.

It is essential that health and social care employees are equipped with the right skills for the future, to enable them to deliver services within new service models where there is increased emphasis on personalisation, on multi-disciplinary team working and on involving

service users themselves in planning and providing service to meet needs.

Providers will need to ensure that staff training and development is informed by the principles of personalisation and family / person-centred planning, and that the use of self-directed support is promoted when and where it is appropriate to do so. To facilitate this, the HSC Board and HSC Trusts should develop the necessary skills and capacity to carry out organisational workforce planning in relevant disciplines.

4.8 Equipment

The timely and adequate provision of suitable equipment is crucial to the promotion of an independent life for many disabled people. This relates the full range of equipment available to people with disabilities including all varieties of mobility aids and also the range of equipment offered to people with sensory disability. It is important too that the range of equipment provided is kept under review to ensure that it remains “fit for purpose” and continues to meet the needs of the disabled person, and is available in an equitable manner across Northern Ireland. Repair and replacement of equipment should be provided in a timely manner as, very often, the use of equipment is key to enabling a disabled person to be socially active and / or to access services. The lack of a timely and responsive service in this regard has, in the past, led to long term social exclusion for some disabled people.

4.8.1 Wheelchairs

In December 2006 the DHSSPS launched a Regional Review of Wheelchair Services with the fundamental principle that it must be undertaken in partnership with wheelchair users and professionals involved in providing the service. The Regional Wheelchair Review Group produced the document ‘Proposals for the Reform of the NI Wheelchair Service’ in August 2008 and a Regional Wheelchair Implementation Board is working to implement the report’s recommendations.

As part of this reform programme, the DHSSPS adopted a Whole Systems Thinking approach using Lean methodology to eliminate waste and streamline wheelchair services in NI. This placed the service user or customer needs at the heart of the design and delivery of services, and produced remarkable improvements in waiting times for basic wheelchairs, as well as successfully increasing choice and quality of service. For example:

- There has been a reduction in waiting times for a basic wheelchair from an average 125 days to an average 15 days.
- Processing times for basic wheelchairs (i.e. the time spent by HSC staff actually processing application referrals for wheelchairs at the different stages of the process) have been reduced from 507 minutes to 90 minutes. Work is completed more rapidly and by the most appropriate staff, which has resulted in a saving on specialist clinicians' time, as well as a significant reduction in waiting times.
- Increased cost benefits are now being realised through the refurbishment of wheelchairs by an approved repairer. A refurbished manual wheelchair now costs £55 instead of £120, and a refurbished powered wheelchair costs £246 instead of £2000 or more.
- Emphasis has also been placed on the establishment of locally based wheelchair resource centres, so that people who need wheelchairs and associated equipment no longer have to undertake difficult and/or lengthy journeys. Each health and social care trust outside Belfast now has at least 2 local wheelchair resource centres.

A guide for wheelchair users on the eligibility criteria for the provision of wheelchairs was issued to HSC Trusts in November 2010⁷. This guide was produced by the Occupational Therapy Wheelchair Working Group, the Community Occupational Therapy Managers Forum and wheelchair users on behalf of the Wheelchair Service Reform Board. It outlines the process of how to get a wheelchair through the Northern Ireland Wheelchair Service. The document was drawn up to take account of the individual needs of wheelchair users and the range of wheelchairs available from the Northern Ireland wheelchair service.

4.8.2 Prosthetics

The Belfast HSC Trust, through its Regional Disablement Service, operates a small regional Prosthetics Service based at Musgrave Park Hospital. It provides services to all its clients in line with their specific assessed clinical needs and with due regard to its equality responsibilities under Section 75 of the NI Act 1998.

The Westminster's Government's 2008 Command Paper, "The Nation's Commitment" challenged administrations across the UK to recognise the particular issues facing military personnel and their families when

⁷ Regional Eligibility Criteria for the provision of wheelchairs through the Northern Ireland Wheelchair Service - A guide for wheelchair users; DHSSPS, HSC, November 2010

seeking to access public services, including health and social care services.

In August 2009, DHSSPS issued “Delivering Healthcare to the Armed Forces – A Protocol for Ensuring Equitable Access to Health and Social Care Services⁸.” Its aim is to ensure that members of the armed forces, their families and service veterans should experience no disadvantage when compared to other members of the community in accessing health and social care services. The protocol provides an opportunity for departmental officials and HSC to work with the armed forces and veterans’ organisations to help resolve any difficulties. In particular, the protocol requires DHSSPS to ensure that the standard of prosthetic limb provision to injured Armed Forces personnel by the Defence Medical Services will, as a minimum, be matched by the HSC system.

The above paragraphs cite examples of the Department’s position and undertaking in relation to the provision of wheelchairs and their commitments regarding the quality of prosthetic limbs to Armed Forces. However, consideration must also be given to other prosthetic services for example prosthetic eyes.

4.9 Rehabilitation

There is a need to improve access to responsive, high quality care and rehabilitation services for disabled people. Services need to be developed to enable more people to benefit from anticipatory care in terms of specialist and vocational rehabilitation and support to improve the knowledge, expertise and skills of specialist and non specialist staff in both the statutory and voluntary sector.

This strategy recognises that there are important areas where policy is well developed which include:

- 1.** A Review of Adult Neurology Services in Northern Ireland was completed in November 2000. The Review Group was charged with advising the Department on the state of service provision and with making recommendations for improvement. The findings were published in May 2002.

In May 2009 the Minister commissioned a full and comprehensive evaluation and report on the effectiveness of the implementation of the 30 recommendations from this Review. This evaluation was taken forward by the HSC Board as regional commissioner of

⁸ http://www.dhsspsni.gov.uk/delivering_healthcare2.pdf

services in NI, and shows that whilst considerable progress has been made in the implementation of the majority of the recommendations, there are some areas where action is still required. The HSC Board has requested further updates from each HSC Trust covering these areas and will continue to work with the PHA and the Department to ensure that these issues are addressed.

In parallel to this work a Neurological Conditions Network has been developed to ensure the delivery of appropriate treatment and support to people with long term neurological conditions in all settings and thereby achieve the best possible outcomes. This important area of work is also being taken forward by the HSC Board and the PHA and has an active membership from the community and voluntary sector.

The Department will continue to receive regular updates in relation to the progress being made in all areas of this work.

2. On 9 June 2008 DHSSPS published *Improving Stroke Services in NI*, which set out recommendations for improving all aspects of stroke care including prevention, treatment and rehabilitation with a view to ensuring that stroke patients, their families and carers receive a more responsive, patient focussed and effective service regardless of where they live in NI. A Regional Stroke Implementation Group (RSIG) has been established to take forward and to oversee implementation of the recommendations.
3. The Acquired Brain Injury Action Plan which was launched in July 2010 by DHSSPS provides clear time-bound goals to drive service improvement and co-ordinate action to improve outcomes for people with acquired brain injury, their families and carers. The key aim will be to promote a person-centred approach to earlier recognition, diagnosis, treatment, rehabilitation, care and support for people affected by acquired brain injury, their families and carers. Work on the implementation of the Action Plan is being led by the HSC Board through the Regional ABI Implementation Group.

The following is a pen picture of a 66 year old man who told us about how rehabilitation and speech and language therapy helped him to recover from the effects of a stroke which he suffered 14 years ago.

John is 66 years old, and lives in Crossgar, Co Down. This is what John told us about the support and assistance he received to help him recover from his stroke



I had a stroke 14 years ago when I was 52 years old. At that time I had my own painting and decorating business and also owned a pub.

After the stroke I spent 9 months in hospital and for three years I could not speak at all. The stroke also left me with limited use of my right arm and right leg and I could only get around in a powered wheelchair.

I attended the Joss Cardwell rehabilitation centre which helped with my mobility and also received speech and language therapy sessions at home. I can now walk with the use of a stick and I can drive

as I have an adapted car provided under the motability scheme.

I have been attending the Stroke Association for about 14 years now. I learned about the Association (then called "*Action for Dysphasic Adults*") from another member. I attend conversation classes most weeks and can now speak well. I can sign my name and can understand the written word but have some difficulty retaining information. The use of symbols or pictures can make things easier to understand and remember.

My painting and decorating business closed immediately after my stroke. My son managed to keep the pub going for about seven years but that too has now closed.

I used to enjoy playing football and darts but am unable to do either now - indeed, I played football for Aston Villa's second team in 1959/60. I also used to go swimming every week from Downpatrick Day Centre but this stopped due to staff shortages.

I enjoy attending the Stroke Association's conversation classes and try to support and encourage other members. I am also Treasurer of the Knockbracken Conversation Group which I find both challenging and rewarding. I also like to go shopping with my wife and going out for meals.

4.10 Short Breaks / Respite

Respite care provides short-term and time-limited breaks for families and other voluntary carers of people with disabilities, either on a planned or emergency basis. The purpose of respite care is to support and maintain the care giving relationship while providing a positive experience for the cared for person. Respite can be anything from a few hours per week to a number of weeks, and services may be used frequently or infrequently.

Respite care takes many different forms. It should be age aligned and can be delivered in different settings, for example:

- People's own homes;
- Day care facilities;
- Residential care homes;
- Short breaks with specially-trained host families; and
- Youth and leisure facilities.

