



**BORD SLÁINTE**  
AN MHEÁN-IARTHAIR

**STRATEGY STATEMENT**

**ON**

**PHYSICAL AND SENSORY**

**DISABILITY**

**Note: The Mid-Western Health Board will not accept liability for any error, omission, misrepresentation or misstatement contained in this Strategy Statement, whether negligent or otherwise, and the statements contained therein are not intended to impose any legal obligation or duty on the Mid-Western Health Board, its servants or agents, in favour of any particular person or class of persons.**

**STRATEGY STATEMENT EDITOR: Liam Mac Mathúna**

**ISBN: 1- 874075-18- 2**

# Strategic Statement of Purpose and Intent

**Cognisant** of the need for development of services in accordance with the principles underpinning the *United Nations Standard Rules on the Equalisation of Opportunities for Persons with a Disability*;

**Mindful** of the three key principles underpinning the health services declared in the *National Health Strategy* of equity, quality of service and accountability and the concept of health and social gain;

**Recognising** the values underpinning service provision adopted in the Health Board's *Corporate Strategy* of Equity, Accessibility, Effectiveness, Efficiency, Appropriateness, Responsiveness, Dignity and Farsightedness;

**Reaffirming** the three guiding principles adopted by the *Commission on the Status of People with Disabilities* of Equality, Maximising Participation and Enabling Independence and Choice;

**Recalling** the core thrust of the deliberations of the *Review Group on Health and Personal Social Services for People with Physical and Sensory Disabilities* of developing services to enable persons with a physical or sensory disability to live as independently as possible in the community;

**Emphasising** that persons with a physical or sensory disability, and their families, guardians, advocates and organisations must be active partners with the Health Board in the planning and implementation of measures affecting their health and social wellbeing;

**Desiring** to facilitate the continued self-empowerment of persons with a physical or sensory disability in the Mid-West Region;

The Health Board affirms as its Strategic Statement of Purpose and Intent for persons with a physical or sensory disability in the region that:

The purpose of services for this client group is to facilitate the development of each individual to their full personal and social potential and to maximize their independence, choice and participation in society. This is achieved by advocating, promoting and developing 'person-centered' services of the highest quality.

The intent of services for this client group will be centered on responsiveness to consumer need and the focus of services will be pivotally placed on the individual person with a physical or sensory disability, their families and carers.

The objective of services is to effect a continuous lifecycle model of service and social support through the provision of an integral 'continuum of support'. The precise nature and mix of the elements in the support continuum will be dictated by the impact on consumer's needs of changing internal and external environments.

The Health Board will focus on assessment of need, service planning/coordination, research, monitoring/evaluation and quality assurance. Service provision by the voluntary/community sector will be encouraged, wherever appropriate. Where a lack of expertise or capacity to provide a service exists within the voluntary/community sector the Health Board may become a direct service provider or invite other providers to deliver designated services. The Health Board will energise the contribution of related statutory bodies and agencies that have a direct impact on the lives of consumers in the region, through its public advocacy role.

The Disability Services of the Health Board will also be proactive in disability proofing other Health Board services and the services of related statutory bodies and their agencies. Particular focus will be directed to catalysing and enhancing the partnership with the voluntary and community sector to facilitate their enhanced provision of health-related services, including provision of information, advice and advocacy.

## **Glossary of Terms**

**The following is a selected glossary of terms used in the Strategy Statement:**

### **County Catchment Area**

These are Health Board administrative areas. In the Mid-West Region there are currently three Areas: Clare, Limerick and Tipperary (N.R.)

### **Sector**

These are Health Board administrative sub-areas that cover populations ranging from 20,000 – 40,000 persons. There are five sectors in Limerick, four in Clare and two in Tipperary (NR).

### **Persons with a Significant Physical Disability**

This client group was originally termed, the Young Chronic Sick, and were first legally defined as a distinct group under the terms of the UK' Chronically Sick & Disabled Persons Act, 1970'. The Act defined the group as those persons, aged between 16 and 65 years "with some form of physical disability, resulting in damage to the central nervous system." It should be noted that, in conjunction with the primary physical disability, mild to severe intellectual disability may also exist.

This client group includes:-

- Congenital abnormalities                      i.e. Friedrick's Ataxia
- Brain damage at birth
- Progressive deterioration i.e. Muscular dystrophy
- Trauma    i.e. Road traffic accidents

The term, Persons with a Significant Physical Disability, which replaces the former term, Young Chronic Sick' in this Strategy Statement, represents a redefinition of the range of conditions envisaged in the UK Act.

# Contents

|                   |  | Page      |
|-------------------|--|-----------|
|                   | <b>Executive Summary</b>                         | <b>1</b>  |
| <b>Chapter 1:</b> | <b>Introduction</b>                              | <b>13</b> |
| <b>Chapter 2:</b> | <b>Strategy Formulation</b>                      | <b>16</b> |
| <b>Chapter 3:</b> | <b>Policy and Service Context</b>                | <b>18</b> |
| <b>Chapter 4:</b> | <b>The Continuum of Support:</b>                 | <b>27</b> |
| 4.1.              | <b>Preventative Support</b>                      | <b>27</b> |
| 4.2.              | <b>Anticipatory Support</b>                      | <b>35</b> |
| 4.3.              | <b>Home and Community Support</b>                | <b>42</b> |
| 4.4.              | <b>Respite/Residential Support</b>               | <b>55</b> |
| <b>Chapter 5:</b> | <b>Discrete Issues:</b>                          | <b>59</b> |
| 5.1.              | <b>Persons with Adult Acquired Brain Injury</b>  | <b>59</b> |
| 5.2.              | <b>Persons with Dual Disabilities</b>            | <b>61</b> |
| <b>Chapter 6:</b> | <b>The Strategy:</b>                             | <b>62</b> |
| 6.1.              | <b>Strategic Statement of Purpose and Intent</b> | <b>62</b> |
| 6.2.              | <b>Strategic Objectives</b>                      | <b>63</b> |
| 6.3.              | <b>Values and Service Principles</b>             | <b>65</b> |
| 6.4.              | <b>Organisation and Management</b>               | <b>65</b> |
| 6.5.              | <b>Supporting Strategies:</b>                    | <b>66</b> |
|                   | <b>The People Strategy</b>                       | <b>66</b> |
|                   | <b>The Resource Strategy</b>                     | <b>67</b> |
|                   | <b>The Information Strategy</b>                  | <b>67</b> |
| <b>Chapter 7:</b> | <b>Strategy Implementation and Review</b>        | <b>69</b> |
| <b>References</b> |  | <b>70</b> |

# Executive Summary

## Introduction:

The complex health, social and economic issues relating to the planning, development, implementation and quality assuring of health and personal social services for this client group make it imperative that a strategy is formulated to guide decision making over the next five years. A costed Action Plan and implementation programme will be developed to ensure that the necessary developments are progressed. The purpose in formulating this Strategy Statement is to focus deliberation and discussion among all stakeholders involved in the development of appropriate, responsive and innovative services for persons with a physical and sensory disability and their families in the region.

The purpose of services for this client group is to facilitate the development of each individual to their full personal and social potential and to maximize their independence, choice and participation in society. This is achieved by advocating, promoting and developing 'person-centered' services of the highest quality.

The objective of the services is to effect a continuous lifecycle model of service and social support through the provision of an integral 'continuum of support'. The precise nature and mix of the elements in the support continuum will be dictated by the impact on consumer's needs of changing internal and external environments.

The *Report of the Commission on the Status of People with Disabilities* identified as one of the key principles that have informed recent international legislation and practice the recognition that disability is a social rather than a medical issue. The Health Board is committed to the ongoing re-focusing of service provision in line with the increasing social context of services.

## The Continuum of Support:

Structuring the range of services delivered to persons with a physical or sensory disability on the basis of a model of continuous support across the individual lifecycle offers the most appropriate means of identifying areas for change and improvement. The model posits a 'support continuum' structure to ensure appropriate support at various points on the 'support continuum' and to eliminate gaps in service delivery. The components of the model are:

- Preventative Support
- Anticipatory Support
- Home and Community Support
- Respite/Residential Support

### □ Preventative Support

The Health Board recognises that there are a range of preventative measures that can reduce the incidence of physical and sensory disability. The successful utilisation of Preventative Support will impact positively on the health and quality of life of all individuals in society.

