

# **NEW DIRECTIONS: NEW OPPORTUNITIES**

*A Strategy for Promoting the Well-being and  
Independence of People with a  
Physical Disability and/or Sensory Impairment*

*September 2002*

## Alternative Formats

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# CONTENTS

	<b><u>Page</u></b>
<b>Executive Summary</b>	i
<b>Introduction</b>	1
<b>Developing the Strategy</b>	6
<b>Information on Population &amp; Needs</b>	10
<b>Improving Daily Living</b>	13
<b>Meeting Specialist Needs</b>	20
<b>Shaping Future Services</b>	40
<b>Conclusions</b>	42
<b>Appendices</b>	43

# **Executive Summary**

## **Background**

This Strategy provides a framework around which it is proposed future services should be developed and reshaped to more appropriately meet the needs of people with a physical disability and/or sensory impairment. Crucial, in developing the strategy, has been the involvement of people, and their carers, who directly use the services as well as a wide range of other key stakeholders from across voluntary and statutory organisations.

## **Developing the Strategy**

The Board has liaised closely with local Trusts and voluntary representatives in undertaking a detailed analysis of all available information relating to the needs of people with a physical disability and/or sensory impairment and the services they access. This information was supported by detailed consumer input using both independent consultants to carry out focus group sessions and through innovative approaches such as teleconference sessions and home visits. Key issues were presented in a discussion paper which was issued for consultation in July 2001. Feedback from this has been taken into account and shared with both the Reference Panel and User Panel established to quality assure the strategy process as well as the Board's Senior Management Team which acted as the Project Board for this work.

The Strategy focuses on three broad areas:

- information and needs;
- improving daily living; and,
- specialist services.

## **Information and Needs**

A key issue in planning and developing responsive services is the need for relevant information. A priority for the Board is to strengthen the availability and quality of information and will:

- work with Trusts to assess how existing approaches to data collection can be improved; and,
- develop a co-ordinated needs assessment programme in partnership with Trusts, DHSS&PS and local voluntary organisations.

## **Improving Daily Living**

People with a physical disability and/or sensory impairment have highlighted a number of general issues which, if addressed, they feel would significantly improve their wider quality of life and independence. These were:

- attitudes and awareness of staff in health and personal social services and the wider public towards disability;
- availability of information in suitable formats and locations;
- opportunities to lead a healthy lifestyle; and,
- accessing health and social care facilities.

It is recognised that addressing many of these issues does not necessarily require significant additional financial resources but is more often about trying to change attitudes, promote good practice amongst all staff and to make reasonable adjustments when planning and delivering future services.

## **Meeting Specialist Needs**

The strategy also looks at the needs of people who require more specialised forms of support and care under the following groupings:

- young people aged 16-25 years;
- people with a physical disability;

- people with a sensory impairment;
- specialist hospital services; and,
- carers.

Identified below are the top priority areas which it is proposed should be addressed:

- review the transition planning process for young people transferring from children's to adult services to ensure that this enables young people to maximise their opportunities at this crucial stage in their lives;
- improve the co-ordination of services provided between hospital and community settings;
- develop a range of emotional support services;
- develop dedicated specialist rehabilitation services to enable people to maximise and maintain their functional ability and independence;
- further develop social and vocational rehabilitation activities to enable people to access appropriate social, leisure, training and employment opportunities;
- develop flexible and tailored respite and domiciliary care services;
- ensure the timely provision of adequate equipment to support people to live more independently; and,
- further enhance the range of information provided and support services available for carers.

### **Shaping future services**

In shaping future services a key element will be to ensure they are organised to support greater integration between the various professional inputs. There is also a need to better utilise the broad range of expertise that is available in the voluntary sector to ensure that

best value is realised in terms of both care outcomes and the resources invested.

### **Implementing the Strategy**

It is proposed that the strategy will be implemented over a five to seven year period and will provide a framework for the Board in determining priorities for care investment. The Board's ability to fully deliver the changes outlined in the Strategy will be dependent upon:

1. the Board being able to realign more closely its current pattern of investment to that identified under the capitation formula;
2. additional funding being made available to the HPSS on an annual basis by Government; and,
3. prioritisation being given to this area by the Department and the Minister when allocating funding.

It is, however, recognised that there are many areas within the strategy where resources are not required to improve the current level of service provided and these must be addressed urgently.

## Introduction

1. This document presents the Northern Board's Strategy for the development of services to better meet the needs of people with a physical disability and/or sensory impairment.
2. The Board's objective is to ensure that care services are developed in ways which enable people with a physical disability and/or sensory impairment to:
  - achieve the highest possible quality of life;
  - maximise their independence;
  - improve their health and well-being; and,
  - increase their wider life opportunities.
3. Services to meet the needs of people with a physical disability and/or sensory impairment have, arguably, had difficulty in securing a fair share of resources. This has been due, in part, to the broad range of needs which people with a physical disability and/or sensory impairment have and the difficulties that this causes in providing a strategic focus as to how services should be developed. This strategy seeks to make positive steps in improving this position and sets clear priorities for where future investment should be targeted, should resources become available.
4. In developing this Strategy, the Board has adopted the Disability Discrimination Act 1995 definition of disability:

***“a physical impairment which has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities”***,

(defined in Schedule 1 of the Disability Discrimination Act, 1995 as mobility, manual dexterity, physical co-ordination, continence, ability to lift, carry or otherwise move everyday objects, speech, hearing or eyesight,

memory or ability to concentrate, learn or understand and perception of the risk of physical danger).

5. The Strategy addresses issues that impact on all people with a physical disability and/or sensory impairment but focuses, primarily, on the needs of people aged 16-64 years. The particular needs of children under 16 years and older people over 64 years with a physical disability and/or sensory impairment will be incorporated in the Children's Services Plan and Strategy for the Care of Older People. It is recognised that children with a disability, aged over 16 years, continue to be protected under legislation, such as the Children (NI) Order 1995, and that the responsibilities of social services for looked after children now extend beyond a young person's 18th birthday. The potential for overlap in this area is significant and the Strategy takes account of this.
6. Given the potential range of physical disabilities and/or sensory impairments, it is not possible to address each one in detail. The aim of the Strategy is to set out the broad context and direction within which the Board wishes to see services developed. Further work will be undertaken to assess how specialist services can be shaped to best meet the needs of people who have a specific condition or disability.
7. Given the wide range of disabilities, we have decided not to focus on the provision of the medical or surgical services that people may require immediately following the onset of a disability, such as a brain injury or a stroke. Following discussion with service users and care providers, our attention has been directed to rehabilitation and community support services. These services are required to enable people with a physical disability and/or sensory impairment to live as independently as possible, to combat social exclusion from their community and to achieve a fulfilling life.
8. As modern medicine and care has improved, the prevalence of certain types of disability is changing. For example, the increase in women taking folic acid prior to pregnancy has resulted in a decrease in the incidence of

spina bifida. At the same time, medical advances have led to more people surviving from conditions or events which would in the past have reduced life expectancy. As a result, there are many more people with a severe disability who are living longer and wishing to live as independently as the rest of the community.

9. In light of these and other changing circumstances, the Strategy identifies where existing services should change to better meet needs. It also considers care needs which are not presently addressed by dedicated services.
10. Services for people with a physical disability and/or sensory impairment must be:
  - responsive (that they can be accessed quickly and are sensitive);
  - effective (that what they do provides a benefit);
  - appropriate (that they actually meet assessed need);
  - equitable (that you get the same standard of service no matter where you live, depending on your assessed need);
  - affordable (that they can be provided within the resources allocated to the Board and take into account other demands that must be addressed); and,
  - achievable (that it is possible to develop them).
11. In attempting to balance these competing considerations within the Strategy, a number of challenges and choices will need to be addressed by everyone who has an interest in this area.
12. The Board is conscious that, increasingly, a larger share of new resources allocated by the Minister for Health, Social Services and Public Safety are being identified for specific priorities, and that this leaves less discretion over how resources can be allocated locally. It becomes increasingly important, therefore, that the Board has a

clear understanding of where there is a need to reshape and develop services so that we can influence the Minister and Department's priorities.