Families and carers should be aware of the full range of options available to them and the services should be flexible and innovative. Some of the feedback from the pre-consultations conducted for this strategy indicated that some of the short break care currently available in NI could be further developed to enable it to be more family-friendly and better tailored to the individual needs of the person with a disability. There is evidence from the development and advancement of initiatives in GB, such as Aiming High for Disabled Children (Department for Education, 2007), which suggests that short breaks in the form of host families or adult placement schemes provide for much more flexibility and family-friendly respite care provision.

In August 2009 work was initiated jointly by the DHSSPS and the HSC Board to establish the activity and expenditure in relation to the provision of respite care services. This resulted in the development of two reports:

- Management Information on Adult Respite Provision – First Phase Report – December 2009; and
- Respite Support – Second Report – December 2010.

The first report examined the various collection and reporting mechanisms within and across Trusts and highlighted the need for robust, consistent information on activity and expenditure in respect of respite services.

The second report contains a number of recommendations to address the issues identified in the first report. The HSC Board has established 2 working groups, one each for children's and adult services, to take forward the implementation of the recommendations. A report on progress will be provided to the Department in April/May 2012.

4.11 Service Re-design

The development of this strategy provides an opportunity to review health and social care services for disabled people with a view to re-design to reflect a shift in emphasis towards personalised, person-centred and self-directed care and support. This could also entail, for example, identifying opportunities for service re-engineering and re-design to promote personalisation in terms of different types of short breaks and respite provision and in a range of more focussed advocacy support. Potential opportunities to identify areas where resources may need to be released in a different way, rather than requiring additional resources, should also be pursued.

4.12 Transitions / Support Planning

The strategy aims to help ensure a smooth transition from hospital to home, school into employment, further or higher education, and community based programmes across a range of statutory, social, recreational, voluntary, vocational and educational sectors, and from paediatric to adult health services.

Person-centred planning is now acknowledged as an important approach to help enable adults with disabilities to live as independent a life as possible. This has led to the development of innovative practices and the evolution of transition services across the statutory and voluntary sectors, which seek to ensure that young disabled people make appropriate choices when leaving school. It is recognised that the process of transition from children's to adult health and social care services can have its difficulties.

There is still significant development work required in terms of making the transition process as seamless as possible for people with disabilities and their families. In addition, the increasing population of young disabled people with complex needs who are surviving into adulthood because of improvements in therapies and medical care requires careful planning and more intricate packages of transitional support. In order for the life-chances of disabled children and young people to be improved, enhanced co-ordination and teamwork across a wide range of departments and agencies, including health and social

care, education, employment and the voluntary sector, is to be encouraged. Any lack of multi-agency working can lead to confusion over roles and responsibilities in transition planning and ongoing support.⁹

For young people with visual impairment, for example, there are issues around transferring from the familiar environment of school and no longer being supported by the specialist visual impairment teaching service. There are particular challenges to be addressed around raising the achievement levels and participation of people with visual impairments in Further and Higher Education.

Access to adult health and service care services is often critical for the physical and emotional well-being of young disabled people, particularly those with complex needs. A poor transition from children's to adult services can threaten the health of young disabled people and undermine other transitions in education, work, social relationships, and independent living.

Similarly during the pre-consultations some young people with a disability advised that they had experienced difficulties in accessing specialist health and social care services once they moved out of children's services. This included access to physiotherapy and occupational therapies, which are readily available for young people, particularly for those who have been in the 'special educational needs' system. Deaf young people described problems with communication when they move clinics and the differences between different models of hearing aids between adult and children's services. Greater support, whether in terms of anticipatory care or pre-planning for transition from children's to adult services is to be encouraged particularly given the progressive nature of many conditions.

A Regional Interagency Transitions Group has been established, under the auspices of the HSC Board, to address the transition issues for young people with complex healthcare needs. The work of the Group will be to focus on the management of transition to adult services with a view to ensuring that services are provided in line with the overarching standard - *"Every child and family should have an agreed transfer plan to adult services in both acute hospital and community services, and no loss of needed service should be experienced as a result of the transfer"*. Some of the key activities to be taken forward by the Regional Interagency Transitions Group are:

⁹ Reference: Promoting Social Inclusion Report, Inter Departmental Working Group on Transitions, Pathways to Further and Higher Education Conference June 2009

- Commissioning and implementing a Regional Integrated Care Pathway for Transition;
- Encouraging formation of multi-agency transition groups at HSC Trust level and ensuring meaningful participation from professionals and young people/families; and
- Developing an education/training module for professionals working with young people (especially managing complex technical equipment etc).

The work of the Inter Departmental Working Group on Transitions, which was established under the auspices of the Ministerial Sub-Committee for Children and Young People, is considering the area of transitions for young people with special educational needs from school to college and from school or college to employment, training or social care settings.

4.13 Day Opportunities

Day opportunities are intended to help people with disabilities to live fuller lives outside their homes by empowering and supporting them in their lifestyle choices to do the things they enjoy in their communities. This has involved a minor shift / progression from the more traditional day care services which are designed to provide company, stimulation, and other support services in a day care setting very often for the benefit of a disabled person and their carer.

The objectives for the continued provision of both day care services and day opportunities for disabled people are two-fold in this regard:

1. To ensure that services support disabled people to realise and access a life lived according to the principles of independent living, but do not take its place; and
2. To ensure that disabled people experience services that are better integrated and which support them to live in their own homes and be active in their own communities.

4.13.1 Inclusive Lifestyle Support

Many disabled people can be socially isolated because of a lack of opportunity for emotional, social and peer support. Many opt out of traditional services, such as statutory day care, because they do not consider that they meet their needs, and evidence shows that even those who do successfully participate in an inclusive service are not guaranteed sustained inclusion. Many disabled people find that they

cannot sustain their inclusive outcome once they have left a service. Therefore, service commissioners and providers might wish to consider service models that promote the development of social networking opportunities that can heighten the community engagement of disabled people. This would have the dual impact of:

- Helping to prevent disabled people needing care and support in the first place or developing long term dependencies on health and social care provision.
- Sustaining outcomes from alternatives to traditional day care and other time limited interventions.

4.13.2 Vocational and Employment Opportunities

Disabled people are still disproportionately dependant on benefits and under-represented in the labour market. They are also more likely to have no qualifications and less likely to be engaged in formal learning and development. Vocational services play a significant role in offering more appropriate alternatives to day care. They open up opportunities for disabled people to develop the personal skills and confidence to access further education and training in mainstream environments and help increase their personal effectiveness, resilience and employability skills, thus reducing dependency on statutory support and ultimately bringing them closer to the labour market.

An infrastructure of socio-vocational services has been developed across the voluntary and community sectors in NI which aims to enhance the social and economic inclusion of people with disabilities. This should be supported and developed as far as resources will allow.

4.13.3 Increased Complexity of Need

Due to improvement in medical technologies and therapies that have prolonged life, there are likely to be proportionately more people with complex needs requiring services in the future. This has implications for day opportunities in terms of the support services provided and the types of outcomes that are achievable for a more dependent group of people.

Consideration should be given to the capacity of the existing provision to meet need; the requirement for improving the capacity of existing services to respond effectively to the emerging needs of individuals with complex needs; and the need for new models that support them to access opportunities for community integration.

4.14 Housing

Housing is an integral component of independent living for disabled people, and the lack of appropriate housing and support can result in people being admitted to inappropriate living environments in residential or nursing homes. The Department for Social Development's Social Housing Development Programme includes provision for new builds that assist with the housing requirements for people with disabilities e.g. supported living. It is the responsibility of the Northern Ireland Housing Executive (NIHE), Housing Associations, the HSC Board and Trusts to work collaboratively to develop housing support services which complement the provision of care to enable disabled people to live as independently as possible.

Supporting People is a UK wide programme which funds a range of housing support services which are designed to improve the quality of life and independence of vulnerable groups. These services range from floating support services designed to deliver housing support to people in their own homes, to the provision of housing support in specialist supported housing projects which provide more appropriate models of independence than residential care provision. The ethos of independent living recognises that many people need some kind of assistance, ranging from personal care and housing support services to assistive equipment and home adaptations.

Advances in technology, including Telecare and Telehealth and SMART technology, are enabling individuals with increasingly complex disabilities to live independently in the community. This requires close working relationships between health and social care providers and housing agencies.

Whilst the NIHE and the HSC Trusts have specific responsibilities for the provision of housing adaptations it is essential that there are strong inter-agency working arrangements in order to develop independent living options for people with disabilities. For example, issues such as waiting times for adaptations can have a major impact on the independence, quality of life and emotional well being of disabled people and their carers, as well as resulting in extra care costs.

The strategy recognises that the DSD and the DHSSPS are currently engaged in an Interdepartmental Review of Housing Adaptations Services which will continue until early 2012. A Joint Housing Adaptations Steering Group (JHASG), established after the last DHSSPS / NIHE Joint Fundamental Review of Housing Adaptations

Services in 2002, provides cross sector support for a core group managing the current review.

The central focus of the group will be on processes that directly affect the lives of disabled people. Among other things, the JHASG will examine:

- Current and potential future demand for the housing adaptations service;
- Joint interdepartmental resources available, including HSC Trust community equipment, to meet the housing and independent living needs of older and disabled people; and
- Interagency co-ordination of complex case work and the range of options/solutions which can be utilised to meet assessed needs.

It is anticipated that the core group will provide a report with recommendations for submission to the Ministers for Health, Social Services and Public Safety and Social Development in early 2012.

4.15 Transport

Transport issues are often highlighted as a major barrier for people with disabilities in accessing goods and services.