Smoking and diet are causative factors in cardiovascular disease that can lead to strokes, peripheral vascular and other conditions resulting in physical or sensory disability. Prevention of these illnesses through lifestyle changes is an important factor in reducing the incidence of impairment and disability. The Health Board operates or contributes to a wide range of programmes and groupings designed to prevent or reduce the incidence of smoking and improve dietary lifestyles in the region.

A reduction in the number of accidents, including accidental poisonings and parasuicide, will lead to a reduction in the number of cases of acquired physical and sensory disability and adult acquired intellectual disability. The principal types of accident resulting in admission to hospital in the Mid-West Region are road traffic accidents, accidental poisonings and falls. The Health Board will continue to contribute to programmes directed at improving safety levels and reducing the incidence of accidents at a regional level. The Health Board also actively supports the initiatives of the Health and Safety Authority with respect to accident prevention. The Health Board's *Action Plan*, prepared in response to the Report of the National Task Force on Suicide, will spearhead the drive to reduce the incidence of suicide and parasuicide in the region.

Regular heavy drinking is strongly linked to a variety of alcohol-related problems such as, accidents. The Health Board subscribes to the strategic aims of the National Health Promotion Strategy (2000 – 2005), with respect to alcohol consumption, and will proactively contribute to the realisation of these objectives at regional level.

Drug misuse can lead to physical disability or acquired brain injury, through the occurrence of accidents and self-harm when under the influence of drugs. The Health Board's drug misuse services can be seen as ranging along a continuum which consists of the elements: Prevention/Education, Treatment, Rehabilitation and Maintenance. The Health Board's *Strategy on Drug Use* will outline the strategic direction of this range of services.

Antenatal and perinatal care are key elements in the Health Board's continuum of support for the reduction of impairments and disability. The need for expectant mothers to avoid exposure to German measles and hence the need for appropriate vaccination will continue to be promoted.

The Health Board is committed to reducing risk among the most vulnerable of the population. Particular attention is focused on supporting parents in the early months after the birth through the public health nursing service and the Community Mothers programme. The Health Board is particularly aware of the extra difficulties encountered by young parents. Programmes already established in this area, to which Health Board staff have an input, include the Social, Personal and Health



Education Programme, the Teenage Pregnancy Prevention programme and the 'Teen Parenting Programme' operated as part of the Community Mothers Programme. The Board's Health Promotion programmes, aimed at reducing the incidence of smoking and moderation in alcohol consumption among the adult population in the region, will serve to reduce the risk factors during pregnancy associated with development of disability in the newborn among pregnant women in the Mid-West Region.

Immunisation remains a safe and effective way to prevent morbidity and mortality from many childhood illnesses. It is important as a strategy for disability prevention that uptake levels of the National Childhood Primary Immunisation Programme reach 95% of the child population as outlined in the Health Board's *Strategy Statement on Child Health*.

A Genetic Counselling Service has started at the Mid-Western Regional Hospital, which is serviced from the National Centre for Medical Genetics, Dublin. Further development of this service will be encouraged.

#### ❑ **Anticipatory Support**

Services and structures are required which anticipate the needs of persons with a physical and sensory disability in the region. By anticipating their needs proactive supports, structures and organisational processes can be planned and implemented in the light of the individual's needs.

The development of the National Physical and Sensory Disability Database is continuing apace. In the Mid-West Region, the Director of Disabilities has been designated as Regional Database Coordinator, with overall responsibility for the Regional Database. A Database Administrator has also been appointed. The Database Coordinator and Administrator are currently working closely with the National Database Committee in preparation for implementation of the Database in the Mid-West Region. The Health Board has established a Physical and Sensory Database Committee to review the operation of the Regional Database. With respect to the Health Board's information provision remit, the 'Directory of Services for Persons with Disabilities' in Braille and audio versions will be regularly updated.

The Health Board's screening programmes of the newborn and of early-childhood are aimed at ensuring early detection and prevention of conditions that may give rise to physical and sensory disability, if undetected. In accordance with the Health Board's *Strategy Statement on Child Health*, enhanced integration of children's services across the region will occur. A key component of anticipatory support services to this client group, is the appointment of Community Consultant Paediatricians, working in both a hospital and community setting, one of whom will have a special interest in children with a disability. The development of a Regional Children's Diagnostic and Assessment Service for young people with complex developmental, physical/sensory, intellectual and psycho-social problems is proposed. The multidisciplinary assessment of a child with a disability brings many benefits to the child, parents and professionals. The above service should be led by a Consultant Paediatrician, with a special interest in disability.

As part of the development of the Health Board's diagnostic and assessment services for children with a disability, the development of a dedicated Paediatric Audiology service for the purpose of the early identification of children with hearing impairment is required.

A central role in the acquisition of relevant information in relation to persons with a physical or sensory disability who require or who, in the future, will require service provision is played by the Counselling Nurses for Persons with Disabilities. A Review of the role and functions of the Counselling Nurses will be undertaken as part of the initial implementation phase of the Strategy Statements on Physical and Sensory Disability and Intellectual Disability.

A direct response, on the part of the Health Board, to recognition of the need for adequate anticipatory support structures, both within the Health Board's services and across agency-provided services, has been the recent appointment of Area Managers for Disabilities and the development of Area Disability Care Groups in each County Catchment Area which enable the planned and coordinated delivery of services. Area Physical and Sensory Disability Advisory Committees will also be established.

As many persons receive services from statutory bodies and their agencies in the region not directly linked to the Health Board during their lifetimes, it is necessary to develop a formal method of exchanging information, enhancing co-operation and defining roles and responsibilities between the Health Board, voluntary agencies and these statutory bodies. Disability advocacy structures will be established which will address advocacy-related issues. Misinformed perceptions of persons with a disability and their needs can be altered by provision of disability awareness training. A planned phased programme of physical/sensory disability awareness training that addresses basic customer service issues and promotes enhanced skills in dealing with this client group is being implemented for all relevant staff.

The issue of physical access for persons with a disability to Health Board building's and facilities is being progressively addressed by the Board. Much of this adaptation of Health Board's premises will be accomplished over the five-year timeframe of the Strategy Statement. Research is an important element, not only in assisting the prevention of disability, but also in ensuring the development of quality-based services that limit the effects of disability. The disabilities research function will be developed in collaboration with the development of the National Institute for Health Sciences and Management.

## **□ Home and Community Support**

### **(a) Community Support and Personal Assistance Services**

The Health Board's *Strategy for Primary Health Care in the Mid-West Region* will develop enhanced models of care, which will result in delivery of enhanced primary care services to persons with a physical or sensory disability.

The Health Board will pursue a policy of developing the full spectrum of the three forms of day centre advocated by '*Towards an Independent Future*': (1) centres with specialised facilities; (2) centres that provide day activation; and (3) community-based resource centres. Increased funding to voluntary agencies in the region for collaborative provision of day services will be required to enable development of a spectrum of day activation, stimulation and therapy services for this client group. The Health Board advocates the integration of children with a physical or sensory disability into the mainstream pre-school services, where possible. The needs of the individual child with a disability will determine the precise form of service provision, whether mainstream or special pre-school. The Health Board's Pre-School Unit will collaborate and work more closely with the disability services in improving service provision to children with a disability.

The Health Board's Home Support Services to persons with a physical or sensory disability include three elements: (1) Personal Assistance Services; (2) Home Care Attendants Service; (3) Socialisation/Transport Services. The relevant implications of the findings of the evaluation report commissioned by the Health Board on the operation of the 'Pilot Personal Assistants Scheme' will be implemented. Continued expansion to a full Personal Assistance Service and Home Care Attendant Service will be developed in partnership with relevant voluntary provider agencies.

The Health Board will establish a joint working group to examine and report on the need for rationalisation of transport services in the region. Through its public advocacy role, the Health Board will strive to ensure the maximum accessibility to public transport services for this client group. The recommendations of the report on the Home Support Services will be progressively implemented and, as an initial response, a significant investment will be made in providing accredited training to home support service providers.

In line with the changed structures following the dissolution of the NRB, vocational training and employment services for persons with a disability will be the remit of the Department of Enterprise, Trade and Employment through FÁS. Within this new framework the emphasis will be on progression pathways to employment. A specialised training service will remain for persons with a physical or sensory disability who do not have the skills or ability to access mainstream training or employment. This training will be rehabilitative/life skills focused and the Health Board will produce a policy document in 2001 on the provision of Rehabilitative Training in the Mid-West Region.

#### **(b) Community Therapy Services**

The Review of therapy services and the *Report of the Working Party on Services to the Young Chronic Sick in the Mid-West* emphasised that therapeutic services, such as occupational therapy, physiotherapy and speech and language therapy require to be

developed. The Health Board will actively strive to realise implementation of the recommendations of these reports.