13. In setting out the range of issues addressed within the Strategy the Board has structured the document as follows:
  - i. Section 1 outlines how the Strategy has been developed and the various approaches that have been used in engaging users, carers and others. It also sets out the issues that need to be taken into account in shaping future services and the challenges that need to be addressed in making choices for the future.
  - ii. Section 2 sets out how available information on the population and the needs of people with a physical disability and/or sensory impairment has been analysed and considers how limitations in the information available can be addressed.
  - iii. Section 3 examines a range of daily living issues that able bodied people would take for granted but impact significantly on the ability of people with a physical disability and/or sensory impairment to live independently and to continue to participate in every day activities.
  - iv. Section 4 looks at the needs of people with a physical disability and/or sensory impairment who may have specialist needs and how specific services need to be changed and developed to meet these needs in the future.

Specific focus is given in this section to the following areas:

- young people aged 16-25 years;
- people with a physical disability;
- people with a sensory impairment;

- specialist hospital services; and,
  - carers.
- v. Section 5 sets out the Board's vision of how future services need to be organised, including possible changes to existing management and professional arrangements to enable future services to be focused on meeting the needs of individuals in a more holistic way.

14. Throughout the document a number of quotations are highlighted in the margins. These quotations are from both the users of services and their carers and are aimed at illustrating specific issues that are discussed within the main document.

15. In response to the draft Strategy document issued for consultation in March 2002 the Board received a number of responses. Broadly, the responses received were supportive of the strategic direction being proposed. Where significant issues were identified these have been considered by the Board and amendments to the final Strategy approved. These are highlighted in italics within this document.

## Developing The Strategy

16. This Section outlines how the Strategy has been developed in consultation with users, carers and care professionals. It also sets out a range of issues and challenges to be taken into account in shaping future services.

### The Approach

17. From the outset of the development of the Strategy, the Board has sought to listen directly to the views and experiences of people who live with a physical disability and/or sensory impairment and to understand those factors that have a significant bearing on their lives. This has involved:
  - focus group sessions with people who are blind or visually impaired using teleconference facilities;
  - home visits to people with severe disabilities and their carers;
  - engaging local community disability groups from across the Board's area; and,
  - employing an independent organisation to undertake a number of focus group sessions with people who have a physical disability or who are deaf or hard of hearing.
18. At the same time, the Board has undertaken a detailed analysis of research material, professional literature, relevant statistical information, key policy documents and legislation. This entailed:
  - examining demographic and prevalence information on the known needs of people with a physical disability and/or sensory impairment;
  - undertaking an audit of services available to people with a physical disability and/or sensory impairment;

- examining expenditure and information on levels of care;
  - analysing changes in policy, legislation and other factors that may influence strategic change (see Appendix 1); and,
  - reviewing academic literature on best practice in the development of future services.
19. Using this wide range of information, the Board was able to make an initial assessment of how existing services were meeting the needs of people with a physical disability and/or sensory impairment. Possible options for how services could be reshaped to better meet needs in the future were identified. These initial thoughts were presented in a discussion paper which was issued for widespread consultation in July 2001. Comments received in response to the discussion paper have been taken into account in developing this Strategy.
20. A diagram setting out the process for developing the Strategy is presented in Appendix 2.

### **A Person Centered Strategy**

21. Within health and personal social services, great efforts have been made to focus on addressing the needs of a person as an individual rather than on their disability when planning and providing services. The Board's Strategy is designed to reinforce this approach and shape how services are delivered in a way that promotes individual choice and independence.
22. This is also consistent with person centred planning at an individual level which stresses that individuals with a physical disability and/or sensory impairment are central to the assessment process and that needs identified are addressed in consultation with them and their carers.

## **Resource Context**

23. In 1998, the Board reviewed its expenditure across various care sectors and localities. This identified an imbalance in certain programmes and localities and, at the time, a degree of under investment on services for people with a physical disability and/or sensory impairment.
24. The Board is committed to redressing these imbalances but this will require additional resources to be made available, either through new priority funding from the Department, or from the redeployment of existing funds from other areas.

## **Key Challenges**

25. In shaping future services, a number of key challenges were identified which are summarised below:
  - the Board is now funding a greater number of people with very complex needs. In some instances, individual care arrangements can cost in excess of £100,000 per year. Whilst the Board is committed to continuing to support existing arrangements, it would appear that, over time, a higher percentage of available resources will be consumed to meet the care needs of a relatively small number of people;
  - the Board recognises that there is strong public support for embracing developments in new technology as well as new drug therapies for conditions such as multiple sclerosis or rheumatoid arthritis. There is a need, given limited resources, to balance the overall benefits of providing such services to relatively few people against the impact these resources could have in providing services to meet the needs of many more people;

- by targeting resources towards those in greatest need, the ability of services to help those people who may have the greatest potential to live more independent lives becomes more limited, as it is impossible to meet all levels of need; and,
- promoting individual choice and greater flexibility in how services are delivered is likely to require additional resources. This must be balanced with the Board's statutory obligation to continue to deliver core services to the wider population.

These issues form a recurring theme throughout the Strategy.

## **Information on Population and Needs**

### **Prevalence**

26. Historically, quantifying the numbers of people who have a physical disability and/or sensory impairment has been difficult and is subject to variation depending on the definitions used. At the broadest level, it is estimated that approximately one in six adults has a physical or sensory disability. Based on the levels of prevalence identified in the Public Policy and Research Unit study “The Prevalence of Disability Among Adults in Northern Ireland” (1992), it is estimated, using 1999 mid year population figures, that there are approximately 25,000 people currently living in the Northern Board area with a physical disability and/or sensory impairment aged 18 - 64 years of which 1,650 would have highly complex needs (see Appendix 3 for further details).
27. Levels of disability within Northern Ireland are likely to have been affected by the impact of civil unrest and conflict over the past 30 years, including more recently the outcome of paramilitary assaults and shootings that are leaving young men in particular, with lifelong disabilities.

### **Information on the use of Services**

28. Access to accurate and meaningful information on the extent to which people with a physical disability and/or sensory impairment use existing services is an essential element in planning how future services should be shaped.
29. The Board has reviewed routine data collected by local Trusts, as well as data available on specialist regional services such as those provided at Musgrave Park Hospital. Whilst this has provided the Board with a broad indication of the extent to which people with a physical disability and/or sensory impairment are accessing services, the exercise has demonstrated

significant limitations with the data that is currently available.

30. In addressing this, it is clear that there is a longer term issue and the Board would wish to work closely with local Trusts and the Department of Health, Social Services and Public Safety to assess what changes can be made to improve the information that is available.
31. Information routinely collected does not allow for the identification of certain groups protected by Section 75 of the Northern Ireland Act 1998 equality legislation, for example, in relation to sexual orientation, dependants or religion. It is important that these areas are addressed, as far as possible, in any future information systems that are developed.

### **Information on Needs**

32. In developing an understanding of the needs of people with a physical disability and/or sensory impairment, information has been drawn from many sources: from service reviews; professional audit; academic literature; and, professional knowledge to information provided directly by users, carers and other interested parties through the various initiatives outlined in Section 1 (Ref page 6).
33. Overall, the availability of local needs assessment information is limited and consideration needs to be given as to how this can be improved for planning future services. The Board will work with local Trusts and voluntary organisations to agree key areas where needs assessment work urgently needs to be undertaken and develop a co-ordinated programme within which this could be taken forward.
34. The Board is currently contributing to work being undertaken by the Regional Capitation Working Group to look at how the needs of people with a physical disability and/or sensory impairment can be more accurately measured in order that resources allocated reflect the levels of need presenting. It is also anticipated that

information from the census undertaken in 2001 will be helpful in providing more accurate information.

### **Summary**

35. Decisions on how future services should be shaped is hindered, in part, by the lack of relevant information. The considerable weight placed by the Board on proactive consultation and engagement with service users, carers, care professionals and others working in this area has been helpful in redressing some of these gaps.
36. In addition, the Board is working with Trusts to assess how improvements to existing approaches to data collection can be made and to ensure that, in developing future information systems, every effort is made to overcome current deficiencies. Information on the levels of prevalence and need also require refinement to ensure that the levels of resources being invested reflect the needs presenting.