In 2005 the Department for Regional Development published the Accessible Transport Strategy (ATS) 2005-2015. This Strategy seeks to address the range of barriers that impede use of the transport system by older people and people with disabilities; barriers which prevent them from carrying out everyday functions or leave them excluded from activities that others are able to enjoy.

Since the launch of the ATS, improvements to the accessibility of the transport network have focussed on providing transport services, infrastructure and information that provides for equitable access and aids more independent living. Work has concentrated on building accessibility for people with disabilities into transport programmes, providing new public transport vehicles which comply with DDA accessibility standards, building in accessibility to new infrastructure and services, making information accessible and improving staff training.

The result of this has been significant improvements to the transport network for people with disabilities. Examples include all Metro bus services in Belfast now being operated by low floor buses,

improvements to the accessibility of the Ulsterbus fleet and by 2012 all NI Railways commuter trains will be fully accessible. The development of other services including Door-2-Door in urban areas and supporting Community Transport Partnerships in rural areas has also improved transport opportunities for those people who find it difficult to use or access mainstream public transport.

Work will continue to further improve the accessibility of the public transport network via DRD in order to ensure that it plays a part in bringing about a more inclusive society for all.

This strategy takes the opportunity to signpost the information that can be found on the NI Direct Website.¹⁰, in relation to the range of transport services available for disabled people.

¹⁰ <http://www.nidirect.gov.uk/index/information-and-services/people-with-disabilities.htm>

Section Five

Supporting Carers and Families

5.0 Supporting Carers and Families

5.1 Introduction

Recognising and addressing the needs and wishes of carers and families is central to this strategy's objectives. That said, it is recognised that not all people with disabilities need or want carers and some people with disabilities are carers themselves.

The definition of a carer will be that used in the Carers Strategy¹¹:

“Carers are people who, without payment, provide help and support to a family member or a friend who may not be able to manage without this help because of frailty, illness or disability. Carers can be adults caring for other adults, parents caring for ill or disabled children or young people who care for another family member”

One of the key principles in providing services for people with disabilities is to support independent living and full citizenship. The care and support for an individual should be a matter of choice and whether an individual takes on caring responsibilities should also be a matter of choice.

No assumptions are to be made, therefore, that caring follows automatically from disability, or that people with disabilities may not take on caring responsibilities themselves: this can be particularly true of older carers, among whom the prevalence of debilitating long-term conditions may be higher. For that reason, any recommendations made in relation to carers here are aimed at those who do provide care where this is required.

There have been a number of significant positive developments in this area in recent years. The Carers and Direct Payments Act (NI) 2002 imposed a duty on HSC Trusts to inform carers of their right to an assessment of their own needs. The purpose of this holistic assessment is to identify what information, training or services are required to support the carer in their caring role. In addition attention is drawn particularly to the following key documents:

- **Caring for Carers** – this is the Carers Strategy published by the DHSSPS in January 2006. The aim of the strategy is to recognise, value and support the caring role. It represents a long term plan of action to deliver on a number of recommendations in support of that aim;

¹¹ “Caring for Carers” – the carers strategy published by DHSSPS in January 2006

- **Circular HSS (ECCU) 4/2006** – this circular was issued by the DHSSPS to the HSC Boards and Trusts and all GPs in November 2006, and provided guidance on the implementation of key aspects of Caring for Carers;
- **Promoting Partnerships in Caring: Inspection of Social Care Support Services for Carers of Older People** – this report was published by the DHSSPS in December 2007. The report's recommendations and the subsequent Standards for Adult Social Care Support Services for Carers, published in June 2008, were intended to contribute to the provision of a clear framework for the provision of social care support services to carers;
- **Audit of Support Services for Carers** – this report was published by the DHSSPS in June 2008 as a result of an audit carried out by PricewaterhouseCoopers (PwC) UK to examine HSC Trust provision of support services to carers in NI. The report makes a number of recommendations relevant to all carers; and
- DHSSPS and DSD undertook a joint **Review of Support Provision for Carers**, which was published in September 2009 and followed a similar review to that of the National Carers Strategy in England in 2007. The Review report made a number of recommendations for both DHSSPS and DSD in relation to carers.

These documents outline current well-developed policy in health and social care on carer support and services, and contain some one hundred and seventy recommendations relating to work ongoing within HSC Trusts for carers. All HSC Trusts are actively engaged in modifying and improving existing services for all carers to bring them into compliance with the published recommendations.

This work encompasses a range of aspects of support and services for carers such as: HSC staff interaction with carers; provision of information for carers; carers as partners in care; young carers; support services for carers; and employment and training for carers. Implementation of these recommendations is being monitored through the use of a "Self Audit Tool", which was developed by DHSSPS and issued to HSC Trusts in April 2009. The findings from this "Audit" were passed to the HSC Board in June 2010 and they have been asked to ensure that all necessary efforts are being made by HSC Trusts to address any weaknesses in service provision. The HSC Board have also agreed to take over responsibility for the Carers Strategy Implementation Group, a group

which was originally established to oversee the implementation of the Carers Strategy but will now also assume responsibility for overseeing the recommendations contained in the Review of Support Provision for Carers.

In light of this ongoing work, this strategy will adhere to what is current policy for carers and will also follow closely the priorities set out in “Caring for Carers” and the subsequent inspections, reviews and audit reports as outlined above. The priority areas, within current policy, for carers are:

- Identification of Carers;
- The relationship between Carers and Service Providers;
- Information and Training;
- Support Services;
- Employment; and
- Help for Young Carers.

Similarly the key principles set out in the Carers Strategy for NI are confirmed for this strategy. They are:

- Carers are real and equal partners in the provision of care;
- Carers need flexible and responsive support;
- Carers have a right to a life outside caring;
- Caring should be freely chosen; and
- Government should invest in carers.

5.2 Young Carers

Either alone or as part of a family, there is a significant number of young carers in NI. A young carer fits the description of a carer as used in the Carers Strategy but is a person of school age.

Young carers have the same rights as adult carers, but their situation brings with it specific additional challenges:

- All children, including those who are carers, have developmental and educational needs which must be met, and young carers specifically must be supported to ensure their needs in this regard are met;

- Their caring role is not always well recognised and understood within the education and health sectors and this can have a significant and specific impact on their lives;
- As children they cannot access Carers Allowance or other social security benefits.

In view of the above analysis, in terms of the ongoing work and current policy in respect of carers, this strategy does not advocate any new or additional actions or recommendations for carers. However, it underpins and adheres to current policies, principles and priorities for carers.

The following is a pen picture of a lady who cares for her son in which she explains the things that are important for her in terms of her caring role.

Anita lives in Enniskillen and cares for her son who is in his early 20's and was badly injured in a road traffic accident. This is what Anita told us about her experiences caring for her son.



When my son was injured, I found out that your whole life can change in a moment. Before the accident, I knew nothing about head injury or disability – I never needed to. I have learned so much since becoming a carer.

The main thing I have learned is that healing the physical injuries is hard, but it's not as hard or as long a process as healing the mental and emotional trauma. And the same is true for carers. At the beginning, caring for my son was very physically demanding, tending to his day-to-day needs, but as he has begun to recover physically, what has been more difficult is

helping him to come to terms with the mental injuries. You can't see the mental scars on the surface, and that makes it more difficult for other people to understand them.

The other striking thing about caring is how much responsibility you are taking on for another person. If you make a bad decision about your own health, that's one thing, but to be responsible for the health and well-being of someone you love, well, that's much more scary. I make sure now that I keep myself as fit and healthy as possible, because I need to be around for my son.

I think that my background, coming from India, has made me more resilient. I grew up expecting that I would have to work hard to overcome obstacles. I have encountered nothing but help and support from health and social care professionals, although sometimes I had to educate them about my son's cultural needs or reassure them that I understood everything that was going on.

I think it's really important for carers to get together to support each other, and to talk about their lives, so other people (including other family members) will understand the pressure and the responsibilities that caring involves.

I have had to put my own career and my own hopes on hold, but I'm happy to do this for as long as my son needs me. I don't complain about the petty things in life, because now I know what's really important.

Section Six

Developing an Infrastructure to Implement Change

6.0 Developing an Infrastructure to Implement Change

6.1 Introduction

This section describes how the strategy will be implemented.

The key aim will be to develop and put in place an infrastructure, both at a regional HSC Board and local HSC Trust level, which will help ensure that all stakeholders are able to contribute to the delivery of the Action Plan. It is envisaged that such support will comprise:

- Technical assistance in identifying the prevalence of disability in terms of understanding what this means for future demand for services, including mapping existing services to establish potential gaps in addressing need;
- Provision of high-quality advice and information to HSC, voluntary and community sectors so that they are empowered to make effective decisions regarding the future planning, commissioning, delivery and monitoring of services;
- Designing, together with local service providers, new service models which build collaboration both between Trusts and their partners across the sectors;
- Facilitating the sharing of emerging service-based learning and good practice across NI;
- Development of fully accessible communication and training materials, (including where appropriate web-based material) both for those using services and for health service professionals and practitioners, to improve awareness of disability and facilitate the sharing of effective good practice.

6.2 Disability Strategy Implementation Group

The Disability Strategy Implementation Group will be established to direct, co-ordinate and manage the implementation of the infrastructure and Action Plan. It will be led by the HSC Board and will work with a range of agencies and groups including the voluntary and community sectors.