A comprehensive multidisciplinary team will be developed in each County Catchment Area to deliver early intervention and therapy services. This service will be developed from the pilot Early Intervention Service for children with an intellectual disability, established by the Brothers of Charity Services in West Limerick. The early intervention services for children with an intellectual disability and children with a physical or sensory disability will be integrated and, following evaluation, the model of service will be extended to the three County Catchment Areas of the region.

The range of family support services such as, psychology, social work and community welfare services, provided to this client group are currently insufficiently developed. The Health Board will facilitate development of a counselling service to persons with a physical or sensory disability. In recognition of the relationship between disability and poverty, the Health Board will pilot a Community Welfare Service within the Disability Directorate to disability proof the Community Welfare Service and to provide client-focussed work to this client group.

#### **(c) Aids and Appliances**

For as long as supplementary funding (additional to core funding) is provided, the Health Board will continue to strive to eliminate the Health Board's annual waiting list for aids and appliances.

The Health Board will develop an integrated, centralised regional system for the provision, maintenance, cleaning and tracking of aids and appliances, following evaluation of the current pilot project. The development of standardised regional policies and protocols for the aids and appliance's service will be an additional aspect of the project.

Within the overall provision of aids and appliances, specialist requirements relating to the visually impaired, the hearing impaired and those with a speech and language disorder exist. The Health Board will provide resources for provision relating to this equipment, on the basis of assessed need, as funding becomes available.

A significant number of persons with a physical disability have difficulty in achieving and maintaining a seated position that is vital for effective functioning in everyday life. The Health Board will establish a Regional Seating Clinic that will provide a focus for seating and a centre of excellence.

#### **(d) Rehabilitation Services**

There is a need to enhance rehabilitation services in the Mid-West Region for persons discharged from the National Rehabilitation Hospital and acute hospitals. The Consultant in Rehabilitation Medicine, recommended in the *Report on Services to the Young Chronic Sick in the Mid-West* would have an expanded remit to manage the

rehabilitation of all persons with a physical or sensory disability in the region. The proposed development of rehabilitation services to Adults with an Acquired Brain Injury from this region, includes the development of a Transitional Living Unit (as outlined below, under 'Discrete Issues')

The Health Board is currently examining a proposal to enhance the existing Prosthetic and Orthotic Service at the Regional Orthopaedic Hospital which will greatly improve the quality of care offered to this client group and which would negate their need to seek services outside the Mid-West Region. In addition, the need for comprehensive Physiotherapeutic Rehabilitation is also being explored. This will enable patients who have undergone amputations to achieve maximum independence and an improved quality of life.

□ **Respite/Residential Support:**

There is a need for adequate provision of respite support, whether residential, in-home, weekday, weekend or holiday for the individual with a disability and their carers. Despite the provision of enhanced community support services and structures there will continue to be a need for residential support facilities for persons with a physical or sensory disability, either for temporary periods or on a long-term basis.

In respect of 'crisis respite support', the Health Board will negotiate with voluntary agencies for the provision of residential respite accommodation in each County Catchment Area, which will incorporate appropriate support from outreach therapeutic teams. 'Planned respite support' and 'multiple-planned respite support' provision by voluntary agencies will also be supported.

In respect of respite support for persons with a significant physical disability, the Board will develop a community-based residential respite facility in conjunction with Rehab Care in the Limerick area. Further provision of respite support for this client group will be effected through the development of a six-bed facility in West Limerick and one each in the Clare and Tipperary Catchment Areas.

The gradual provision of independent living units for persons with a physical or sensory disability in each County Catchment Area will be facilitated through the advocacy role of the Health Board with local authorities and social housing organisations in the region.

The Health Board is of the opinion that the optimal arrangement for provision of the residential needs of persons with a significant physical disability is the development of appropriate community residential facilities, with access to community supports, in each County Catchment Area.

A sub-committee of the Regional Coordinating Committee will be established to examine and report on the need for any further development of residential facilities in the region.

## **Discrete Issues:**

### **□ Persons with Adult Acquired Brain Injury**

Persons with an Acquired Brain Injury present with significant treatment, caring and emotional needs because the conditions are acquired in adolescence or early adult years. Currently there is no specific dedicated service for this client group within the Mid-West Region. Consequently services for these clients are being provided in ad-hoc manner, with some inappropriate placements and funding not being utilised in an effective and efficient manner. It is recognised, however, that there is a need for planned and coordinated service provision.

Persons with an Acquired Brain Injury generally have the following service needs:

- Acute Hospital Care
- Acute Rehabilitation
- Transitional Living Units
- Independent Community Living

Acute Hospital Care can be provided at the Mid-Western Regional Hospital, with Acute Rehabilitation generally provided at the National Rehabilitation Hospital, Dun Laoghaire. Development of a Transitional Living Unit (TLU) within the Mid-West Region is currently being explored to provide a service for:

- (1) Those who have completed an acute rehabilitation programme but whose needs are such that they are unable to return to, or remain at, home;
- (2) Those with cognitive impairment and psychosocial functioning problems, affecting areas such as poor motivation, social skills and interpersonal skills, limited insight into their impairment and the milder syndromes of inappropriate behaviours. However, these clients would have the potential to improve through participation in therapeutic programmes.

Services could be provided to those who have been discharged from acute hospital care and, if appropriate, medical rehabilitation or, alternatively, clients could be referred directly from the Community or other continuing care settings. A multidisciplinary team would provide an intervention and rehabilitative training programme of intensive input. An initial six-bedded unit would be developed to provide services to this client group within the Mid-West Region, with Day Therapy and Out-Reach Services within an appropriate Catchment Area. This client group, on discharge from the Transitional Living Unit, would avail of the generic community support services put in place, as outlined in the 'Home and Community' and 'Respite/Residential Support' elements of the 'continuum of support'.

The National Rehabilitation Hospital is to establish provincial advocacy groups to involve the brain-injured and their families and other interested parties. The Health Board will support this advocacy process.

(The needs of persons of age under 18, with acquired brain injury, fall within services to persons with an intellectual disability and are addressed under that Strategy Statement).

#### □ **Persons with Dual Disabilities**

In many instances a person may have both a physical or sensory disability and an intellectual disability. In some cases there may also be multi-disabilities impacting on the full sphere of human functioning. Clear protocols for the management and referral of persons with a dual disability will be developed, in conjunction with the voluntary agencies.

### **The Strategy:**

The Health Board affirms as its Strategic Statement of Purpose and Intent for persons with a physical or sensory disability in the region that:

The purpose of services for this client group is to facilitate the development of each individual to their full personal and social potential and to maximize their independence, choice and participation in society. This is achieved by advocating, promoting and developing 'person-centered' services of the highest quality.

The intent of services for this client group will be centered on responsiveness to consumer need and the focus of services will be pivotally placed on the individual person with a physical or sensory disability, their families and carers.

The objective of services is to effect a continuous lifecycle model of service and social support through the provision of an integral 'continuum of support'. The precise nature and mix of the elements in the support continuum will be dictated by the impact on consumer's needs of changing internal and external environments.

The Health Board will focus on assessment of need, service planning/coordination, research, monitoring/evaluation and quality assurance. Service provision by the voluntary/community sector will be encouraged, wherever appropriate. Where a lack of expertise or capacity to provide a service exists within the voluntary/community sector the Health Board may become a direct service provider or invite other providers to deliver designated services. The Health Board will energise the contribution of related statutory bodies and agencies that have a direct impact on the lives of consumers in the region, through its public advocacy role.

The Disability Services of the Health Board will also be proactive in disability proofing other Health Board services and the services of related statutory bodies and their agencies. Particular focus will be directed to catalysing and enhancing the partnership with the voluntary and community sector to facilitate their enhanced provision of health-related services, including provision of information, advice and advocacy.

The Statement of Purpose and Intent is an expression of the strategic vision envisaged for the services to persons with a physical or sensory disability in the Mid-West Region. The Strategic Objectives of the Strategy, which bring a focus to the vision, are as follows:

**Strategic Purpose and Intent:-**

- ❑ Promotion of 'person-centered' services of the highest quality that enable consumers to live the life of their choice within their desired community setting through the provision and facilitation of the appropriate supports and social resources.
- ❑ Delivery of a continuous lifecycle model of service and social support through the provision of an integral 'continuum of support'.
- ❑ Formalising of the Health Board's relationship with the voluntary sector and enhancing organisational and operational capacity of the sector.
- ❑ Ensuring high standards and timeliness in service delivery.