## Improving Daily Living

37. The discussions held directly with people with a physical disability and/or sensory impairment highlighted a number of general issues, which, if addressed, would significantly improve their quality of life and independence. These included:

- awareness amongst staff in health and personal social services and the general public regarding the needs of people with a physical disability and/or sensory impairment;
- access to information at the point of diagnosis or immediately afterwards. Information needs to be understandable, provided in an appropriate format and in a sensitive way;
- support in maintaining their general health and well being;
- physical access to public facilities (particularly parking, signage and physical obstacles) and a lack of specialist and technical support; and,
- the need for greater interagency co-ordination, in particular, between housing, health, education and training and employment.

### Attitude and Awareness

38. Within health and personal social services and the general public, there is a general lack of awareness of the circumstances and needs of people with disabilities. This is due in part to the fact that:

- many people with a physical disability and/or a sensory impairment do not access services on their own and have a carer or friend accompany them. This reduces the need for others to be aware of their disability;

"It is not that you want anything special or different from anybody else. We just want to have the same chances to go out and go shopping or keep fit and to have the same quality of life as somebody who is not visually impaired"

"The doctor I am with knows I have got a problem and comes outside his door and shouts on me They are doing what they can for me".

- people do not wish to be seen to ‘cause a problem’ and either do not make people aware of their disability or simply do not use the services available; and,
  - many people working in health and personal social services do not know how to be of assistance to people with a physical disability and/or sensory impairment and have not received any training in this area.
39. With the introduction of the Disability Discrimination Act (1995) and the Northern Ireland Act (1998), there is now greater recognition of the importance of being aware of disability issues.
40. In addressing this issue the Board shall progress the following initiatives:
- review existing approaches to training and disability awareness and, where possible, ensure that people with a physical disability and/or sensory impairment are actively involved in such programmes;
  - ensure that all care professional staff who have direct contact with the public have received training on disability awareness;
  - have disability awareness training included as a key element of the pilot primary care training initiative, Northern TARGET, currently being implemented across the Board’s area;
  - work in partnership with other organisations to promote disability issues jointly where it would be beneficial to do so; and,
  - undertake an audit of how people with a physical disability and/or sensory impairment feel their needs have been accommodated when using acute hospital services.
- “Deaf awareness in A&E is particularly poor. The waiting and calling system is inefficient”.

41. It is essential that information available is understandable, easy to access and in a format suitable to individual needs.

42. Historically, difficulties have arisen due to the vast amount of information that is available, and the ability to keep this information up to date and in a format that is appropriate, for example, large print, Braille, video or audio tape.

“Finding information is very difficult”.

43. There is now a greater expectation that information will be made available in a way that adequately meets the needs of people with a physical disability and/or sensory impairment. Advances in technology also mean that it is possible to present information in a variety of formats which are more easily accessed.

44. To improve how information is presented, the Board will establish a forum consisting of local Trusts, voluntary organisations and users of services to agree standards of best practice and to examine approaches that could be introduced to make information more easily accessible for people as and when they may need it. The Board will also work with other statutory agencies to consider the feasibility of developing a number of locally based information centres which could provide information on all services and activities.

45. It is recognised that the effective provision of information is not simply about ensuring that leaflets and booklets are available. It is as much about enabling people with a physical disability and/or sensory impairment to contact each other and share information about services they are receiving or social activities that are being organised. In this regard the Board is aware of the Ballymoney Disability Development Forum pilot project which provides a focal point for people with a physical disability and/or sensory impairment living in the area. This pilot also assists in raising the profile of disability issues in the area and is a model of service the Board would support.

“That was the best support... talking to other people in the same situation”.

## Leading a Healthy Lifestyle

46. Supporting people with a physical disability and/or sensory impairment to lead a healthy lifestyle and to pursue wider social and leisure activities was identified in discussions with people being very important.
47. Currently, there is limited advice provided to people with a physical disability and/or sensory impairment through the broad health promotion initiatives that are taken forward by health promotion staff.
48. It is recognised that to effectively address this issue all staff who have responsibility for providing direct care services should take responsibility for monitoring the wider health and well-being needs of their patients and clients. In particular, care staff should be actively encouraging individuals to go for regular check-ups to their General Practitioner, Optometrist or Dentist. Where it is not possible for a person to leave their home, or where it may not be possible to physically access a facility, the service should be provided in the person's home. Where appropriate, staff should coordinate referrals to specialist services such as the Community Dental Service.
49. A number of target areas for improving the general health and well-being of the whole population have been identified in the Government Strategy 'Investing for Health' issued in March 2002. These include: smoking; physical activity; eating for health; harm related drugs and alcohol; mental health; sexual health; and, accidents. It is important that these regional initiatives take account of the specific needs of people with a physical disability and/or sensory impairment.
50. The Board will expect health promotion staff to engage directly with people through, for example, Community Disability Forums to identify what the key areas of need are in relation to health promotion and to assess how best these can be addressed. Opportunities for working in partnership with voluntary organisations should also be explored.

"As much should be done to keep you young and mobile because then you will be fitter and happier for longer".

## **Accessing Health and Social Care Services**

51. It is essential that when people with a physical disability and/or sensory impairment need to use health and social care services they are able to access the facilities and that the necessary support is available to enable them to communicate effectively and understand what is being said. In order to address this there should be a specific focus on providing: specialist equipment such as loop systems or textphones; interpreters; and, support for people who have a speech impairment.
  
52. Based on evidence from work undertaken by the Northern Health and Social Services Council in their report "Breaking the Silence - A Study of the Needs and Experiences of Those who are Deaf or Hard of Hearing in the Northern Area" (2000) and from the access survey undertaken by the Board entitled "Getting There - A Survey of Standards of Accessibility to Health and Social Care Facilities for People with a Sensory Impairment" (1998), it is acknowledged that several difficulties need to be addressed. These are:
  - a general lack of awareness by staff of the needs of people with a disability/impairment;
  - provision of staff training in using specialist equipment;
  - limited use of the equipment by people with a physical disability and/or sensory impairment; and,
  - difficulties for staff in retaining skills.
  
53. In 1999, the Northern Health and Social Services Board provided over £140,000 to ensure that all health and social care facilities, where there was public access, had basic equipment to assist people with a visual or hearing impairment. The Board will continue to monitor Trusts to ensure that this specialist equipment is provided and that staff are appropriately trained.

54. The Board will also review with Homefirst Trust the current arrangements for providing interpreters for people across the Northern Board area who are deaf to ensure that this continues to be the best approach to providing this service.
55. The Board recognises specific difficulties experienced by people who have a speech impediment and will liaise with voluntary and community organisations to assess what assistance could be provided to support people.
56. The Board will also raise awareness amongst dentists, optometrists and pharmacists of their obligations to ensure appropriate support is available to people with a physical disability and/or sensory impairment.
57. By the end of October 2004, all health and social care facilities should be accessible to people with a physical disability and/or sensory impairment. The Board is aware that Trusts are undertaking an audit of the structural changes that would need to be undertaken to achieve this aim and the resources that would be required. Whilst every effort will be made to comply with the target deadline set in the Disability Discrimination Act, it is recognised that the ability of Trusts to achieve this objective will be subject to the necessary resources being made available by the Department of Health, Social Services and Public Safety.

“I was to attend outpatients in Magherafelt for 7 weeks.... But not for the life of you would you get parked anywhere near it”.

### **Interagency Working**

58. People with a physical disability and/or sensory impairment may need to access services from a variety of statutory agencies. In many instances this proves to be a difficult and frustrating experience. It is important that the various statutory agencies are clear about their role and responsibilities. Where there is joint responsibility for providing services or where responsibility may pass from one agency to another it is essential that the respective agencies ensure that a co-ordinated approach is in place, that clear information is available to individuals at all stages of the process and that the process is made as straight forward as possible.

## **Summary**

59. This section has highlighted that basic issues such as how information is presented can have a significant impact on the wider quality of life a person with a disability and/or impairment may lead. Addressing many of the issues does not, however, necessarily require significant additional financial resources. They are more often about trying to change attitudes and breakdown historic misperceptions of disability through greater integration, understanding and social inclusion. It is also about working together across organisational and professional boundaries to provide the best solution to meeting an individual's needs and maximise the potential of limited resources available to enable people to live as independently as possible.