6.3 Monitoring and Reporting

The Disability Strategy Implementation Group will be accountable to the DHSSPS for implementation of the Strategy. The Group will be responsible for ensuring that Summary Progress Reports within each Trust area are provided to the HSC Board and submitted to the Director

of Mental Health, Disability and Older People Policy on a six-monthly basis.

The measures of outcome and improvement achieved across the region will be assessed by performance against Key Performance Indicators.

The Implementation Group will commence its work from June 2012 and an initial report should be submitted to the HSC Board and the Department in December 2012.

6.4 Duration of the Group and Review of Terms of Reference

The Implementation Group will continue in existence over the three year period 2011/12 – 2014/15, and it will produce an End of Year report at the end of each financial year. In line with this, the HSC Board will review the Group's Terms of Reference on an annual basis to determine and reflect changes required going forward over the three year term.

6.5 Quality Assurance

The Department and the Implementation Group will consider the need for a formal review of the implementation of the Strategy's recommendations and Action Plan. Any review, whether carried out internally or independently, will consider the extent to which the recommendations and Action Plan are being implemented and may make recommendations to assist in the implementation process.

Section Seven

HSC Action Plan

7.0 HSC Action Plan

7.1 Introduction

This HSC Action Plan reflects the issues and priorities raised in the body of the strategy, relevant to health and social care and partnership working.

The Plan recognises the importance of family and person-centred care planning involving service users, their families and carers, and partnership working with the third sector including the community, voluntary and independent sectors.

The same key policy principles outlined in the strategy have been reflected in the recommendations and actions contained within the Action Plan. They are:

- Equity;
- Prevention / Early Intervention ;
- Partnership with the Third Sector;
- Positive Risk Assessment;
- Self Directed Support;
- Social Inclusion; and
- Personal and Public Involvement.

The Action Plan provides a framework for action which sets out the key actions that will be taken forward over the period 2011 – 2015. It seeks to draw forward the best and most efficient models of service in an era of unprecedented economic pressure. Many of the actions are not resource dependent but are intended to drive innovation and reform within existing services. Accordingly the Action Plan seeks to develop that innovation and generate the implementation of existing best practice across all HSC Trusts in NI.

Over the course of implementation there may be a requirement to develop key indicators for some of the actions to ensure that the Action Plan remains outcome focused and measurable. This may result in the development of some more detailed actions. In so doing the Action Plan specifically sets out to improve the lives of those with a disability by promoting independence and supporting a more personalised approach to the provision of services in terms of choice, control and self directed support.

The Action Plan has been divided into four main sections as follows:

1. Prevalence and Need;
2. Promoting Positive Health, Wellbeing and Early Intervention;
3. Providing Better Services to Support Independent Lives; and
4. Infrastructure to deliver.

The sub-sections within Section 3 – Providing Better Services to Support Independent Lives are:

- Personalisation;
- Information, Advice and Advocacy;
- Provision of a Skilled Workforce;
- Equipment – Procurement and Standardisation;
- Rehabilitation;
- Respite / Short Break Care;
- Service Redesign;
- Transition Support and Planning;
- Day Opportunities;
- Housing; and
- Transport.

7.2 Action Plan

Section One – Prevalence And Need			
Recommendation - Given the paucity of reliable data on which to base planning and commissioning decisions the following actions are recommended.			
Actions	Expected Outcomes	Responsibility	Target Completion
1. Determine and agree key outcome measures to inform future service commissioning provision and improvement in the lives of individuals.	1. Outcome measures for people with disabilities that will result in improved quality of life.	HSCB will lead on this action with input from PHA, HSCTs and Service Users	December 2012
2. Work in partnership with other key agencies and stakeholders to commission work to collate and compile data in relation to Section 75 groups and take action to address inequalities and identified gaps in service provision.	1. Inequalities and gaps identified for Section 75 Groups 2. Improved equality in service provision.	DHSSPS will lead on this action with input from HSCB, PHA and HSCTs	December 2013

Section Two – Promoting Positive Health, Wellbeing And Early Intervention

Recommendation –All relevant policies, strategies, service frameworks, programmes and services should reduce health inequalities by improving the health and social wellbeing of disabled people and support them to maximise their capabilities.

Actions	Expected Outcomes	Responsibility	Target Completion
3. Examine how disabled people can be targeted in future health promotion initiatives.	Targeted messages to be developed particularly for those with multiple needs.	PHA will lead on this action with input from DHSSPS	September 2012
4. Examine how a “prevention” message can be made known regarding preventative hearing and sight loss – this could include for example PHA incorporating messages in their public health education campaigns about positive steps that the public can take in order to avoid sight and / or hearing loss.	Method for inclusion of prevention messages in public health campaigns relating to preventative hearing and sight loss agreed.	PHA will lead on this action with input from DHSSPS	September 2012
5. Early detection, assessment and intervention services are provided for all disabled people, and assessments, particularly those for complex conditions, are carried out by properly trained personnel – for example HSC could ensure that appropriate services are provided for deafblind people - remembering that individual services for people who are deaf or who are blind may not be appropriate for someone who is both deaf and blind.	Timely detection, assessment and intervention for people with all disabilities.	HSCB will lead on this action with input from HSCTs and PHA	December 2013

<p>6. Consider endorsing the Eye Care Liaison Officer (ECLO) model or other appropriate models available in NI as the preferred option in supporting those with newly diagnosed sight loss.</p>	<p>Preferred and approved best practice model may be adopted as support solution for people with newly diagnosed sight loss.</p>	<p>PHA will lead on this action with input from HSCB</p>	<p>March 2013</p>
<p>7. The provision and delivery of appropriate positive risk taking training to HSC staff which would encompass:</p> <ul style="list-style-type: none"> a) Understanding of risk b) Improved quality of life. 	<p>Positive risk taking will be promoted where possible, supported by the provision and delivery of appropriate training to HSC staff, with the aim of empowering children and adults with disabilities to fulfil their goals and ambitions to the maximum potential, ie. improved quality of life.</p>	<p>DHSSPS will lead on the issue of guidance with input from HSCB and HSCTs. HSCB will lead on implementation with input from HSCTs.</p>	<p>Ongoing</p>

Section Three – Providing Better Services to Support Independent Lives

Personalisation

Recommendation – To promote independent living options that afford people with disabilities the maximum possible choice and control over the services they receive.

Actions	Expected Outcomes	Responsibility	Target Completion
<p>8. Explore the feasibility of introducing in NI provisions equivalent to Part Two of the GB Welfare Reform Act 2009, “Disabled people: right to control provision of services” either through administrative means or by means of legislation.</p>	<p>Decision on feasibility of NI legislation covering provisions of Part Two of the Welfare Reform Act 2009 “Disabled people: right to control provision of services” developed.</p>	<p>DHSSPS will lead on this action and will work in partnership with other Departments, on determining the implications of taking forward legislation in NI</p>	<p>September 2012</p>
<p>9. Determine the feasibility of introducing self directed support / personalised / individualised budgets in NI which take account of the need for specialist support and lessons learned through their implementation in other parts of the UK.</p>	<p>Pilot schemes evaluated, feasibility study commissioned and relevant legislation, if necessary, amended.</p>	<p>HSCB will lead on this issue with input from the DHSSPS.</p>	<p>March 2013 for completion of feasibility study.</p>

<p>10. Increased uptake of Direct Payments will continue to be promoted.</p>	<p>Increase in uptake of Direct Payments by people with disabilities.</p>	<p>HSCB will lead on this action with input from PHA & HSCTs</p>	<p>Quarterly and Annual Monitoring through Priorities for Action progress reporting</p>
<p>11. Produce a policy framework / guidance on long-term conditions management across primary and secondary care sectors which includes details on the promotion of self management</p>	<p>1. Policy Framework for the management of long term conditions. 2. Individuals as experts in their care.</p>	<p>DHSSPS will lead on this action with input from HSCB/ PHA.</p>	<p>March 2012 (subject to Minister's approval)</p>

<p>Recommendation –To commission more personalised services appropriate to the needs of individuals.</p>			
<p>Actions</p>	<p>Expected Outcomes</p>	<p>Responsibility</p>	<p>Target Completion</p>
<p>12. Person-centred planning will be adopted as mainstream practice & evidenced in person centred plans.</p>	<p>Person-centred planning adopted as mainstream practice, which will contribute to the Equality and PPI Agenda.</p>	<p>HSCB will lead on this action with input from PHA & HSCTs</p>	<p>April 2013</p>

<p>13. The Wraparound Initiative or similar model of good practice for providing multi-agency / multi disciplinary services for children and young people with disabilities should be rolled out to and deployed in all Trust areas.</p>	<p>Wraparound adopted as regional model and approach in all HSCTs.</p>	<p>HSCB (Children and Young People's Strategic Partnership) will lead on this action with input from PHA & HSCTs</p>	<p>March 2013</p>
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Information, Advice And Advocacy

Recommendation – To enhance access to information, advice and advocacy for patients, clients, families and carers with a view to increasing independence for people with disabilities.