**Preventative Support:-**

- ❑ Promotion of preventative strategies to reduce incidence of physical and sensory disability in the region.

**Anticipatory Support:-**

- ❑ Full implementation of the Regional Physical and Sensory Database.
- ❑ Development of Regional Children's Diagnostic and Assessment Service
- ❑ Development of internal and public advocacy role of Disabilities Directorate.
- ❑ Disability proofing of all Health Board services and facilities.
- ❑ Forging effective linkages, developing coherent coordination and defining areas of responsibility with other statutory bodies that interface with health and personal social service provision for persons with a physical or sensory disability.

**Home and Community Support:-**



- ❑ Development of full spectrum of Day Services.
- ❑ Enhancement of Personal Assistance, Home Care Attendant and Family Support Services.
- ❑ Expansion and development of therapy services.
- ❑ Development of Early Intervention/Therapy Teams and pre-school services for children.
- ❑ Development of comprehensive range of home and community services for Persons with a Significant Physical Disability.
- ❑ Enhancement of the quality of Rehabilitative Training service in the region.
- ❑ Development of an integrated regional system for provision and recycling of aids and appliances and development of a Regional Seating Clinic.
- ❑ Enhancement of Rehabilitation Services in the region, including provision for Adults with an Acquired Brain Injury.

**Respite/Residential Support:-**

- ❑ Development of respite support services in the region.
- ❑ Appropriate development of residential facilities, with particular emphasis on facilitation of independent living units.

**Human Resource Function:-**

- ❑ Development of effective staff recruitment and retention policies/structures and appropriate training programmes

The service principle, outlined in *'Towards an Independent Future'*, of developing services to enable persons with a physical or sensory disability to live as independently as possible in the community and the principle of mainstreaming services for persons with disabilities, to enable inclusion, outlined in *'A Strategy for Equality'*, will underpin the strategic action designed to achieve health and social gain for persons with a physical or sensory disability.

The design of services along the continuum of support will facilitate the development of an holistic, continuous lifecycle model of service delivery that is person-centered and appropriately supportive.

The Health Board values the significant complementary role played by voluntary agencies in addressing the needs of persons with a physical or sensory disability in the region. This will require the Health Board and the voluntary agencies developing both

inter- and intra-agency organisational and collaborative capacities. The Health Board has initiated a partnership project to give effect to this commitment.

The implementation of this Strategy Statement will impact on staffing structures and levels, capital and revenue resources and information and communication policies. The pivotal supporting strategies are the People Strategy, the Resource Strategy and the Information Strategy. In order to address the issues arising within the Resource Strategy, the Health Board will compile a detailed costed Action Plan that will identify and outline the infrastructural, financial, staffing, training and information technology resources required to give effect to the objectives of the Strategy Statement. The Action Plan will embrace the developments prioritised in the National Development Plan over the period 2001 – 2006 for the region with respect to services for persons with a physical or sensory disability.

A half-yearly Review of the progress in implementing of the Strategy Statement will be held, which will involve senior management of the disabilities services and representatives of the voluntary agencies. Prior to the holding of the half-yearly reviews submissions will be sought from all stakeholders on their perceptions of the implementation process and summarised feedback from these submissions will inform deliberations at the Reviews.

## **Chapter 1: Introduction**

Disability is usually thought of as being multidimensional for the individual concerned. There may be effects on organs or body parts; effects on certain activities, such as lifting objects with the hand; or effects on a person's participation in a full community life. The World Health Organisation's new draft version of the International Classification of Impairments, Disabilities and Handicaps, ICDH-2, incorporates elements of all three effects.

Physical and Sensory Disability Services are provided to enable persons with a physical or sensory disability to live as independent, equal, inclusive and fulfilling a life as possible, within their home and community setting.

The intention of the National Health Strategy, '*Shaping a Healthier Future*' (1994) was to provide extra facilities on the basis of locally assessed need. The provision of extra facilities for day, respite, home, personal and residential support services was emphasised. The need to significantly develop community therapy and social support services was highlighted. The key role of provision for aids and appliances that increase the independence and expand their range of activities was acknowledged. The *National Health Strategy* also emphasised the need to address the funding and relationship with the voluntary agencies operating in the physical and sensory disability area.

The *National Health Strategy* stressed the significance of adequate data and information structures and establishment of a national database in order to facilitate an orderly planning of services. The need for greater organisation and coordination of services was noted, with specific reference to inter-departmental cooperation, greater integration of services within the health boards and inter-agency collaboration. The necessity for a coordinated approach on the part of all those with responsibilities towards this client group was emphasised if a 'seamless' service was to be provided. In recognising this, the Board identifies its important function of advocacy and disability awareness raising among other statutory and non-statutory bodies in the region.

In terms of organisational structures, the emphasis in the *National Health Strategy* on developing a service-user oriented health service is welcomed. The requirement is for a holistic approach designed to enable individuals achieve their personal outcomes through the development of organisational processes.

The service principles, outlined in '*Towards an Independent Future*' (1996) of enabling persons with a physical or sensory disability to live as independently as possible in the community and, where possible, of integrating services within mainstream services, which facilitate inclusion, underpin the provision of services to this client group.

'*Towards an Independent Future*', in recognising the major role played by voluntary agencies in representing people with disabilities and in meeting their needs, strongly recommended that the effective delivery of services and the achievement of the maximum benefit to service users and families/carers can be obtained only if improved organisational structures are implemented. The Health Board and the voluntary

agencies need to develop the inter- and intra-organisational and collaborative capacities of the agencies. The Health Board recognises the challenges this might place on voluntary agencies and is therefore committed to providing the necessary support to ensure that they are equipped, both in management and operational terms, to carry out their role.

The Health Board subscribes to and will actively seek to realise implementation of the three guiding principles of equality, maximising participation and enabling independence and choice adopted by the Report of the Commission on the Status of People with Disabilities, *A Strategy for Equality* (1996). The Commission identified as one of the key principles that have informed recent international legislation and practice the recognition that disability is a social rather than a medical issue. The Health Board is committed to the ongoing re-focusing of service provision in line with the increasing social context of services. The principles of equality and maximising participation for persons with a disability imply the implementation of the policy of mainstreaming of services for this client group that facilitate inclusion. The Health Board welcomes the mainstreaming of vocational training and employment services under the remit of FÁS and the mainstreaming of information and advice services under the remit of Comhairle. The Health Board, in terms of its delivery of health and personal social services, and through its advocacy role with other statutory bodies, will actively support the mainstreaming of services that facilitate inclusion for this client group.

The Health Board has expressed its commitment to the promotion of health and social gain for the population of the Mid-West Region, based on the principles of equity, quality and accountability, in its Corporate Strategy and Corporate Quality Statements. A health gain focus aims to improve the health status and quality of life of this client group and their families through the provision of appropriate, equitable, accessible and timely interventions and services. A social gain focus aims to improve the person's life by minimising the effects of the disability and resulting disadvantage. The health and social gain targets for this client group are concerned with:

- reduction of the incidence of disability , and
- limitation of the disabling effects, greater independence and improved social functioning and inclusion.

The complex health, social and economic issues relating to the planning, development, implementation and quality assuring of health and personal social services for this client group make it imperative that a strategy is formulated to guide decision making . The purpose in formulating this Strategy Statement is to focus deliberation and discussion among all stakeholders involved in the development of appropriate, responsive and innovative services for persons with a physical and sensory disability and their families in the region.

This Statement, and its sister Strategy Statement on Intellectual Disability, are part of a suite of Strategic Statements being developed in order to give strategic direction to the different Care Groups. A costed Action Plan and implementation programme will be developed to ensure that the necessary developments are progressed over the five-year timescale of this Strategy Statement.



## Chapter 2: Strategy Formulation

All publications, both national and international that influenced this strategy formulation identified the basic right of persons with a disability to equal participation and involvement in decisions relating to their health. Therefore the process of informing the future direction and approach to services for persons with a disability was designed on the basis of three strands of inquiry, consistent with the corporate aim of creating a learning organisation, i.e.

- ❑ **Stakeholder Perceptions**
- ❑ **Internal Review Data**
- ❑ **External General Reviews**

### **2.1. Stakeholders:**

A stakeholder analysis of both internal and external key stakeholders was undertaken through a series of focus groups. This work was undertaken on behalf of the Health Board by an external consultant in order to ensure objectivity. The main issues addressed by the focus groups were:

- By whom and how should needs be determined?
- What options for provision of services are / should be available?
- What is the role of the person with a physical or sensory disability and their families?