## **Meeting Specialist Needs**

60. This Section focuses on how specific services accessed by people with a physical disability and/or sensory impairment are meeting their needs, where they could be improved and the Board's approach to achieving that improvement. In doing so, the section looks at the needs of people under the following groupings:
- young People aged 16 - 25 years;
  - people with a physical disability;
  - people with a sensory impairment;
  - specialist Hospital services; and,
  - carers.

### **Young People Aged 16 - 25 Years**

61. Under the Children (NI) Order 1995, children with a disability are considered to be 'children in need'. They are, therefore, protected under the legislation and should receive services to meet their assessed need. It is also important to highlight that under the forthcoming Children Leaving Care Bill, any children with a disability who have been looked after by Social Services after their 16th birthday are entitled to 'aftercare services' until they are 21 years and, in exceptional circumstances, until they are 23 years. In developing future services the Board shall ensure that those responsible for the planning of services for adults, work in partnership with those responsible for the planning of children's services and in particular the Board's Children's Services Planning Sub Group for Children with a Disability, Long Term Illness or Terminal Illness also Requiring Services.
62. A key stage in any young person's development is their transition from childhood to adulthood. For a young person with a physical disability and/or sensory impairment, potential problems at this stage in life are

- magnified. The opportunities and support provided to young people aged 16-25 years will significantly influence how the remainder of their lives will be shaped.
63. Based on the information available, there appears to be a substantial gap between the numbers of young people aged 16-25 years who have a physical disability and/or sensory impairment known to local Trusts and the projected level of prevalence. Though it is recognised that young people who have a physical disability and/or sensory impairment may not need to access health and personal social services, it is important to understand what level of unmet need may exist. The Board is aware that under the Childrens' Services Planning process, a Regional Disability Register for Children will be established. Whilst all children with a disability may not be on the register, the Board would wish to assess how it may be used to establish a baseline against which the extent children continue to access services, as they grow older, can be mapped.
  64. A key concern for young people aged 16-25 is that support services such as day care, respite care, domiciliary care and rehabilitation services are sufficiently flexible to meet their specific needs and circumstances. Rather than examine these in detail at this stage, consideration is given as to how these services need to be shaped when looking at individual services under the section on Adults with a Physical Disability. (Ref. Pg 22)
  65. *A key issue impacting upon the needs of young people aged 16-25 is the transfer of responsibility for their support and care services from those providing childrens services to those responsible for adult services. Currently, there is limited information as to the effectiveness of the process for those young people who have made the transition.*
  66. *A further issue is the Educational Code of Practice on the Identification and Assessment of Children with Special Needs which only provides guidance to schools on the transitions process for those children with a formal statement of special educational needs.*

*Extension of this process to children with special needs who do not have a statement is at the discretion of individual schools. It is the Board's intention to continue to work with provider Trusts and other agencies to ensure a more co-ordinated approach to the transition to adult services for those aged 16-25 years.*

67. Planning must ensure that the young person, where possible, has the opportunity to access wider social, leisure, training and employment options and to achieve their ambitions in the same way as their able bodied peers. In addressing this issue, the Board has provided funding to Homefirst Trust to undertake a detailed assessment of need and to review the effectiveness of the existing transitions planning process. This project will be completed by March 2003. It is the Board's intention to use the findings and recommendations to shape future developments across the Board in this area.

### **Services for Adults with a Physical Disability**

68. This section looks at how individual services are meeting the needs of adults with a physical disability and outlines how the Board would wish to see these reshaped or developed. Where appropriate, specific focus is given to addressing the needs of young people aged 16-25 years.
69. The objective in providing support to people with a physical disability is that it will minimise, as far as possible, the impact that the disability has on their lives and enable them to live independently and retain control over their own life and circumstances. Where support services are required, the goal is that these are delivered in a timely and co-ordinated manner and are tailored to meet the needs of each person.
70. Prior to addressing the provision of specific services, it is important at the outset to consider difficulties that people experience following initial diagnosis of their condition.

## **A Seamless Service**

71. People with a physical disability who have used care services have identified to us a perception that the level of co-ordination and communication between hospital and community services is variable, particularly for those diagnosed with a degenerative condition such as multiple sclerosis or diabetes. In particular, there would appear to be no guarantee that following diagnosis in hospital, people will automatically be referred on to community services.
72. Whilst the Board recognises the difficulties that exist, there appears to be a gap in the information that is provided to people using hospital services about what community support services they are able to access, should they wish or need to do so.
73. The Board proposes to work with relevant Trusts to review the information available to people on services in these circumstances to ensure that key staff can provide appropriate information at this time. The Board also recognises the important role that voluntary organisations have in developing innovative initiatives and will explore ways in which the voluntary sector and volunteers can be used to promote the availability of useful information.

## **Emotional Support**

74. A key issue raised by people with a physical disability is the need for emotional support services to be available both at the time of diagnosis and, if required, over the longer term. In many instances the emotional impact of acquiring a disability and learning to live with it can be a greater challenge to overcome than coping with the loss of physical function. This can also put a great strain on the relationship between an individual and his/her family or friends who may be caring for them. Currently, there are few specific emotional support services other than Trust Social Workers, Rehabilitation Workers or voluntary sector services and this is proposed as a priority for development. As resources become
- “I was given no emotional support at all. I just had to deal with it”.
- “I need someone I can sit down and talk to about MS and my uncertainties and stuff”.

available, the Board will invest in services which focus on the provision of emotional support to help people deal with the effects of their disability.

### **Rehabilitation Services**

75. Timely and appropriate rehabilitation following the onset of a disability and/or impairment can significantly reduce the long term impact it may have on a person's life and help prevent dependence on longer term support services.
76. Many people associate rehabilitation with restoring physical functioning. However, the need for people to be able to access wider social and leisure pursuits or return to employment is equally important. Many people who have a physical disability will also require equipment, housing adaptations and assistive technology to enable them to live more independently. The importance of the environmental, educational and occupational issues cannot be underestimated. It is in these wider aspects of rehabilitation where people who have a physical disability often experience the greatest difficulties.

"I got physiotherapy for six weeks. I have now gone back to the way I was before because you need continual physiotherapy".

### **Physical Rehabilitation Services**

77. Timely access to physical rehabilitation services is essential if a person is to regain and maintain his/her optimum level of mobility and functioning as well as helping to prevent unnecessary deterioration.
78. Feedback from the focus group sessions has identified the lack of specialist therapy services as a key gap and something that needs to be addressed urgently.
79. Currently, the Health and Social Services Trusts within the Northern Board have no specialist therapy services dedicated to individuals with a physical disability. The Board considers the development of additional posts in the Allied Health Professions as a top priority and will work with local Trusts to assess how best future services in this area could be developed. While there are many

"I had speech therapy for about 2 hours and that was it".

pressing needs, it will be the Board's intention to invest initially in Speech and Language Therapy, Physiotherapy and Occupational Therapy. Further priorities for the Allied Health Professions are identified in paragraph 103, page 31.

## **Social and Vocational Rehabilitation**

### **Day Care Services**

80. The objectives of day care include:

- providing people with a physical disability with opportunities to develop their social skills;
- equipping people with daily living skills to promote greater independence;
- developing skills that may help people to access further education or employment; and,
- maintaining peoples' overall health and well-being.

“He would like to get back into employment, not the way he was but perhaps working in a garden centre. He loves it and it would give him some life back again. I would like to know how we would go about this”.

81. The Board is concerned that the range of day care services available currently, does not provide a sufficiently wide range of skills and opportunities to enable people to live more independently. This is evidenced by the fact that only a small number of people with a physical disability leave day care to take up paid employment either independently or within a supported environment. The Board plans to carry out a review of day care services which will be informed by existing work where this is available and will take into account the views of people with a disability.

82. *The Board is aware of difficulties local Trust's are experiencing in providing transport for clients accessing day care services, particularly from rural areas. The Board would wish to explore with Trusts possible options that may be available to improve access to these services, particularly for those clients who may have more complex needs. On a broader front, the Board acknowledges difficulties that people with a physical disability and/or sensory impairment encounter in accessing wider transport services. The Board is not able to implement changes in this area directly but will continue to highlight these difficulties with relevant agencies where possible.*
83. The Board is particularly concerned at the lack of suitable day care provision for young people aged 16-25 years and would see the development of progressive initiatives in this area as a priority.