Actions	Expected Outcomes	Responsibility	Target Completion
<p>14. Ensure that information and advice about services is accessible and staff are trained to communicate appropriately with people with disabilities - this could include, for example, establishing a regional best practice model for communicating HSC appointments to people who are blind or partially sighted.</p>	<p>Accessible information and advice in a range of formats.</p>	<p>All service providers</p>	<p>April 2013</p>
<p>15. Publish "A Policy for Developing Advocacy Services – A guide for Commissioners".</p>	<p>Agreed principles and standards for the future commissioning and delivery of advocacy services.</p>	<p>DHSSPS will lead on the finalisation of the policy guidance.</p>	<p>March/April 2012</p>

		The associated implementation plan will be taken forward by the HSCB with input from the PHA, LCGs and HSCTs.	October 2012
16. Advocacy models, supported by training programmes, to help maximise decision making and control for disabled people will be available.	Range of advocacy models / training programmes adopted.	HSCB will lead on this action with input from PHA and HSCTs	April 2013

Skilled Workforce

17. All health and social care staff should be given disability awareness training which includes equality and human rights training inclusive of PPI agenda.	Skilled and informed workforce.	HSCTs will lead on this action with input from HSCB, PHA & BSO	Assessed annually through training evaluations – Ongoing
18. All health and social care staff in regular direct contact with clients or patients with a disability will be given disability equality and PPI training relevant to their level of involvement.	Skilled and informed workforce who are enabled to respond appropriately to the needs of people with disabilities whilst respecting their rights to privacy, dignity and equality.	HSCTs will lead on this action with input from HSCB, PHA & BSO	Assessed annually through training evaluations - Ongoing

<p>19. All health and social care staff in regular direct contact with clients or patients with a disability should be given human rights training on legislation, on a human rights approach and on incorporating the new convention rights of people with disabilities.</p>	<p>Skilled and informed workforce.</p>	<p>HSCTs will lead on this action with input from HSCB, PHA & BSO</p>	<p>Assessed annually through training evaluations – Ongoing</p>
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Equipment (Procurement and Standardisation)			
<p>20. A rationalisation of budgets for the provision of the range of sensory equipment will be developed and implemented and a regional approach to procurement will be adopted where possible. The new arrangements and protocols should be supported by training for HSC staff.</p>	<p>Regional model for procurement of sensory equipment.</p>	<p>HSCB will lead on this action with input from BSO/HSCTs</p>	<p>September 2013</p>
<p>21. Ensure that the Procurement and Logistics Service (formerly Regional Supplies Service) procures wheelchairs and their accessories, from the agreed and approved range of products in line with the National Framework Agreement, at best cost from suppliers and that relevant staff are trained appropriately in the new procedures.</p>	<p>Regional approach to procuring wheelchairs and wheelchair accessories.</p>	<p>BSO / HSCB will lead on this action with input from PHA and HSCTs</p>	<p>September 2012</p>

Rehabilitation			
<p>22. Promote effective rehabilitation taking account of the user's perspective to include:</p> <ul style="list-style-type: none"> ○ Good quality information appropriate to people with a disability; ○ A focus on anticipatory care planning as part of a care pathway approach; ○ Shared best practice within available resources; and ○ A standardised approach to assessment and documentation in HSC organisations. 	Best practice approach to rehabilitation services adopted.	HSCB will lead on this action with input from PHA, PCC & HSCTs	December 2012
<p>23. Review of sensory rehabilitation services from a user perspective with a view to promoting provision of cost effective and timely services.</p>	Services redesigned from a user's perspective.	HSCB will lead on this action with input from PHA, PCC, HSCTs and other organisations	June 2013

Short Breaks And Respite			
<p>Recommendation – Appropriate short break and respite services should be available to meet the needs of individuals and their parents and carers.</p>			
Actions	Expected Outcomes	Responsibility	Target Completion
<p>24. Ensure the recommendations from the HSCB Respite Review Group are equitably implemented for the benefit of disabled people.</p>	<p>1. Baseline established. 2. Wider range of short breaks / respite available.</p>	<p>HSCB will lead on this action with input from DHSSPS and HSCTs</p>	<p>Annual Review / Ongoing</p>

25. Explore the developments and regional opportunities for crisis response interventions in respect of respite services which could be used by for people with disabilities.	Crisis response interventions identified.	HSCB will lead on this action with input from HSCTs	December 2012
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Service Redesign

Recommendation – Consideration will be given to the potential to improve equity of services across the region, whereby Trusts work collaboratively to share resources.

Actions	Expected Outcomes	Responsibility	Target Completion
26. Examine areas where sharing resources between Trusts creates the potential for more equitable efficient support and services through economies of scale and sharing of scarce resources.	Regional protocol for sharing resources established.	HSCB will lead on this action with input from HSCTs	March 2013

Transition Support And Planning

Recommendation – To build and sustain good practice models for transitions and address apparent inconsistencies in the provision and availability of transition planning.

Actions	Expected Outcomes	Responsibility	Target Completion
27. Improve joint working across relevant Departments, with the aim of ensuring that young people with disabilities are offered the same opportunities as other young people for learning and personal development. (PSI Recommendation)	Joint working approach adopted to improve access to opportunities for young people.	DHSSPS will lead on this action to collaborate with DE and DEL	June 2013

<p>28. Ensure arrangements are developed to improve the transitional arrangements between child and adult health services.</p>	<p>Models of good practice and transition planning operational teams established.</p>	<p>HSCB (Regional Transitional Implementation Group) will lead on this action with input from PHA & HSCTs</p>	<p>September 2013</p>
<p>29. Develop palliative and end of life care services for people with disabilities within the framework of the palliative and end of life care strategy.</p>	<p>Appropriate palliative / end of life care services will be available.</p>	<p>PHA / HSCB will lead on this action with input from HSCTs</p>	<p>In line with palliative care strategy</p>

Day Opportunities

Recommendation – To review existing statutory day support services, with a view to refocusing commissioning on models of day opportunities that promote independence and inclusion and meet the needs of disabled people

Actions	Expected Outcomes	Responsibility	Target Completion
<p>30. Examine the potential for the development of social networking services focussed on enabling sustained community engagement for disabled people, eg, with the view to helping prevent disabled people needing care and support in the first place or from developing long-term dependencies on health and social care provision.</p>	<p>Review containing agreed model for social networking services completed.</p>	<p>HSCB will lead on this action with input from PHA, HSCTs and the Vol / Com Sector</p>	<p>June 2013</p>

<p>31. Examine ways of working more closely with other government departments and voluntary/community bodies to support the development of vocational orientation/rehabilitation services for disabled people.</p>	<p>Joint working approach developed.</p>	<p>DHSSPS will lead on this with input from HSCB/PHA/HSCTs /Vol/Com Sector and in collaboration with other government departments</p>	<p>December 2012</p>
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Housing

Recommendation - To provide a comprehensive choice of housing accommodation and housing support services for disabled people, ranging from supporting people to remain in their own homes in their own community, with assistance from the Supporting People programme, to specialised supported living projects, including new builds identified in the Social Housing Development programme, within the resources available.

Actions	Expected Outcomes	Lead Responsibility	Target Completion
<p>32. Collaborate to</p> <ul style="list-style-type: none"> a) Address issues around delays for adaptations and b) Progress the Ministerial approved actions and recommendations from the Interdepartmental Review of Housing Adaptations. 	<p>Performance targets for housing adaptations achieved.</p> <p>Improved infrastructure to maximise housing choices for disabled people.</p>	<p>DSD will lead on this action with input from NIHE, HSCB/PHA, and DHSSPS</p>	<p>June 2013</p>

33. Jointly review the commissioning of assistive technology and telecare to enhance the quality of life and independent living options for disabled people and carers.	Options and best practice approach considered and evaluated.	PHA will lead on this action with input from HSCTs and HSCB.	September 2013
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Transport

Recommendation – To enhance personal mobility options for disabled people.

Actions	Expected Outcomes	Lead Responsibility	Target Completion
34. Engage with relevant stakeholders with a view to enhancing independent travel training as part of rehabilitation programmes.	Range of travel programmes available.	HSCTs will lead on this action with input from voluntary sector	March 2013

Section Four - Infrastructure to Deliver Action Plan

Recommendation – To Improve the lives of those living with disabilities through coordinated HSC action and partnership working.

Actions	Expected Outcomes	Lead Responsibility	Target Completion
35. Convene a Disability Strategy Implementation Group to coordinate Implementation of the Action Plan – supported by a dedicated Project Manager	Full Implementation of Action Plan by 2015.	HSC Board and PHA (DHSSPS to fund Project Manager post)	June 2012
36. Regular reports on Implementation of Actions inclusive of progress made in progressing equality and human rights duties including screening and impact assessment where relevant.	Publish 6-monthly progress reports.	HSC Board and PHA	Successive years over lifespan of Strategy.