External stakeholders had the opportunity to ensure inclusion of the views of the members of their organisations through discussion of these key areas prior to attending the focus groups.

From the above process a draft of the Strategy was compiled which was progressed through the structure of the Area Managers for Disability Services, the Disabilities Directorate and the Coordinating Committee for Physical and Sensory Disability Services.

### **2.2. Internal Review Data:**

A review of internal activity data relating to these services was undertaken. Other evaluation of services, which were or are currently being undertaken by the Health Board, were also included in the development of this Strategy. These include the strategies/evaluations relating to Intellectual Disability, Personal Assistance Services, Aids and Appliances, Young Chronic Sick, Therapy Services, Primary Care, Mental Health, Child Care and Family Support Services, Maternity Services, Child Health, Women's Health and Health Promotion. In undertaking these reviews it became clear

that all these services are of themselves essential to persons with disabilities during their lifecycles.

### **2.3. External General Reviews:**

The major sources of external review were:

- ❑ United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993)
- ❑ The National Health Strategy: 'Shaping a Healthier Future" (1994)
- ❑ Report of the Advisory Group on Personal Assistance Services for People with a Physical Disability (1995)
- ❑ 'A Strategy for Equality': Report of the Commission on the Status of People with Disabilities (1996)
- ❑ 'Towards an Independent Future': Report of the Review Group on Health and Personal Social Services for People with Physical and Sensory Disabilities (1996)
- ❑ Report of the Review Group on Aids & Appliances (1999)
- ❑ 'Towards Equal Citizenship': Progress Report on the Implementation of the Recommendations of the Commission on the Status of People with Disabilities (1999)

# Chapter 3: Policy and Service Context

## 3.1. National Policy Context

The three core documents relating to national policy in the area of physical and sensory disability are: 'Shaping a Healthier Future', 'A Strategy for Equality' and 'Towards an Independent Future'.

### 3.1.1. 'Shaping a Healthier Future' - The National Health Strategy (1994)

The National Health Strategy, '*Shaping a Healthier Future*' defined the primary aim of the health services as the achievement of health and social gain through enforcement of the principles of equity, quality and accountability. (DOH, 1994 : 1)

The following objectives of the *Strategy* are of particular relevance to services for persons with disabilities:

- ◆ Prevention, treatment and care services will be more clearly focused on improvements in health status and the quality of life, and will place an increased emphasis on the most appropriate care.
- ◆ The management and organisational structures will provide for more decision-making and accountability at regional level, allied to better methods of performance measurement
- ◆ Greater recognition will be given to the key role of those who provide the services and there will be greater sensitivity to the right of the consumer to a service that responds to his or her needs in an equitable and quality-driven manner in an appropriate setting. (DOH, 1996: 1)

The Strategy outlined an action plan for specific services to be implemented during the period, 1994 - 1997. The plan for development of services for persons with physical or sensory disability included the following:

- A commitment to further develop services on the basis of locally-assessed need.
- To provide extra facilities for day care, respite care, home care, personal support services and residential care/ independent living.
- To provide additional residential facilities for the young chronic sick
- To improve the organisation and co-ordination of services
- To build up information on the service needs of clients - this will be facilitated by the establishment of a national database on physical disability



- To employ additional occupational therapists, speech and language therapists and physiotherapists
- To improve the counselling and psychological support services for persons with disabilities and their families
- To improve vocational training standards and facilities with a view to greater economic integration of people with a disability in society
- To address the funding base for voluntary bodies who provide services and supports to persons with a physical/sensory disability
- To improve the availability of technical aids and appliances

In addition, action was to be taken to help reduce the incidence of neural tube defects by increasing the awareness among women of child-bearing age of the need to have adequate folic acid in their diet. **(DOH, 1994: 2).**

### **3.1.2. 'A Strategy for Equality' - Report of the Commission on the Status of People with Disabilities (1996)**

The Report identified three key principles that have informed recent international legislation and practice:

- ◆ The recognition that disability is a social rather than a medical issue;
- ◆ The adoption of a civil rights perspective, and
- ◆ The recognition of equality as a key principle of the human rights approach

The United Nation's Standard rules on the Equalisation of Opportunities for Persons with Disabilities, adopted in 1993, integrate these principles. While not legally binding on UN member states they are intended to provide the basic international legal standard for programmes, laws and policy on disability in the coming years. Their objective is to ensure that all people with disabilities can exercise the same rights and obligations as other people. **(DOE&LR, 1996 : 1)**

The three guiding principles adopted by the Commission to inform its work were:

- (1) **Equality:** this key principle underlay all the recommendations in the report of the Commission. The Commission recommended that the State provide for programmes of affirmative action and positive discrimination to address past inequalities experienced by persons with disabilities
- (2) **Maximising Participation:** this principle implies that people with disabilities have the right to participate in all areas of Irish life to the fullest extent and, conversely, the State should have regard to the needs and interests of persons with disabilities.
- (3) **Enabling Independence and Choice:** this principle implies that persons with disabilities have the right to be able to achieve their full potential; the right to make

their own choice concerning the conditions of their lives and the right to quality services. **(DOE&LR, 1996 : 2)**

The problems most often encountered by persons with disabilities when dealing with the health services were:

- inaccessibility of hospitals, health centres and doctor's surgeries
- the concentration of vital services in Dublin
- the unpredictable availability and underfunding of community services such as, home helps and respite care
- a widespread lack of disability awareness
- the lack of consumer control of services
- lack of clearly defined complaints procedures **(DOE&LR, 1996 : 3)**

The Report issued 36 recommendations in respect of the health services. The main issues that arose for implementation, with respect to persons with a physical or sensory disability, were:

- ❑ The accessibility of hospitals and other settings in which services are provided and the allocation of a key worker to facilitate communication between hospital staff and people with disabilities and their families.
- ❑ The need for close liaison between hospital maternity units and all community services for children with disabilities
- ❑ The need for hospital staff at all levels and doctors at both undergraduate and postgraduate level to receive disability awareness training.
- ❑ The need for research into the development of technical aids and equipment to be encouraged by Government
- ❑ The expansion of the home help scheme and respite care services for persons with physical and/or sensory disabilities
- ❑ The provision of personal assistance services for people with significant physical disabilities and the need to support and develop peer counselling and peer support services for deaf people
- ❑ The need for additional revenue funding to address shortfalls in services for people with disabilities
- ❑ The development of special units throughout the country, specialising in continuing therapeutic care for people who have been discharged from medical rehabilitation centres
- ❑ The development of national standards by the Department of Health and Children for services to people with disabilities in the community
- ❑ The rights of patients, the development of effective complaints procedures and the employment of Rights Advisers and Patient Advocates
- ❑ The need for health boards to review existing levels of services with reference to the principles of equity, accountability and quality of services

Since a '*Strategy for Equality*' was published, £21.495m additional revenue will have been invested by the health and personal social services in the physical and sensory disability sector by 2000. (DOJE&LR, 1999 : 1).

### **3.1.3. 'Towards an Independent Future' - Report of the Review Group on Health and Personal Social Services for People with Physical and Sensory Disabilities (1996):**

The Report considered that the objectives of health and personal social services for persons with disabilities should be to enhance their health and quality of life by:

- ◆ enabling them to live as independently as possible in the community;
- ◆ where possible, integrating services with mainstream services;
- ◆ providing services in a manner that respects the right of service users to have a say in the services they receive;
- ◆ ensuring service provision is respectful of the dignity of the service user as well as equitable, accessible, appropriate and available within a reasonable period of time
- ◆ providing appropriate support to, and involvement of, families / carers;
- ◆ ensuring services are accountable to the user and funder;
- ◆ preventing impairment and disability and lessening the effects of disability and handicap (DOH, 1996: 2)

The key issues which emerged from the submissions received by the Review Group from interested parties and which formed the basis of the Report were:

- lack of comprehensive data on the numbers and service needs of persons with physical and sensory disabilities;
- inadequate access to information on service provision and entitlements (with particular reference to the communication needs of people with sensory disabilities);
- disparities in eligibility criteria for services and benefits between different health boards and between different community care areas of the same board;
- inadequate statutory financial support for individuals with disabilities;
- uncertain funding of voluntary organisations leading to uncertainty in service provision;
- service shortfalls in relation to therapy services, day care and activation, counselling, home support, respite, residential and independent living arrangements
- uneven geographic distribution of services such as therapy services and low vision clinics;
- inadequate transport services;
- inadequate co-ordination of services between and within the statutory and voluntary sectors leading to fragmented and ad hoc service provision;
- need for specialist services for certain groups, such as people with sensory disabilities and people with head injuries;
- poor consumer choice in service provision;
- handicap caused by inadequate provision of health and other services. (DOH, 1996 : 3)

The Report adopted as its key focus the development of services to enable persons with a physical or sensory disability to live as independently as possible in the community. The Review Group recommended that priority be attached to the provision of more day care, respite care, nursing and therapy services, personal assistants and residential accommodation to achieve this goal. The Review Group attached great importance to integrating services for people with disabilities with mainstream services, wherever possible.