### **Vocational Rehabilitation**

84. Vocational rehabilitation primarily means helping people with a disability to pursue action which will enable them to access employment opportunities. Provision of effective vocational rehabilitation depends on a range of agencies such as Health and Personal Social Services, Education and Training and Employment as well as those in the voluntary and private sectors. Working in partnership is essential to deliver a flexible range of services. The Board is committed to working in partnership with all groups with an interest in this area and will establish a strategic planning group or taskforce that will seek to improve co-ordination and clarify roles and responsibilities with the aim of providing a seamless service. At the same time, the Board would wish to see local Trusts establish a number of forums, consisting of key statutory, voluntary and community organisations to focus on how the needs of specific individuals could be better co-ordinated at a local level.
85. A good example of an integrated approach to

rehabilitation has been the establishment of a multi-disciplinary area wide Brain Injury Team. This Team works closely with the Cedar Foundation who provide prevocational training and support for people aged between 16-60 years to facilitate access to further education, training and employment opportunities. The Board recognises that the demands on these services are growing and will seek to expand the service further, taking into account the development of a Regional Brain Injury Unit at Musgrave Park Hospital and other competing priorities.

86. Not all people who have a physical disability will be able to work or pursue other activities. Services that can deliver some form of maintenance, social support, leisure opportunities and interaction for these people are equally important. A “Leisure Quest” service has been piloted in the Causeway Trust area as part of the Pavestone Project offering such opportunities for people with a disability. The Board is currently undertaking an evaluation of the pilot to ensure that it is providing an effective option for young disabled people. The Board would wish to see schemes developed across its area that offer wider social and leisure opportunities.

### **Community Support Services**

87. People with a physical disability and/or sensory impairment may also require access to a wide range of other services which are considered under the following headings.

## Domiciliary Care Services

88. The provision of appropriate domiciliary care services is key to enabling people with a physical disability to maintain their independence. As far as possible, domiciliary care should be provided in a manner that suits the particular needs of people and be sufficiently flexible to enable them to pursue wider life opportunities.
89. From the information supplied by local Trusts, it would appear that there is a significant variation across localities in the level of domiciliary care provision available for people with a physical disability. In addition, there may also be variations across Trusts and localities in the application of access criteria. The Board is committed to ensuring that all people with a disability have equitable access to domiciliary care services, based on an assessment of individual need, regardless of their location and will explore with Trusts the reasons for the differences in levels of service provision. While the Board will need to be satisfied that any variations are justifiable, the goal will be the establishment of eligibility criteria which can be applied equitably and fairly.
90. Feedback from the discussions with people with a disability would suggest that existing domiciliary care support services are perceived as limited in availability, inflexible and that the time spent in a person's home is often inadequate. The Board recognises that if domiciliary care services are to be effective in enabling people to live independently and pursue wider life opportunities, then the levels of domiciliary care available must be increased and must be more flexible.
91. The Board proposes to review how current levels of domiciliary care provision are meeting the needs of people with a physical disability. The Board will wish to be assured that every effort is being made to promote both Direct Payments and the involvement of the independent sector in day to day provision. The Board will establish agreed monitoring procedures for existing and planned legislation in this area.
- "At the age of 30 I have to go to bed at 7.30pm to fit in with their schedule. I thought they were trying to encourage people to live independently"
- "I had to stop going to church because I had to go to bed between half eight and half nine because the Carers finished at half nine"

## **Respite care**

92. The provision of appropriate and timely respite care is important for both the individual and their carers in continuing to support independent living in the community. The Board acknowledges that there is a need to enhance the existing range of options available. As a priority, the Board would wish to see the development of services specifically tailored to meet the needs of younger people and will invest in this area as resources permit in order to address considerable unmet need. The Board acknowledges the work of the MS Centre in Ballycastle in relation to respite care and will explore with Causeway Trust ways in which this service might begin to meet a wider range of client need.

"I went to a respite centre and lasted one day. I hated it. The people who were there were much older than me and it was really depressing".

## **Accommodation Needs**

93. Families and carers may not always be able to provide the levels of support required to meet the needs of someone with a disability. In addition, more people with a physical disability wish to live independently. In addressing this area, the Board will work jointly with the Northern Ireland Housing Executive, local Trusts and relevant independent sector agencies to plan how future accommodation options should be shaped and developed. The Board will also need to consider the implications of the introduction of 'Supporting People', a new way of funding supported housing schemes to be introduced in April 2003.

"I would like my own place but I don't think that I will ever be able to afford it"

## **Residential and Nursing Home Care**

94. A small number of people whose needs can no longer be met within their own homes or in supported living arrangements will require access to residential or nursing home care. The Board will wish to be assured by Trusts that those people with a physical disability aged 18-64 who are in residential or nursing home places are appropriately placed and that their needs are periodically assessed.

"They offered a nursing home .. And at that stage my husband was 34. They told me they didn't have the funds to put in the care plan my husband needs to come home"

## Community Teams

95. *As an integral part of the Community Teams activities, social workers engage and intervene with clients, families, carers and groups in promoting social change, problem solving and empowerment to enhance social well-being.*
96. Information provided by local Trusts would indicate that these teams spend significant time addressing the needs of people who are terminally ill. This was not the original intention when these services were commissioned and the Board will seek to adjust the level of provision as resources permit.
97. Information from Homefirst Trust on social work caseloads would indicate that people in the Newtownabbey/Carrickfergus/Larne areas receive a significantly lower level of access to social work than those in Magherafelt/Cookstown. Given the important role that these teams play in enabling people with a physical disability to continue to live independently, the Board would wish to review the reasons for this apparent inequity and to assess how this could be redressed in the future. The medium to long-term aim will be to increase the overall level of provision to that of the Magherafelt/Cookstown sector.
98. A key issue arising from discussion with people with a physical disability is that there appears to be a significant variation in the levels of continuing contact that people have with their social worker. In moving forward it will be important to ensure that services are resourced to allow the necessary levels of support and contact to be maintained.
99. A rehabilitation worker and an environmental technical officer are attached to most of the Community Teams. The important role of these workers in providing support and training to people in daily living skills has been highlighted to the Board but users have indicated that it is increasingly difficult to access this service. The Board will wish to review how these posts operate within each
- "I really have high praise for my social worker. She sorted out my care plan and I got extra care".
- " I saw a social worker after I came home....I haven't seen anybody since and that was 1997"

of the Teams and assess how better access to daily living skills could be improved. One option is to promote a model which empowers people with disability to act as support workers and the Board will explore how such a model might be developed.

### **Community Nursing Care**

100. Many people who have a physical disability may also require treatment and advice in a number of specific areas such as pressure sores, continence management and stoma care. These conditions, if not managed effectively, can have a significant impact on a person's quality of life. Many of these conditions can however be avoided, or their impact minimised, if treatment is provided early. Early intervention can also avoid unnecessary admission to hospital. In this regard, the Board is aware of the CREST guidelines relating to wound management and will seek to adhere to these as resources permit.
101. Currently, many of these conditions are only being managed when they become problematic. As with many of the services for people with a disability, there are no dedicated staff to address these specific issues. Many older people will also experience these conditions and the Board will explore opportunities for developing services jointly to address the needs of both client groups.
102. With specific reference to continence services, there is evidence to suggest that these services could be developed with minimal additional resources as savings can be realised as a result of the reduced need for specialist pads, nappies and sheets. It is also important to highlight that the effective management of incontinence can also impact on an individual's ability to enjoy an active working and social life.

## Community Allied Health Professional Services

*103. Allied Health Professionals are crucial to the immediate rehabilitation of individuals and as such, the priority will be to invest additional resources in occupational therapy, speech and language therapy and physiotherapy services. It is recognised that other professionals such as dietetics and podiatry also have a key role to play in enabling people to retain their independence and to maximise their ability to take part in wider leisure and employment activities through out their lifetime. The Board is also committed to assessing how such input can be enhanced.*

### Equipment

104. Advances in technology have greatly improved the quality and range of equipment now available for people with a physical disability and/or sensory impairment. Public awareness of these developments has also increased, leading to higher expectations of what can be provided. Improvements in technology however, also result in the need for increased funding.