Project Team Members

Member	Area	Organisation
Maura Briscoe (Dr) (Chair – until 11 May 2011)	Director of Mental Health and Disability Policy	DHSSPS
Christine Jendoubi (Chair – from 12 May 2011)	Director of Mental Health and Disability Policy	DHSSPS
Kevin Keenan	Commissioner – Older People	HSCB
Kieran McShane	Children and Young People	HSCB
Joyce McKee	Principal Social Worker	HSCB
Jacqueline Magee	Services Facilitator	HSCB
Garry Hyde	ADSS	WHST
Bernie Kelly	ADSS	BHST
Bria Mongan	ADSS	SEHST
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Brian Symington	Director	RNID
Eileen Thomson	Deputy Chief Executive	The Cedar Foundation
Monica Wilson	Chief Executive	Disability Action
Patricia Carey	Equality, Rights and Social Need	OFMDFM
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Project Team Members

Member	Area	Organisation
Doris Fairfull	Education	DE
Jan Harvey	Employment / Learning	DEL
Paraig O'Brien	Housing	NIHE / DHSSPS
Jenny Pyper	Transport	DRD
Charles Bamford	Office of Social Services	DHSSPS
Ian McMaster (Dr)	Chief Medical Officer Group	DHSSPS
Maurice Devine	Nursing Officer (Mental Health, Learning Disability and Older People)	DHSSPS
Michael Sweeney	Physical and Sensory Disability Unit	DHSSPS
Michael Swann	Elderly and Community Care Unit	DHSSPS
Bernie Redmond	Physical and Sensory Disability Unit	DHSSPS
Paul Cassidy	Physical and Sensory Disability Unit	DHSSPS

List of Legislative and Policy Document References for this Strategy

Legislation

The Chronically Sick and Disabled Persons (NI) Act 1978

The Disabled Persons (NI) Act 1989

The Disability Discrimination Act 1995

The Children (NI) Order 1995

The Northern Ireland Act 1998

The Children's Services Planning Order 1998

The Human Rights Act 1998

The European Union Employment Directive 2000 / 78 / EC

The Carers and Direct Payments (NI) Act 2002

Health and Personal Social Services (Quality Improvement and Regulation) (NI) 2003

The Disability Discrimination Order 2006 / The Disability Discrimination (NI) Order 2006

United Nations Convention on the Rights of Persons with Disabilities 2008

Other Documentation

Physical and Sensory Disability – An Action Plan 1992 – 1997 (DHSS)

Investing for Health 2002 (DHSSPS) and the healthy lifestyle strategies flowing from it

Review of Neurology Services 2002 (DHSSPS) and its current review

Joint Fundamental Review of the Housing Adaptations Service (March 2003)

From Dependence to Independence – Agenda for Action (Inspection by SSI of services for young adults aged 16 to 25 with a Physical Disability and / or Sensory Impairment - January 2003)

From Dependence to Independence (As above – Key Standards and Criteria – January 2003)

List of Legislative and Policy Document References for this Strategy

The Home Accident Prevention Strategy and Action Plan 2004-2009 (DHSSPS)

Accessible Transport Strategy 2005 – 2015 (DRD)

A Healthier Future 2005 - 2025 (DHSSPS)

Challenge and Change - May 2005 (DHSSPS)

Strategy for adults with a Physical Disability including Sensory Impairment – 2005 – 2015 (EHSSB)

Care at its Best – Overview Report of the Multidisciplinary regional inspection of the Service for Disabled Children in Hospital – October 2005

A Ten Year Strategy for Children and Young People – ‘Our Children and Young People – Our Pledge’ (OFMDFM) 2006 - 2016

Aiming High for Disabled Children - May 2007 (HMT Department for Education and Skills)

Complex Needs – June 2007 (DHSSPS)

A Transport Strategy for Health and Social Care Services in NI - August 2007 (DHSSPS)

UK Vision Strategy 2008 / NI Vision Strategy 2009

Wheelchair Reform - August 2008 (DHSSPS)

Speech and Language Therapy Task Force Report – 2008 and subsequent development of SLT Action Plan – September 2110

Independent Review of Acquired Brain Injury - September 2008 and subsequent publication of Acquired Brain Injury Action Plan - April 2009

Sexual Health Promotion Strategy and Action Plan 2008 - 2013 (DHSSPS)

Families Matters – Family Support Strategy 2009 (DHSSPS)

Is it my turn yet? – March 2009 (RNIB, RNID, BDA Sign Community)

Developing Services to Children with Complex Physical Healthcare Needs – June 2009 (DHSSPS)

Management Information on Adult Respite Provision – First Phase Report – December 2009

List of Legislative and Policy Document References for this Strategy

Telecare and Physical Disability and Telecare and Sensory Impairment - Dementia Services Development Centre / University of Stirling Joint Improvement Team – March 2010

Reforming Northern Ireland's Adult Protection Partnership Arrangements Government Response – March 2010

Living Matters, Dying Matters - A Palliative and End of Life Care Strategy for Adults in Northern Ireland – March 2010 (DHSSPS)

Healthy Child Healthy Future: A Framework for the Universal Child Health Programme – May 2010

Safeguarding Vulnerable Adults, A Shared Responsibility – Standards and Guidance for Good Practice in Safeguarding Vulnerable Adults – October 2010.

Lost for words – RNIB – October 2010

Respite Support – Second Report – December 2010.

Developing Eyecare Partnerships, Improving Eyecare Provision in NI (DHSSPS) - launched for public consultation - July 2011

Safeguarding Vulnerable Adults Framework (currently in development - scheduled to be launched for consultation during 2011)

Long Term Conditions Policy Framework (DHSSPS – expected to be published early in 2012)

National Plan for Rare Disease UK (currently in development - scheduled to be launched for consultation early in 2012)

Minimum Standards for Adult Day Care Settings – DHSSPS - January 2012

List of Pre-Consultation Events

Date	Event / Organisation / Attendees
01.12.09	Initial scoping workshop in Lisburn with representatives from HSC organisations and other NI Government Departments
18.01.10	Initial scoping workshop in Omagh with representatives from the voluntary and community sector and service users
25.01.10	Initial scoping workshop in Lisburn with representatives from the voluntary and community sector and service users
10.03.10	Huntington's Disease Association representatives, service users and carers
16.03.10	RNIB (Omagh) representatives, service users and carers
24.03.10	The Cedar Foundation representatives, service users and carers
29.03.10	RNIB (Cookstown) representatives, service users and carers
14.04.10	Parkinson's Disease UK representatives, service users and carers
16.04.10	The Multiple Sclerosis Society representatives, service users and carers
22.04.10	Progressive Supra-nuclear Palsy Association representatives, service users and carers
26.04.10	RNIB (Belfast) representatives, service users and carers
27.04.10	Fleming Fulton School pupils, past pupils, therapists and teachers
30.04.10	Workshop (Londonderry) 'hard to reach' service users
06.05.10	Workshop (Belfast) 'hard to reach' service users
11.05.10	Centre for Independent Living representatives, service users and carers
12.05.10	Barnardo's (Armagh) children and young people and their support worker
15.05.10	Clic Sargent children and young people and their support workers
26.05.10	Northern HSC Trust Transitions Team

List of Pre-Consultation Events

29.05.10	The Cedar Foundation representatives, children and young people
01.06.10	Little Orchids parents and carers of disabled babies and toddlers
02.06.10	Workshop (Lurgan) 'hard to reach' service users
07.06.10	Parents and Carers Council on Disability
16.06.10	Angel Eyes parents and carers of visually impaired children and young people
21.06.10	Action on Disability representatives, service users and carers
22.06.10	Stroke Association representatives, service users and carers
26.06.10	RNID, British Deaf Association (BDA), NI Deaf Youth Association, National Deaf Children's Society (NDCS) and Hands that Talk representatives, service users and carers

Equality Impact Screening

Section 75 Group	Description of impact of policy
Gender	Some disabilities affect proportionately more women than men e. g. multiple sclerosis, however the strategy aims to improve services for all disabled people with physical, communication and or sensory disability regardless of gender. The 2007 NISRA statistics show that there is a higher prevalence of disability among adult females with 23% of females indicating that they had some degree of disability compared with 19% of adult males ; However male prevalence rates are higher than female rates amongst young people (16 to 25) 6% of males compared with 4% of females and for children where 8% of boys aged 15 and under were found to have a disability, compared with 4% of girls of the same age. Based on these statistics the equality impact differential in terms of gender is considered to be neutral.
Age	It is widely accepted that disability tends to increase with age and therefore the equality impact is likely to be positive for older disabled people however the strategy aims to improve services for all disabled people with physical, communication and or sensory disability regardless of age.
Religion	No data available which suggests any obvious positive or negative difference between groups of different religion.
Political Opinion	No data available which suggests any obvious positive or negative difference between persons with a referenced political opinion
Marital Status	No data available which suggests any obvious negative impact in terms of marital status but as the strategy is promoting a family and person-centred approach to care it is anticipated that this will have a positive impact for families with disabled parents and or children including lone parent families.
Dependent Status	This strategy will have a positive impact for parents / carers with one or more children with a disability given the promotion of the family and person-centred approach to care adopted by the strategy.

Equality Impact Screening

Disability	The strategy relates to all disabled people with physical, communication and or sensory disability in NI and will have a positive impact for them.
Ethnicity	No data available which suggests any obvious positive or negative difference between persons of different ethnic origin.
Sexual Orientation	No data available which suggests any obvious positive or negative difference between persons of different sexual orientation.