The lack of reliable information on the numbers of people needing a service and their precise service needs was identified as a major deficiency. The Report recommended that immediate attention be given to developing a database of information on the needs of persons with physical and sensory disabilities to provide a firm basis for planning services. New structures to encourage the co-ordination of service planning and delivery between the statutory and voluntary sectors were also recommended. **(DOH, 1996: 4)**

Currently a greater emphasis is placed in public social policy on:

- \* Development of integrated responses involving the statutory, voluntary and community sectors
- \* Participation, inclusiveness and mainstreaming of services for people with disabilities
- \* The development of outcome measurement with an emphasis on the quality of efficient and effective service delivery
- \* The involvement of local populations and individuals in matters relating to health and social gain
- \* Accountability to consumers and society
- \* Co-ordination and co-operation between disciplines and service providers at local, regional and national levels
- \* Preventing impairment and disability and lessening the effects of disability and handicap

In response to *'Towards an Independent Future'* the Board has commenced a process of identifying priorities necessary for ensuring that persons with a physical or sensory disability are enabled to live as independently as possible within their own communities. Central to this process is the ongoing development of a model of provision that is characterised by partnership. Each element of the partnership - be it statutory, voluntary or community - must be seen as having a role in identifying and responding to the needs of the cohort of persons who have a physical or sensory disability.

## **3.2. Service Context**

### **3.2.1. General**

Central to the service context in which services to persons with a physical or sensory disability are provided is the Health Board's dual role as direct provider of services and endorser of service provision by other organisations. This is reflected in the range of its activities and relationships in a complex environment of statutory and contracted support provision. The balance between these functions has evolved differently in different areas of the region. The Health Board is committed to reviewing the balance between these complementary roles to ensure that the optimum service is provided.

The Health Board is committed to ensuring that service developments occur in an integrated manner to facilitate a comprehensive and accessible service. Central to the Health Board's approach to the future is the development of appropriate agreed performance measures that reflect the needs of this client group. The development of these performance measures based on research and evaluation will lead to transparency and accountability in resource allocation and application.

The Health Board is committed to the ongoing development and re-focusing of service provision in line with the decreasing medical context and increasing social context relating to disability. In this context, public education is required regarding expectations of health and personal social services to this client group.

The Health Board is committed to increasing participation by this client group, their families and communities through involvement in the planning and monitoring/evaluation of services, publishing guidelines on policy and practice and through its appeals procedures. This commitment recognises the difference in perspectives that can arise between the Health Board and persons with a physical or sensory disability or support groups due to the traditional model of viewing disability as a health issue rather than as a social and society-wide issue. The Health Board is establishing constructive linkages with external statutory and non-statutory agencies in recognition of its advocacy role aimed at furthering the recognition of disability issues in eliminating social disablement and marginalisation.

The Health Board aims to ensure a cohesive and comprehensive discrete range of effective and efficiently resourced services, based on sector populations, in line with developments for other care groups within the region.

### **3.2.2. Regional Disabilities Directorate**

In response to a perceived lack of co-ordination and focused management of disability services in the region the Health Board created a regional Disabilities Directorate. The functions of the Directorate include the achievement of service plan objectives, the implementation of key strategic initiatives, the planning and development of services (in conjunction with the Regional Coordinating Committee) the development, implementation and monitoring of quality initiatives and the maintenance of up-to-date databases. With the recent development of Area management structures in each

County Catchment Area the Directorate has a specific role in facilitating the development of partnerships and networked alliances with stakeholders. The role of the Directorate is evolving to that of 'Commissioners', 'standard setters/evaluators' and 'Compliance Assurer' of statutory and best-practice requirements.

### 3.2.3. Planning and Database Structures

Recommendation 85 of the report of the Review Committee states that "The Chief Executive Officer of each health board should establish a **regional co-coordinating committee for services for people with physical and sensory disabilities**." The functions of the co-ordinating committee would be to advise the Chief Executive Officer on the following:

- the commissioning of an assessment of needs of persons with a disability
- the formulation and review of a multi-annual plan for the development of services for persons with disabilities which is costed and prioritised;
- opportunities for co-operation and flexibility among service providers to ensure best utilisation of resources;
- issues relating to quality and effectiveness of service;
- the effective provision of information to service users;
- opportunities for inter-sectoral co-operation and the drawing up of protocols in this regard;
- the prioritising of programmes for the allocation of development funds;
- supporting the development of a comprehensive database in co-operation with the national Database Development Committee. **(DOH, 1996 : 5)**

The Coordinating Committee on Physical and Sensory Disabilities, which is representative of statutory and voluntary interests in the region who are involved in this area of disabilities, holds its meetings, on average, once a quarter. The Committee debates the full range of issues pertinent to persons with a physical or sensory disability in the region and, in particular, provides a forum where the co-ordination and integration of statutory and voluntary services can be facilitated.

Consistent with the creation by the Health Board of the organisational structure of Area General Managers and Area Teams, the post of Area Manager for Disability was created in each of the three Catchment Areas. Disability Care Groups, operating under the direction of the Area Managers, have been developed in each County Catchment Area which will further effect integration and coordination of services at local level. The creation of Area Physical and Sensory Disability Advisory Committees will provide a mechanism for the prioritised, planned and coordinated development of services and will facilitate appropriate and adequate representation of local views from service providers and advocates.

The Review Group identified the lack of reliable information on the numbers and requirements of persons with a physical and sensory disability as a significant deficit

with respect to the efficient planning and provision of services. They, consequently, recommended the establishment by the Department of Health, health boards and voluntary bodies of a database which would provide a picture of need over a five-year period on individuals who currently receive, require or will require specialised health and personal social service. The Review Group further recommended the establishment of a **National Database Development Committee**, which was established in December 1998. (DOH 1996: 6).

The Committee has resolved that the objectives of the database should include:

- Planning service developments
- Prioritising service needs
- Assisting in resource allocation decisions at national, regional and local level.
- Research

The Committee decided that the criteria for inclusion on the database should include persons who:

- Have a persistent physical or sensory disability, arising from disease, disorder or trauma
- In the case of dual disability, where the predominant disability is physical or sensory
- Are 65 years of age or younger
- Are receiving or require a specialised health or personal social service which is related to their disability **and**
- Have consented to being included on the database

The Committee has defined the term *specialised health and personal social services* as:

“the range of health and personal social services, additional to generic services, which may be required by people with physical or sensory disabilities for the purpose of achieving health and social gain and maximum quality of life. These services are provided by, or on behalf of, the health boards.” (HRB, 1999: 1)

A Database Form has been developed to collect the information on the persons with a disability that contains five categories of information:

- Personal details
- Details of disability – information on the type of disability and an indicator of the person’s level of ability and functioning.

- Current service provision – the type of treatment and rehabilitation, personal support, personal assistant, respite, day and residential services that the person is currently receiving and the agencies providing these services.
- Future service provision – the service provision, under the above categories, that the person requires over the next five years.
- Additional information – information on whether the person has a medical card and/or a long-term illness card. **(HRB, 2000: 1)**

The process of evaluating the Development Committee's proposals for the national database has begun with the implementation of a Phase 1 of the Physical and sensory Database in four Community Care Areas two urban areas, ERHA (Dublin – CC4) and WHB (Galway City), and two rural areas, SEHB (South Tipperary) and NEHB (Louth). Phase 1 will act as a pilot for the national implementation of the Database and will allow systematic testing and evaluation of all the main features of the national Database, including identification of the target population and data collectors and the collection, processing and interpretation of the data. Phase 1 will be staggered to maximize potential benefits. The SEHB and the ERHA Phase 1 sites will commence data collection, followed by the NEHB and the WHB. The design of the second stage of Phase 1 implementation will be refined in accordance with the findings from the first stage. Following Phase 1 implementation, detailed proposals regarding the national implementation of the database will be presented to the Department of Health and Children early in 2001. **(HRB, 2000: 2)**

In this Region, the Director of Disabilities has been designated as Regional Database Coordinator, with overall responsibility for the Regional Database. A Database Administrator has been appointed, to whom day-to-day operations of the Database are being delegated. The Database Coordinator and Administrator are currently working closely with the National Database Committee in preparation for implementation of the Database in the Mid-West Region. The Health Board has established a Physical and Sensory Database Committee to review the operation of the Regional Database, agree arrangements for providing access to the Database and advising the Database Coordinator on operational issues and problems that may arise.