105. Given resource limitations, it will not be possible for the Board to meet all demands. In addressing this issue, the priority for the Board must be to ensure that access to all levels of equipment is based on assessed need and targeted appropriately. It is also vital that equipment provided is maintained in accordance with the appropriate Health and Safety Regulations. When such equipment is no longer required by clients it must be reclaimed and, where appropriate, recycled to ensure best value of limited resources. In order to overcome difficulties in assessing need and prioritising allocation of equipment, it is important that clear criteria are set down and followed to ensure that services are managed in a fair and equitable way.

“There is a chair that I have seen in the MS magazine that exercises your legs but this isn’t available to us and I can’t afford £3,000 to buy it myself”.

106. The Board is aware of several reviews that have recently been undertaken regarding the provision of specialist equipment such as wheelchairs, orthotics and prosthetics as well as community loan equipment. The Board would wish to ensure that the recommendations from these reviews, pertaining to specialist aids and equipment, are addressed by Green Park Healthcare Trust which has a regional responsibility for the delivery of these services. The Board would also wish to pursue the implementation of recommendations with local Trusts in respect of community loan equipment. The Board will work with Trusts to identify to the Department of Health, Social Services and Public Safety any additional resources required to meet these new standards.

107. Whilst the Board recognises that additional investment will be required to meet the increasing need for equipment, it would wish to work with both Green Park Healthcare Trust and local Trusts to assess what actions can be taken to ensure the efficient and effective management of this service.

108. Provision of housing adaptations is another area of service provision requiring particular attention. Many people with a physical disability find that their home is no longer suitable for their needs and may require an adaptation. Over the years there has been an increasing level of dissatisfaction with this service, both in the length of time spent waiting for an initial occupational therapy assessment, and in the length of time it takes to complete the adaptation. Responsibility for completing the adaptation resides with the Housing Executive and the Board would wish to work in partnership with local Trusts and the Housing Executive to ensure that recommendations emanating from the joint Health and Personal Social Services and Public Safety and Northern Ireland Housing Executive review of this service area are implemented.

“It is a constant battle. It took over 3 years to go through the process of getting the house adapted”.

109. During 2001/02, the Board invested additional resources to improve the existing waiting times for an initial

occupational therapy assessment. Information available to the Board suggests that the majority of those clients with high priority needs are currently assessed within Community Charter Standards. The Board will continue to work in partnership with local Trusts to ensure that all Occupational Therapy assessments are carried out in a timely and appropriate manner. In undertaking this work, it is recognised that a significant proportion of equipment and assessments for an adaptation are allocated to older people and that a joint approach with those responsible for the planning and delivery of services to this client group will be required.

“My social worker tried to talk to me and I said look I don’t understand. She just gave up and walked off and she is meant to deal with the deaf”.

## **Services for Adults with a Sensory Impairment**

110. Whilst the changes proposed elsewhere in this document are equally applicable to people with a sensory impairment, this section specifically highlights a number of areas which address their particular needs.
111. The Board’s service audit has revealed that people with a sensory impairment are having to wait longer for an initial assessment from a social worker than people who have a physical disability. We are also aware from discussions with people that other difficulties are being experienced, specifically in relation to: accessing training in basic living skills; communicating effectively with staff; and, having needs reassessed on a routine basis.
112. In addressing these concerns, the Board will undertake a review of specialist services available to meet the needs of people with a sensory impairment. Given that many older people will also have a sensory impairment, this work will be undertaken in partnership with those responsible for the planning of services for older people. As a first step however, the Board wishes service providers to adhere to the standards identified in the document ‘Best Practice Standards - Social Services for Deaf and Hard of Hearing People (RNID, July, 1999) and will be incorporating these in Service and Budget Agreements with Trusts.

113. It is important, particularly for people who are deaf, or hard of hearing that those responsible for delivering specialist services are able to communicate adequately with them. In particular, staff who have direct responsibility for supporting people with a sensory impairment should be trained appropriately and, where necessary, have specialist skills such as sign language. Improving the communication skills of professional staff who are in direct contact with people is a priority for the Board. It will wish to ensure that all specialist staff working with people who are deaf have at least Stage 2 Sign Language qualification by 2005. Specialist training in communicating effectively with people who are visually impaired or have a speech impairment should also be provided.
114. In 1999, the Department of Health, Social Services and Public Safety published the document, "Review of Services for People Aged 16-65 with a visual impairment". A key recommendation was that locally available low vision assessment clinics should be established to address the acknowledged problem of low uptake at the existing clinics in the Royal Victoria Hospital and Altnagelvin Hospitals. The Northern Board has recently provided funding to establish a low vision clinic in Ballymena. Whilst the Board will wish to evaluate the impact of this service and consider the need for extending it further, future developments will need to be considered in the light of other competing priorities.
115. A number of people with a visual impairment who have young children have highlighted that no routine assessment has been made of their children's eyesight. The Board would wish to discuss with Trusts what procedures are in place for genetic screening of children whose parents have a disability.
116. As a result of the isolating effects of deafness, people who are deaf or hard of hearing can experience a higher level of mental health problems and psychiatric illness. The four Health and Social Services Boards are commissioning specialist psychiatric hospital services

from the John Denmark Unit in Salford near Manchester. This Unit also provides an outpatient service every two months at clinics held usually in Belfast. Currently, no-one from the Northern Board area is accessing this service. The Board is reviewing, in partnership with other Boards, if this approach to meeting the mental health needs of deaf people is the most appropriate and is seeking to develop an alternative specialist service within Northern Ireland.

117. Special mention must be made of the needs of people who have dual sensory impairment. In England, the Department of Health has recently issued new guidance to local authorities with regard to their responsibilities in this area. The Board does not propose to apply this guidance in advance of a regional initiative but would wish Trusts to familiarise themselves with its contents in anticipation of its local application.

### **Specialist Hospital Services**

118. Specialist hospital services such as neurology, trauma and orthopaedics and ophthalmic services are primarily provided on a regional basis by the Royal Group of Hospitals Trust. Specialist rehabilitation services and elective orthopaedic services are provided by Green Park Healthcare Trust. The Board is committed to continuing to develop these services to ensure that people receive high quality care and that the long-term impact of any disability or impairment can be minimised. Future priorities for the development of these services will be determined on a regional basis.
119. The Board is aware of the difficulties that currently exist with discharging patients from acute facilities to specialist rehabilitation services or to local community services. In considering how future resources should be invested, the Board must balance further developing hospital based services with enhancing the level of community support available.
120. The Board has recently approved a Full Business Case for the development of a Regional Brain Injury Unit to be

located at Musgrave Park Hospital in Belfast which would provide inpatient specialist rehabilitation services. The development of the Business Case for this service was identified as a priority by the Minister of Health, Social Services and Public Safety in the document "Priorities for Action 2001 /2002". The Minister has also highlighted the early development of a spinal injury service at the Royal Victoria Hospital.

121. The Board shall work with the Trusts over the coming period to establish these services as resources become available.
122. The Board is aware of proposals by Green Park Healthcare Trust to develop a Regional Rehabilitation Service. Whilst the Board acknowledges the potential merits of such a service, it would consider the development of more locally based rehabilitation services to be the immediate priority.
123. Currently within the Northern Board area, stroke services are provided as part of general medical services in hospital. The Board would wish to ensure that younger people who suffer a stroke have access to high quality services that will minimise the impact and enable them to return, as far as possible, to leading a full and active life. The development of stroke services is currently being examined by the Board as part of a wider review of services for older people. The importance of the needs of younger people who suffer a stroke is recognised and will need to be taken into account in shaping future services.

124. Feedback from people who have accessed specialist hospital services has indicated that in some instances the level of communication between acute hospital services and community services is poor and that the attitude and approach of staff in the hospitals towards people who have acquired a disability or impairment could be more helpful. It is essential that communication between care professionals is clear and that people are treated with dignity and respect.

" He (the consultant) is the best but he just doesn't have the time to see us properly"

125. It is acknowledged however, that many of the perceived attitudes regarding consultants and other health and social care staff "not having any time" for individuals or "not caring" is due, in most instances, to the large numbers of patients that are having to be assessed and cared for.

"The Consultant makes us feel like we are just a number - he has moved on to the next person before you have even got out of your seat".

### **Meeting the Needs of Carers**

126. Family members continue to be the first line of support for individuals living in the community who need support and care. Often people may not make a conscious decision to become carers. More often they simply have become involved through having to respond to circumstances.