Rural Proofing Screening

Policy Stage	Rural issues
Design	<p>The Physical and Sensory Disability Strategy has been developed to improve outcomes and support for all people in NI with a physical, communication or sensory disability. The strategy examines the services provided to disabled people under a number of key themes and makes recommendations for improved, more equitable access to services for all disabled people.</p> <p>The strategy includes action plan which contains a set of time bounded actions under the above themes for improving outcomes for disabled people.</p> <p>As the objectives of the Physical and Sensory Disability Strategy focus on improving outcomes for all people with physical or sensory disabilities, it is not expected to have specific rural impacts.</p>
Evidence	<p>A pre-consultation exercise was conducted which included three initial scoping workshops to seek the views of health and social care professionals, service users, carers and families, representatives from a number of voluntary and community organisations and representatives from other government departments.</p> <p>These were followed by a substantial programme of further pre-consultation events with some twenty voluntary and community organisations and some of their service users, carers and families and three further workshops with 'hard to reach' service users i.e. those individuals who are not affiliated with a local voluntary or community group and therefore might not ordinarily be afforded the opportunity to be consulted regarding the Strategy.</p> <p>Individuals and groups from rural areas participated in this process and the main issues raised were the lack of an adequate transport service for disabled people, and some concerns at the location of many services in large regional centres in Belfast, Antrim and Londonderry.</p>

Rural Proofing Screening

Consulting	No particular rural issues were raised during the public consultation. See above re pre-consultation process.
Monitoring and outcomes	Implementation of the Strategy and Action Plan will be monitored by a Disability Strategy Implementation Group which will be Chaired by the HSC Board.

The SHSSB Wraparound Manifesto – August 2003

This “Manifesto” has been developed as part of the Wraparound Project. Its purpose is to identify standards that agencies should consider when dealing with families of children with a disability and children with a disability. This includes all hospital and community settings. It will be subject to regular review in the future.

1. Inclusion

Disabled Children and their families should be fully supported to participate in valued childhood experiences and to have access to the same opportunities, life experiences and services as other children and families.

2. Early Identification and Diagnosis

Often parents are first to express concerns about their child’s wellbeing and development. GP and Health Visitors should make a prompt response to the first referral (within one month) and a degree of urgency and parental anxiety should be considered when arranging the first appointment.

The process of “news breaking” should follow established guidelines, whichever professional undertakes the task. There should be arrangements for an early follow-up appointment and / or home visit and telephone support should be available.

3. Information

Information should be accessible using jargon free language and provided regularly to families. Every family should be offered:

- Full information about their child’s condition including information and prognosis;
- Where appropriate and desired, a link should be offered with another parent whose child has a similar condition;
- The name and phone number of a voluntary organisation for children with this condition (such as Down’s Syndrome Association) and Contact a Family.

Information should be provided about all available services within a Trust area, along with contact names and telephone numbers. A designated agency will be given this responsibility.

The SHSSB Wraparound Manifesto – August 2003

4. Co-ordinated Multidisciplinary and Multi-Agency Care

Services for children with a disability and their families should be co-ordinated, providing family and child centred assessment and care with an identified point of contact for families. This will most often take the form of a named worker. Parents will have a contact phone number for their named worker.

5. Partnership And Participation

The ethos is to support and empower parents to meet the needs of their child. Disabled children and their parents should be active partners in decisions made about their individual care in the planning of services. Feedback will be sought from parents and if possible children themselves about the services they have received.

6. Treatment and Therapy

The child should receive either regular follow up and referral onwards to appropriate specialists, or access to the appropriate service in the event of new problems.

The family should know what kind of therapy or teaching their child is receiving, what it is intended to achieve and how they can help.

An individual family plan will be drawn up for each child by all professionals and family members. This will be shared and reviewed regularly.

7. Equipment and Adaptations

Disabled children and their families should have the equipment and housing needed for their health and wellbeing, development and social inclusion and for their families' health and wellbeing.

8. Children With Complex and Continuing Health Care Needs and / or Life Limiting Conditions

Children with complex and continuing health care needs and / or life limiting conditions need support (medical, nursing, therapeutic, social and educational) to enable them to live at home and participate in family, school and community life. There should be arrangements for children with complex needs to be seen urgently on request. The family should know who to contact in the event of new problems.

The SHSSB Wraparound Manifesto – August 2003

9. Training for Personal Working In Family Services

All staff in contact with children with disabilities and their families should offer services that are family and child-centred. Multi-disciplinary training in child and family centred care should be available for all staff.

10. Short Breaks, Respite

Respite care, domiciliary support, after school clubs and school holiday clubs should be available for children with disabilities.

11. Carers

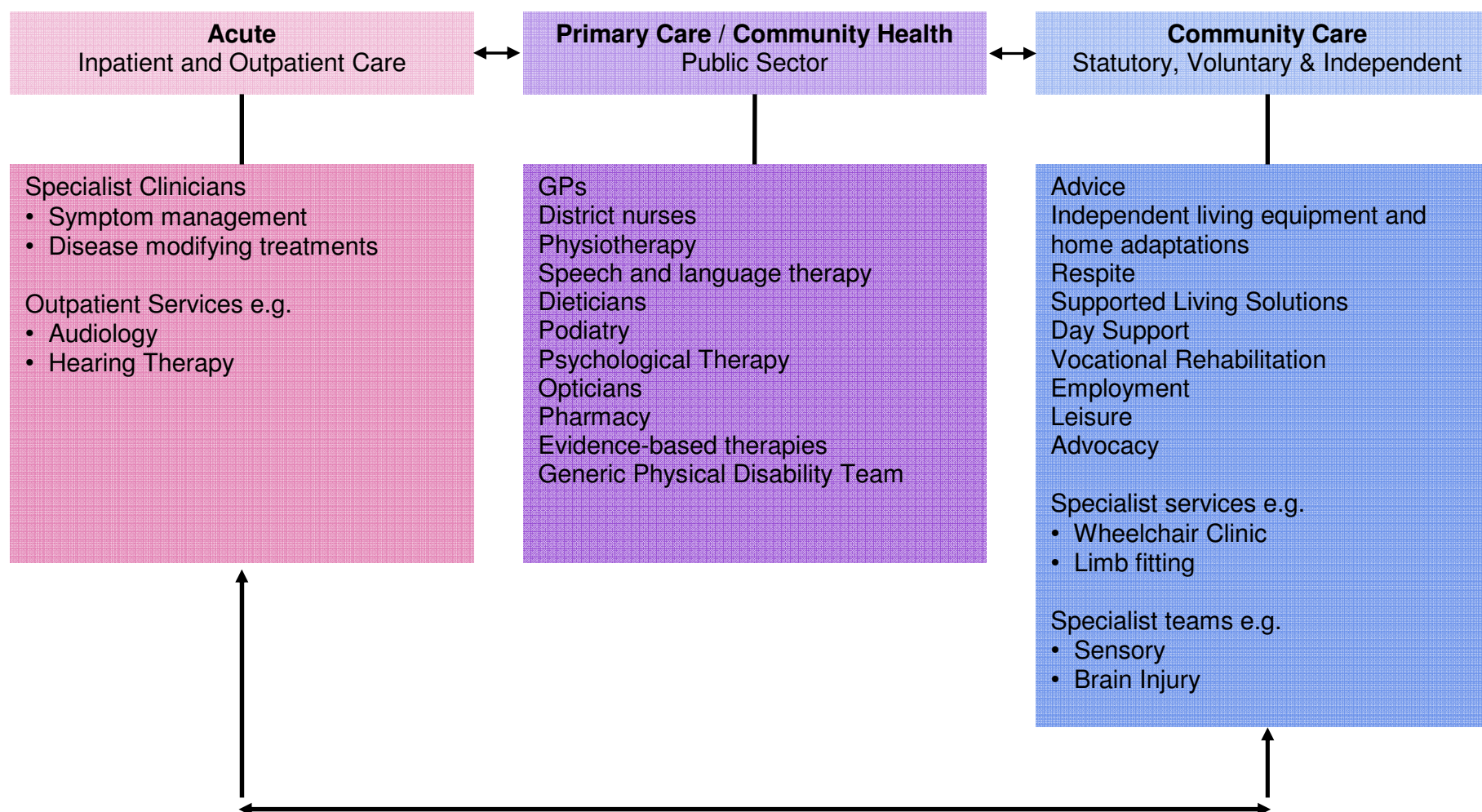
All carers should be offered an assessment of their needs which can be used to inform future provision of services.