## Chapter 4: The Continuum Of Support

During the consultative process with stakeholders a consensus of opinion identified the model of support which best responded to the needs of persons with physical and sensory disabilities as **the lifecycle model**. This approach acknowledges that impairment and disability are issues that may impact on people at any stage from birth to old age. This model facilitates the introduction of interventions appropriate to the needs of individuals and their families that aim at minimising the disabling factors and maximising the enabling factors when providing or commissioning services for persons with disabilities. The lifecycle model supports the development of a continuum of support that is adaptive and flexible in response to the complex needs of this client group. The components of the model are:

- ❑ **Preventative Support**
- ❑ **Anticipatory Support**
- ❑ **Home and Community Support**
- ❑ **Respite/Residential Support**

Gaps in service provision or interventions affect the effective functioning of the continuous lifecycle model of support. Services are structured within a support continuum in order to ensure effective prevention, timely assessment, focused intervention, relevant support and community and residential/respite provision across the lifecycle and across conditions.

### 4.1. Preventative Support

The Health Board recognises that there are a range of preventative measures that can be implemented to reduce the incidence of physical and sensory disability. The health and quality of life of all individuals in society will be enhanced by the successful realisation of Preventative Support.

#### 1. ***Stakeholder View:***

The process of stakeholder consultation identified the following issues;

- ❑ Health promotion, especially with respect to smoking, dietary lifestyles, drinking patterns and drug use were emphasised as significant issues in the prevention of physical and sensory disability.

- ❑ The need for proactive policies and programmes to reduce the incidence of accidents and accidental poisonings, which can lead to significant impairment was highlighted.
- ❑ Stakeholders identified the provision of enhanced information and education, with respect to pre-conception, antenatal and perinatal care.

## **2. *Position of ‘Towards an Independent Future’:***

The report, *‘Towards an Independent Future’*, refers to the (1995) Health Promotion Strategy, *‘Making the Healthier Choice the Easier Choice...’* which recognises that the chief causes of premature mortality and morbidity are associated with unhealthy behaviours and lifestyles. This includes smoking, alcohol misuse, drugs misuse, as well as accidents - which are the single greatest cause of death in persons under 45 years. Alcohol misuse and smoking may result in significant disability.

The initiative of the Office for Health Gain in preparing an accident prevention strategy was welcomed. The Report also makes reference to a study on accidental injury as the chief cause of morbidity and mortality in Ireland in people up to 45 years of age. A recommendation of the study is the establishment of a representative multi-sectoral national committee to achieve a co-ordinated approach to injury prevention. **(DOH, 1996: 7)**

The promotion of a healthy lifestyle during pregnancy to facilitate antenatal care has received increasing attention in recent years. Good nutrition, moderate intake of alcohol and the elimination of other addictive substances, the cessation of smoking and the careful prescription and consumption of therapeutic agents are significant elements of a health promotion initiative directed at antenatal health. The effectiveness of folic acid supplements prior to conception in preventing the occurrence of neural tube defects, such as spina bifida and anencephaly has been established. Provision of educational materials and advice in relation to these matters should be an important element of antenatal care provided to mothers in hospital out-patients or in the combined mother and infant care scheme. **(DOH, 1996: 8)** The Report considered that the practice of encouraging mothers to attend hospitals for their confinement where services are available should be continued. Special emphasis should be placed on monitoring the needs of those most at risk in pregnancy teenage mothers, the Travelling Community, women at the extremes of their reproductive life and women with chronic illnesses such as, heart disease or diabetes. **(DOH, 1996 : 9)**

The objective of the National Childhood Primary Immunisation Programme is to achieve and maintain an uptake level of not less than 95% of the total childhood population to eliminate conditions such as diphtheria, polio, Hib diseases, tetanus, measles, mumps, rubella and pertussis. The programme has contributed to a significant reduction in the incidence of many disabling conditions. There is a concern

that some disadvantaged groups, such as, children of the Travelling Community, may not be participating in the immunisation service. (DOH, 1996: 10)

Conditions such as retinitis pigmentosa, Friedreich's ataxia, cystic fibrosis and congenital cataracts are genetically determined. Guidance and assistance in understanding the implications of inherited diseases is provided through the consultant-led genetic counselling service, based in Our Lady's Hospital for Sick Children. The Review Group recommended that urgent attention be given to the expansion and development of this service in Dublin and other centres. (DOH, 1996: 11)

### **3. *Mid-Western Health Board's Position:***

#### **(a) Influence of smoking and diet on incidence of disability:-**

Smoking and diet are causative factors in cardiovascular disease that can lead to strokes, peripheral vascular and other conditions resulting in physical and sensory disability. There were 6,289 discharges from hospitals in the Mid-West Region in 1997 with a principal diagnosis of circulatory disease. (MWHB, 1999: 1). Prevention of these illnesses through lifestyle changes is an important factor in reducing the incidence of impairment and disability. A study, investigating the smoking habits, alcohol and drug consumption of almost 4,000 post-primary school students in Counties Clare and Limerick in 1998 revealed that smoking was a common habit among students: 58% of the total group surveyed had smoked at some stage in their lives, while almost 29% were current smokers (MWMB, 1999: 2). The Board has established a Regional Smoking Action Group, consisting of representation from hospital staff, area medical officers, environmental health officers, schools health promotion officers and public health nurses, which will continue to develop policy initiatives and programmes on smoking prevention and cessation in the Mid-West Region. The Health Promotion Unit of the Board provides training for Health Board staff such as, public health nurses, to enable them act as facilitators for smoking cessation among members of the public they engage with.

The 'Being Well' community lifestyle course offers an eight week programme to members of the public in the region whose aims include providing information about specific health topics, such as healthy eating, physical activity, stress, relaxation and legal drugs and raising awareness of a positive, holistic concept of health. The remit of the programme will be extended to include smoking cessation, as one of its elements. The Health Board works in partnership with community organisations operating from Community Development Centres and Family Resource Centres in identifying persons who would be interested in smoking cessation and providing trained facilitators to enable them cease. The Health Board will continue to work with STAG (the national Smoking Target Action Group) that advises on national policy and supports policy development Continuing cooperation with professional groupings, such as, the Irish College of General Practitioners and the Irish Centre for Continuing Pharmaceutical

Education, in brief interventions and motivational interviewing to maximise opportunities for encouragement of smoking cessation will occur. Policies and programmes to encourage smoking prevention and smoking cessation will be augmented through the further development of the health promoting hospitals and health promoting colleges in the region.

Programmes, directed at improving dietary lifestyles in the region, apart from the above-mentioned 'Being Well' course include working with low income families, through the development of food cooperatives whereby local groups, operating from facilities such as, Family Resource Centres, purchase fruit and vegetables from wholesalers and sell them to the community at cost. One such cooperative is currently in operation in Southill, Limerick and the project will be extended to other areas in the region. A pilot cookery and healthy eating project is currently being run in conjunction with Clarecare. Following evaluation, this will be extended to other areas, if successful. In May of each year the Health Board actively participates in Healthy Eating Week. The focus this year was on cardiovascular disease and this theme will also provide the focus for Healthy Eating Week in 2001. A Regional Cardiovascular Disease Steering Committee has been formed to oversee the development of services for people with cardiovascular disease in the Mid-West Region **(MWHB, 2000: 1)**

#### **(b) Influence of accidents on incidence of disability:-**

The principal types of accident resulting in admission to hospital in the Mid-West region are road traffic accidents, accidental poisonings and falls. In 1998, road traffic accidents accounted for 604 discharges from hospitals in the Mid-West region, accidental poisonings accounted for 212 discharges and falls accounted for 1,964 discharges. With respect to the 604 RTA discharges, rates were high in both males and females in the 15 –34 age group. With respect to the data on accidental poisonings, the majority of patients are not admitted following accidental poisonings – rather treated in casualty departments or by G.P.s - and the largest age group among the 212 discharges was children in the (0-4) age group. With respect to falls, the age profile of the 1,964 discharges shows a dramatic increase with age. **(MWHB, 2000:2)** A reduction in the number of accidents, including accidental poisonings and parasuicide, will lead to a reduction in the number of cases of acquired physical and sensory disability and adult acquired intellectual disability. There were a total of 5,333 discharges from hospitals throughout the country of people resident in the Mid-West region with a principal diagnosis of injury or poisoning in 1997. Of these 587 had a diagnosis of brain/head injury, 105 a diagnosis of open head wound and 273 a diagnosis of fracture of facial bones. In 1997 four hundred and fifty six admissions to hospitals throughout the country of people resident in the Mid-West Region were due to poisoning by ingestion of psychiatric drugs and simple painkillers, such as aspirin and paracetamol **(MWHB, 1999: 3).**

The Health Board is represented on the Regional Accident Committee, which was established under the aegis of the National Safety Council during 2000, and will continue to contribute to the programmes directed at improving safety levels and reducing the incidence of accidents at a regional level. The Health Board also actively

supports the initiatives of the Health and Safety Authority with respect to accident prevention.