"He (the Consultant) seems to be a completely different man when you are in the hospital".

127. The needs of carers have been recognised for a number of years both through the Carers Recognition and Services Act (1995) and as a key priority within the Regional Strategy 1997/2002. Whilst an assessment of carers needs should be undertaken and reviewed on a regular basis, the Board acknowledges that local Trusts are not able to adequately meet carers needs and that in many instances the demands now being placed on carers are increasing. The Board proposes to discuss with Trusts the current arrangements for undertaking assessments and the potential resource implications for ensuring that all carers receive an assessment.

128. Currently, the constraints on Trusts are such that they

only able to target available resources to carers where arrangements have reached crisis point and they are no longer able to cope. Given the pressure on services, it is not possible to provide sufficient levels of support at an early stage in order to prevent the need for long term intervention. The current approach is neither beneficial to carers, who in most instances would wish to continue to care for their loved ones as long as possible, nor to provider Trusts.

"As the years go on it's a struggle to look after her but I won't let her go to a home"

129. The Board is aware that young people may also provide care for siblings, parents or family members. It is important that the needs of children and young people, under the Children (NI) Order 1995, are appropriately addressed. Support for children who care for family members remains a priority and the Board will seek to develop services under the guidance of the Northern Area Children and Young People's Committee.

130. A Carers Strategy is currently being developed by the Department of Health, Social Services and Public Safety. The Board welcomes the development of a strategy in this area and will seek to implement the recommendations should resources be made available.

131. At the most basic level, it is important that carers have access to information about support services available from both statutory and voluntary organisations and financial benefits to which they are entitled. The Board is currently funding, for a three year period, an information and development worker through the Carers National Association to raise awareness and encourage the development of support groups for carers across its area. The Board proposes to evaluate this pilot exercise and consider how best future support in this area can be shaped.

132. Suitable respite arrangements need to be developed to allow carers to have the opportunity of a break. These services need to be developed to meet the specific needs of individuals and maintain the level of independence of the person with a physical disability

"It does help to talk"

and/or sensory impairment.

## **Shaping Future Services**

133. This section draws together the Board's vision of how future services should be organised and proposes changes to existing managerial and professional boundaries to enable future services to be focused on meeting the needs of individuals in a more holistic manner.
134. The challenge is to create a service structure that is capable of providing specialist intensive services for those few people who may need 24-hour support whilst ensuring that those who may only need a minor adaptation or a low level of home help support are also assisted in a timely and appropriate manner.
135. In considering how this can be achieved, the Board proposes to continue to target available resources towards people with the most complex needs. At the same time however, the Board is convinced that with relatively small levels of additional investment, innovative and creative approaches can be adopted that will enable those with less complex needs to access wider life opportunities and potentially prevent the need for longer term support being required prematurely.
136. A recurring theme from people using the services is that they are often fragmented and difficult to access. There appears to be a lack of co-ordination across the various services available and across professional groupings. Lack of specialist staff dedicated to meeting the needs of people with a physical disability and/or sensory impairment, particularly within Allied Health Professional services, further contributes to this position.
137. The range and choice of rehabilitation and leisure opportunities available, especially for younger people who have a physical disability and/or sensory impairment, are also limited and do not appear to achieve long-term positive outcomes for those people

who access them.

138. In setting out a vision for how future services could be improved, there is a need to fundamentally reassess how existing services are structured. It is also necessary to look beyond statutory services provided by health and personal social services and to recognise the extensive expertise that exists in both the voluntary sector and at a community level and to assess how this can be embraced in partnership to improve the overall quality of services provided to Board residents.

139. With respect to statutory services, the Board would wish to review with local Trusts, opportunities that exist for more effectively utilising existing staff who currently provide services to people with a physical disability and/or sensory impairment. In particular, it would wish to assess how existing linkages between the physical disability and sensory impairment social work teams, Allied Health Professionals and nursing staff operate and to consider the potential for creating integrated multi-disciplinary teams under single management.

140. It is anticipated that the majority of time available to care professionals within statutory services will need to be increasingly directed towards meeting the needs of a relatively small number of people. To meet the needs of people with less complex needs, the Board would wish to see a greater level of working in partnership with voluntary and community-based organisations, particularly in relation to activities such as mobility training, social support, befriending and promoting greater levels of integration and social inclusion. Such activities are invaluable in enabling people to live independently.

141. In promoting individual choice and flexibility, the Board fully supports the rights of individuals to receive direct payments and will expect Trusts to provide the necessary advice and support to people who may wish to pursue this option.

## Conclusions

142. In developing this Strategy, the Board has attempted to identify the action which it believes will be necessary to develop, shape and improve future services for people with a physical disability and/or sensory impairment.
143. Based on the information available, it would appear that despite the best efforts of staff and organisations, many of the basic needs of people with a physical disability and/or sensory impairment are not being met in keeping with expectations. It is clear from the feedback we have received from people who use the services that there is much that could be done to improve the services they use. These changes do not necessarily require additional resources but could have a big impact on the responsiveness and quality of the services available. There are also opportunities where minimal additional investment could have a positive impact in improving a person's quality of life, for example, in making information on services and activities more accessible. At the same time, gaps in essential services are evident, such as speech and language therapy and domiciliary support and these will require the provision of additional investment over the coming years if they are to be addressed.
144. It is clear from the discussions held with all stakeholders in this area that a unique opportunity exists for statutory, voluntary, community and private sector organisations and groups to work collaboratively to improve the quality and effectiveness of services, so ensuring that these are more flexible and more capable of accommodating individual choice.

# **APPENDIX 1**

## **Policy and Legislation**

Over the past number of years there has been significant changes in both policy and legislation which will influence how future services are shaped. These include:

### **Legislation**

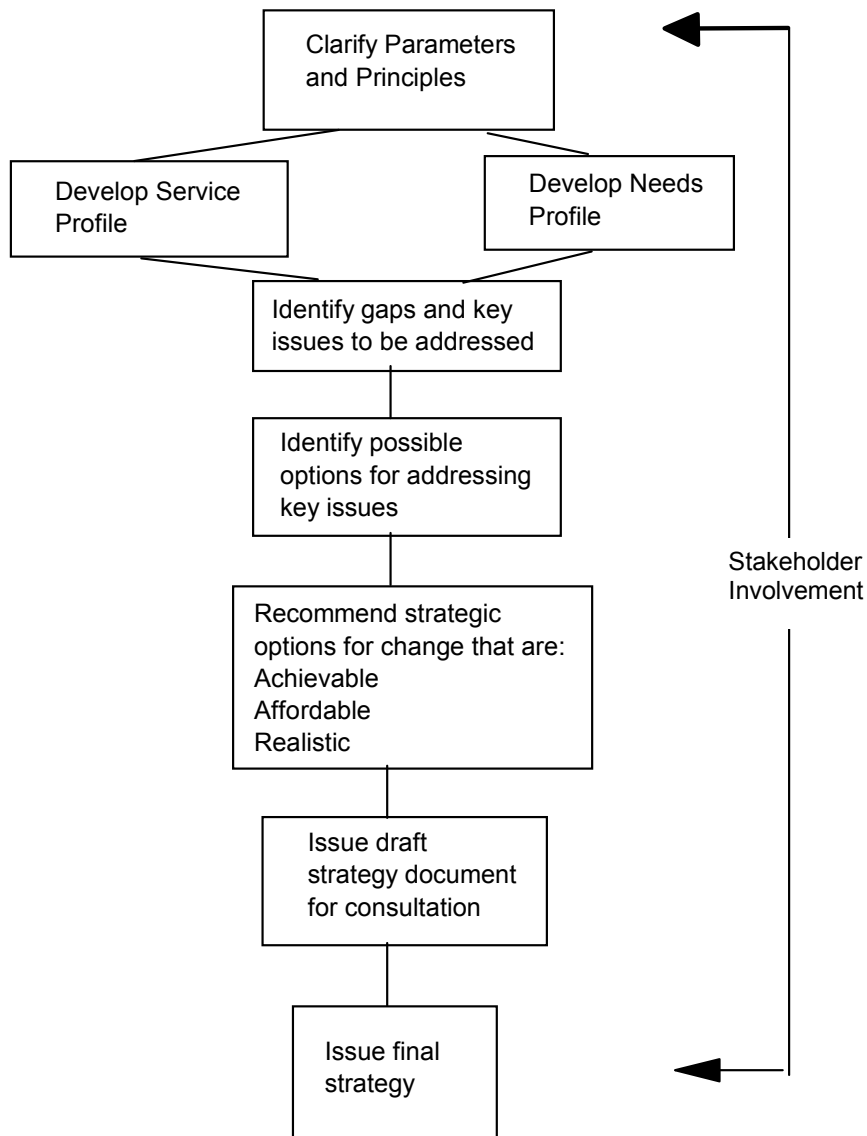
- Disability Discrimination Act 1995
- Carers Recognition and Services Act 1995
- Children (NI) Order 1995
- Direct Payments Act 1998
- Human Rights Act 1999
- Northern Ireland Act 1998

### **Policy**

- Regional Strategy 1997-2002
- New TSN (Targeting Social Need)
- Investing for Health
- “From Dependence to Independence Agenda for Action: Inspection for Services for Young People (aged 16-25) with a Physical Disability and/or Sensory Impairment”.
- Review of Services for People Aged 16-25 with a Visual Impairment.