12. Transition

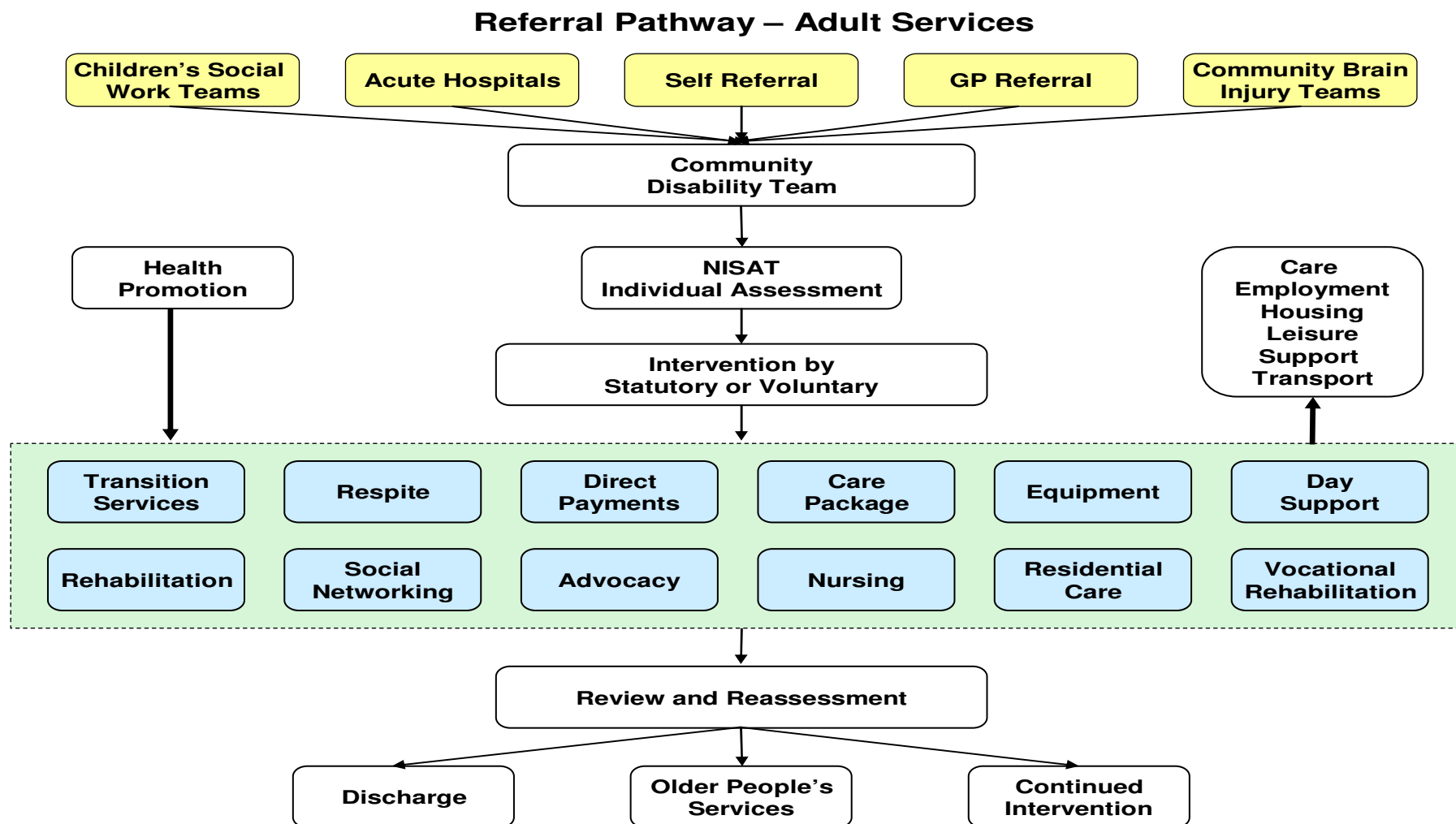
Disabled teenagers from age 14 onwards and their families should receive high quality multi-agency support, allowing them to have choice and control over life decisions in order to maximise education, training and employment and leisure opportunities and to live independently. Young people should be encouraged to be active participants in the development of the transition plan.

Care and Referral Pathway Diagrams

GENERIC CARE / SUPPORT PATHWAY - Disability

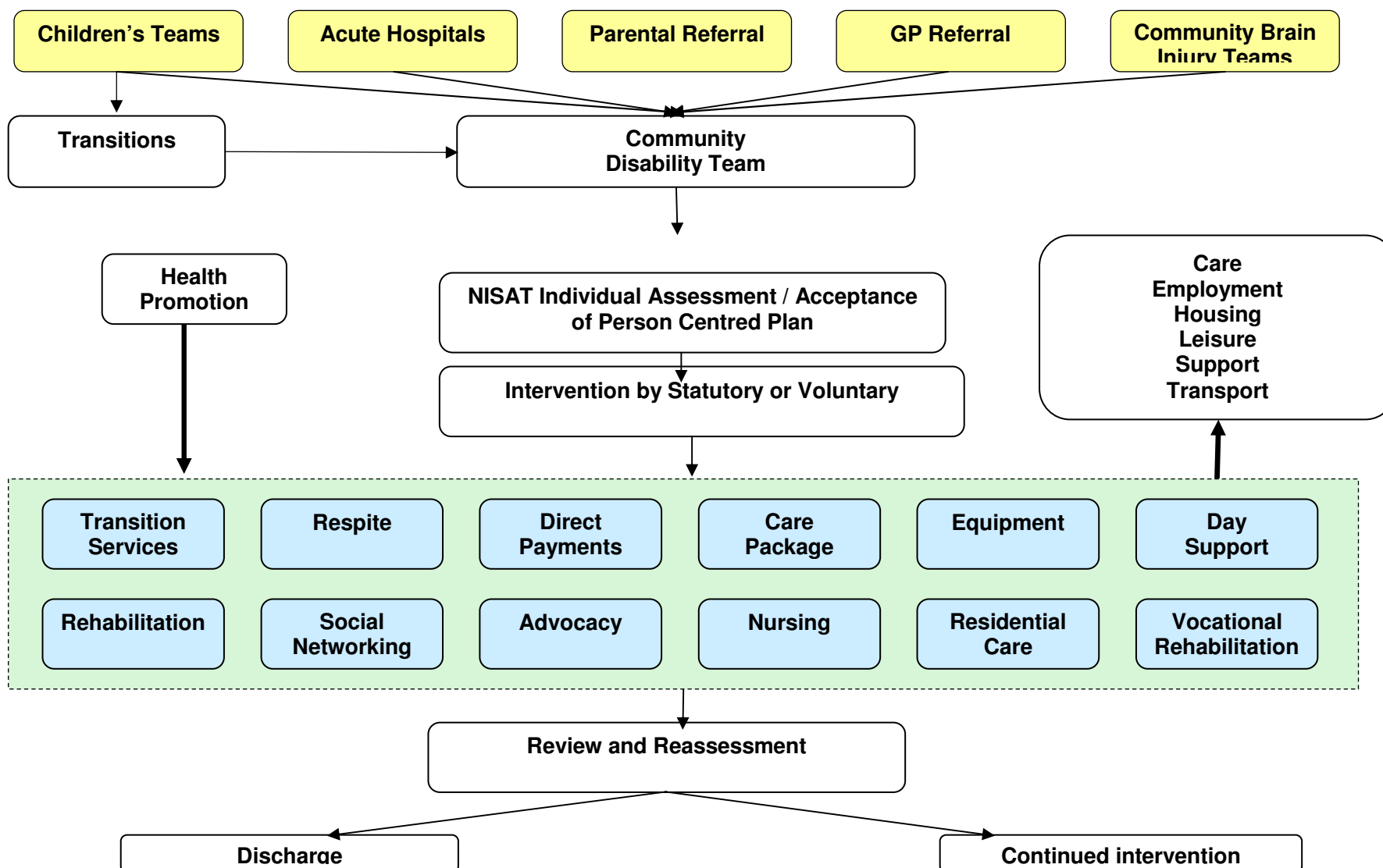


Care and Referral Pathway Diagrams



Care and Referral Pathway Diagrams

Referral Pathway – Children’s Services



List of Abbreviations

ABI	Acquired Brain Injury
AHP	Allied Health Professional
ATS	Accessible Transport Strategy
BHSCT	Belfast Health and Social Care Trust
BSL	British Sign Language
CSR	Comprehensive Spending Review
CYPSP	Children and Young People's Strategic Partnership
DCAL	Department of Culture Arts and Leisure
DDA	Disability Discrimination Act
DFP	Department of Finance and Personnel
DHSSPS	Department of Health, Social Services and Public Safety
DoH	Department of Health
DRD	Department for Regional Development
DSD	Department for Social Development
DWP	Department for Work and Pensions
ECCU	Elderly and Community Care Unit
ECLO	Eye Care Liaison Officer
ELB	Education and Library Board
EQIA	Equality Impact Assessment
GB	Great Britain
GP	General Practitioner
HMT	Her Majesty's Treasury
HPSS	Health and Personal Social Services
HSC	Health and Social Care
HSCB	Health and Social Care Board
HSCT	Health and Social Care Trust
IAD	Information and Analysis Directorate
ICT	Information and Communication Technology

List of Abbreviations

ISL	Irish Sign Language
JAWS	Job Access With Speech
JHASG	Joint Housing Adaptations Steering Group
LCGs	Local Commissioning Groups
NI	Northern Ireland
NICEM	Northern Ireland Council for Ethnic Minorities
NICVA	Northern Ireland Council for Voluntary Action
NHSCT	Northern Health and Social Care Trust
NISALD	Northern Ireland Survey of people with Activity Limitations and Disabilities
NISRA	Northern Ireland Statistics and Research Agency
OFMDFM	Office of the First Minister and Deputy First Minister
OPPCD	Older People and Primary Care Directorate
PBNI	Probation Board for Northern Ireland
PCC	Patient Client Council
PHA	Public Health Agency
PSI	Promoting Social Inclusion
PSNI	Police Service of Northern Ireland
RABIIG	Regional Acquired Brain Injury Implementation Group
RNIB	Royal National Institute for the Blind
RNID	Royal National Institute for the Deaf
POC	Programme of Care
PPRU	Policy, Planning and Research Unit
RQIA	Regulation and Quality Improvement Authority
RIT	Reform Implementation Team
PwC	PricewaterhouseCoopers
SAT	Single Assessment Tool
SEHSCT	South Eastern Health and Social Care Trust
SHSCT	Southern Health and Social Care Trust

List of Abbreviations

SHSSB	Southern Health and Social Services Board
SEN	Special Educational Needs
SEND O	Special Educational Needs Disability Order
SLT	Speech and Language Therapy
SSA	Social Security Agency
UK	United Kingdom
UN	United Nations
UNCRC	United Nations Convention on the Rights of the Child
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNOCINI	Understanding the Needs of Children in Northern Ireland
WHO	World Health Organisation
WHSCT	Western Health and Social Care Trust
YJA	Youth Justice Agency