## APPENDIX 2

### Process for Developing the Physical Disability and/or Sensory Impairment Strategy for People Aged 16-64 years



## APPENDIX 3

### Prevalence

Detailed below in Table 1 is the level of projected disability for the Northern Board area by level of severity for people aged 18-65 years. Level 1 is the least severe level of disability whilst level 10 is people with highly complex needs. An outline of how the severity index is calculated is provided. Figures specifically relating to visual and hearing impairment for people aged 16-64 are also provided in Tables 2 and 3.

**Table 1: Prevalence of Disability for People aged 18-65 years in the Northern Board Area (1999)**

<b>Severity Level</b>	<b>Number of Disabled Adults</b>
1 - 2	9278
3 - 4	5760
5 - 6	4928
7 - 8	3289
9 - 10	1638
<b>TOTAL</b>	<b>24893</b>

**Table 2: Prevalence of People who are Deaf or Hard of Hearing aged 16-64 years in the Northern Board Area (1999)**

<b>Age (Years)</b>	<b>Homefirst</b>	<b>Causeway</b>
16 - 59	5683	1265
60 - 64	2681	642

**Table 3: Prevalence of People who are visually Impaired aged 16-64 years in the Northern Board Area (1999)**

<b>Age (Years)</b>	<b>Homefirst</b>	<b>Causeway</b>
16 - 59	2703	816
60 - 64	1063	321

**Note: Figures in tables 1, 2 and 3 based on PPRU (1992), updated based on 1999 mid year population estimates.**

### **Severity of Disability: Office of Population Censuses and Surveys**

When surveying the prevalence of disability in Great Britain, the Office of Population Censuses and Surveys needed to equate severity between different disabilities so that it could be aggregated. It reviewed available scales from other surveys and decided that none were sufficiently wide-ranging to be adequate as a comprehensive measure of severity for all types of disability. Consequently, it developed a system of its own.

The criteria recognised ten areas of disability:

- locomotion;
- reaching and stretching;
- dexterity;
- seeing;
- hearing;
- personal care;
- continence;
- communication;
- behaviour; and,
- intellectual functioning.

Within each of these ten areas, levels of ability to perform functions were set, and each was allocated a severity score for example:

Inability to walk scored 11.5 points on the locomotion scale, and a need to hold on whilst climbing stairs 2.5 points.

Lower levels were set for disabilities below which no points were allocated for example:

A need to hold on occasionally to keep balance, and having fallen once or twice during the past year.

The surveys were carried out on the basis of face-to-face interviews during which, the type and severity of disabilities was assessed. A score was allocated within each area of disability to the most severe disability within each category that each interviewee could not perform. Thus, a score, or nil return, was established across each of the ten areas. The three highest scores were used to calculate the severity of disability according to a simple formula:

Highest score + (0.4 x second highest) + (0.3 x third highest)

The total score was translated into a severity category ranging from one (least severe) to ten (most severe) according to a pre-determined scale:

<b>Severity Category</b>	<b>Total Score</b>
10 (most severe)	19 - 21.40
9	17 - 18.95
8	15 - 16.95
7	13 - 14.95
6	11 - 12.95
5	9 - 10.95
4	7 - 8.95
3	5 - 6.95
2	3 - 4.95
1 (least severe)	0.5 - 2.95

# APPENDIX 4

## Equality and Human Rights Screening

### Background

This Strategy provides a framework around which it is proposed that future services should be reshaped and developed to appropriately meet the needs of people with a physical disability and/or sensory impairment aged 16 - 64 years.

In developing the Strategy the Board has consulted and engaged with a wide range of people with a physical disability and/or sensory impairment, their carers and key stakeholder organisations at every stage of the process.

This has been achieved through the following approaches:

- a number of home visits were undertaken to those people with complex disabilities;
- the Board commissioned independent consultants to hold a number of focus group sessions across the Boards area for people with a physical disability, people who are deaf or hard of hearing, and for carers;
- a number of innovative teleconference sessions were organised in partnership with local Trusts, Voluntary organisations and British Telecom to facilitate people with a visual impairment;
- a user panel has been established, involving representatives from local disability fora from across the Board's area; and,
- a reference panel has also been established involving representatives from key voluntary organisations and local Trusts.

At all stages of engagement consideration was given to issues that may need to be addressed in relation to Equality, Human Rights and Targeting Social Need.

## **Key Questions**

### **Equality**

**Is there any evidence of higher or lower uptake of services by different groups within any of the nine categories?**

Limited evidence available.

**Is there any evidence that different groups have different needs, experiences, issues and priorities in relation to the particular policy?**

The Strategy recognises that within the area of physical disability and/or sensory impairment there is a variety of groups of individuals whose needs will vary. The objective of the Strategy is to set the broad context within which it is proposed that services should be developed. Further work will be required to refine how services will need to be shaped for specific client groups. Account will also be taken of these differences as part of the assessment process undertaken for all individuals who receive services.

### **Human Rights**

**Could the policy potentially interfere with any of the Articles under the European Convention on Human Rights?**

It is recognised that the Board will be unable to meet all the needs of individuals and that in some instances this may be argued as contravening a persons human rights. For example it may not be possible to provide a person with an electric wheelchair or with the level of domiciliary support they may feel they require to enable them to access wider social, leisure or training and employment opportunities. This could possibly be argued as inhuman or degrading treatment

under Article 3 - Prohibition of torture, inhuman or degrading treatment.

### **Can this interference be Justified?**

The principle objective of this Strategy is to ensure that, as far as possible, people with a physical disability and/or sensory impairment receive appropriate support services to allow them to live as independently as possible and to reach their full potential. In achieving this the Board will ensure that all decisions are based on a thorough assessment of an individual's needs. **The level of support provided will however be constrained by the fact that there are only limited resources available to Health and Personal Social Services and that it is the Board's duty to ensure that services will be targeted towards those whose needs are considered to be most complex.**

### **New Targeting Social Need**

#### **Is the policy applicable to known disadvantaged people/groups/areas?**

The Strategy relates specifically to people with a physical disability and/or sensory impairment.

#### **Could it help reduce the inequalities experienced by people with a physical disability and/or sensory impairment?**

The objective of the Strategy is to ensure that, within the resources available, a range of support services is available that will enable people with a physical disability and/or sensory impairment to regain their maximum level of functionality, to live as independently as possible and to integrate back into mainstream society.

**Does the Policy create problems specific to any of the consultees ?**

No issues have been raised by any of the consultees.

**Can any adverse impact be reasonably mitigated?**

It is not anticipated that the Strategy will have an adverse impact.

**Is there opportunity to promote equality of opportunity by altering the policy?**

The Strategy is seeking to promote equality of opportunity by raising awareness of disability issues and by developing services that will enable people with a physical disability and/or sensory impairment to live more independently and to integrate into mainstream society.

**Is there an opportunity to promote good relations by altering the policy?**

The Policy will help promote good relations by attempting to raise awareness of disability and removing barriers that currently prevent people with a physical disability and/or sensory impairment from integrating into mainstream society.