The Health Board's *Action Plan*, prepared in response to the Report of the National Task Force on Suicide, will spearhead the drive to reduce the incidence of suicide and parasuicide in the region. Measures outlined in the Action Plan to increase awareness and prevention include:

- the distribution of information leaflets
- media campaigns
- public poster displays
- promotion of the Samaritan's service
- development of the Health promoting Schools concept for students
- provision of information packs for Counselling Offices in colleges
- provision of an education programme by the Health Promotion Unit for students to reduce the risk factors of drug and alcoholism associated with suicide.

The Action Plan outlines a suite of developments in the mental health services (and related services) to reduce the incidence of suicide and parasuicide that are currently being implemented by the Project Co-Coordinator. Activities, focusing on prevention and training, are being coordinated in the voluntary sector and ongoing liaison with the local authorities on issues surrounding suicide is occurring. Training programmes for health care professionals in the region on issues relating to suicide and parasuicide are being implemented and specific resources have been provided to compile research on the issues. **(MWHB, 1999: 4).**

### **(c) Influence of drinking on incidence of accidents:-**

Regular heavy drinking is strongly linked to a variety of alcohol-related problems such as, accidents. Conservative estimates indicate that alcohol is associated with at least 25% of road accidents and 33 % of all fatal accidents, nationally. Overall, on a typical drinking occasion, approximately one third of Irish adults drink to excess and, in the 18 –34 age group, over half drink to excess. **(DOHC, 2000: 1).** In 1998, an extensive survey into the use and knowledge of alcohol among adults living in Limerick revealed that 71% were regular drinkers and 9% of men were classified as being dangerous drinkers, compared to half that for women. In the Mid-Western study of teenage lifestyle habits (previously referred to) almost 82% of respondents were found to have tried alcohol and almost 68% were current drinkers. **(MWHB, 1999: 5).**

The Health Board subscribes to the strategic aims of the National Health Promotion Strategy (2000 – 2005), with respect to alcohol consumption, and will proactively contribute to the realisation of these objectives at regional level:

- ❑ To **promote** moderation in alcohol consumption, with the message that less is better.
- ❑ To **delay** the onset of alcohol consumption among children and adolescents, especially those in the under 15 age group.

- ❑ To **contribute** to a decrease in the number of young people and adults who drink to excess on any one occasion.
- ❑ To **continue** to support the National Alcohol Surveillance project in monitoring alcohol-related problems.
- ❑ To **work in partnership** with...local communities to bring about positive change in attitudes and to provide a supportive environment.
- ❑ To **support** the National Alcohol Coordinator in the review of the *National Alcohol Policy*.
- ❑ To **support** the implementation of the recommendations in *Building Healthier Hearts* that relate to alcohol. (DOHC, 2000: 2)

#### **(d) Influence of drug misuse on incidence of disability:-**

Drug misuse can lead to physical disability, through the occurrence of accidents and self-harm when under the influence of drugs. There is a disturbing trend of an increasing number of young people using both legal and illegal substances at an ever-decreasing age. In 1998, 58% of cases in drug treatment centres were under 25 years of age. (DOHC, 2000: 3) The Mid-Western study of teenage lifestyles revealed that 30% of students surveyed had used some form of drug, this figure being almost 20% for 13 year olds. (MWHB, 1999: 6).

The Health Board's drug misuse services can be seen as ranging along a continuum which consists of the elements: Prevention/Education, Treatment, Rehabilitation and Maintenance. Prevention/Education services include community-focused work relating to information provision, education and development of support structures. The Drugs and Alcohol Education Officer of the Sláinte Office will continue to promote the Substance Abuse Prevention Programme in secondary schools in the region, as part of the Social and Personal Health Education programme. The Health Board has supported local authorities in developing a drug peer-education programmes with teenagers. The information service provided through the telephone help line and the drop-in information service operated by the Sláinte Office will receive continued support. An increased level of information and support to families of drug misusers to enable them to support their family members is required. The employment of outreach counsellors who will deliver information, education and counselling services to local communities in the region is required. Consideration is being given to providing financial support to local communities in order to assist them in compiling and disseminating locally relevant and locally accessible information on drug misuse. As part of its information/education remit the Health Board intends to further raise awareness of drug-related issues in the community through enhanced support for voluntary agencies in the region who have a remit in the drug misuse area. Enhancement of existing training programmes to professionals within the Health Board on drug-related issues will be required to address the information and educational needs of staff in this area.

Treatment services for drug misusers, include, level 1 treatment by G.P.s and access to symptomatic detoxification treatment at outpatient level by the Mental Health Services. Achievement of level 2 prescribing of methadone by G.P.s in the region is required, as

currently drug misusers in the region have to be referred to Dublin for this treatment. Current rehabilitation services include service agreements with Cuan Mhuire Centre, Bruree and Ashling Centre, Ballyraggett, Co. Kilkenny. Current maintenance services include, level 1 prescribing by GPs, limited counselling and encouragement to attend Narcotics Anonymous and Alcoholics Anonymous. The Health Board aspires to developing service agreements with specific agencies, within and outside the region, for the provision of discrete elements of service with respect to drug misuse, including the development of specific counselling, family therapy and life-skills programmes for adolescents in the region. Full support will be given, at a regional level, to the review of the Report of the 2<sup>nd</sup> Ministerial Task Force on Measures to Reduce the Demand for Drugs. The Health Board's *Strategy on Drug Use* will outline the future strategic direction of these services.

**(e) Role of antenatal and perinatal care in disability prevention:-**

Antenatal and perinatal care are key elements in the Health Board's continuum of support for the reduction of impairments and disability. The Health Board has informed all obstetricians and general practitioners of the advisability of commencing supplemental folic acid therapy eight weeks prior to conception and information leaflets have been provided for the information of women in the region. The Health Board will participate in the national Folic Acid Awareness Campaign that has recently been initiated. The need for expectant mothers to avoid exposure to German measles and hence the need for appropriate vaccination will continue to be promoted. The survey of post-primary school students in Limerick and Clare revealed the extent of smoking, alcohol and drug usage among teenagers in the region. In view of the research that has shown that a healthy lifestyle during pregnancy makes a major contribution towards the health of children this is a worrying trend, in respect of impairment and disability prevention, as these are the potential parents of the next decade.

The Health Board is committed to reducing risk among the most vulnerable of the population. Particular attention is focused on supporting parents in the early months after the birth through the public health nursing service and the Community Mothers programme. This latter programme, piloted in Limerick City from 1993-1997, is a structured visiting programme whereby experienced parents visit parents who have just had a baby. This programme was expanded to Nenagh and County Limerick in 2000. The Health Board is particularly aware of the extra difficulties encountered by Young Parents. Programmes already established in this area to which Board staff have an input include the Social, Personal and Health Education Programme, the Teenage Pregnancy Prevention programme and the 'Teen Parenting Programme' operated as part of the Community Mothers Programme. The objectives of the 'Teen Parenting Programme', which is part of a national pilot initiative include:

- ❑ targeting of the most vulnerable teen parents,
- ❑ provision of support to these parents before and after the birth of a child,

- ❑ harnessing of all existing support services and making them known and accessible to these parents
- ❑ addressing gaps in service provision by establishing support groups and services in targeted settings
- ❑ acting as a forum for the exchange of information and sharing resources

The Health Board will continue to provide funding to the CURA pre- and postnatal service for expectant single mothers. The Board's Health Promotion programmes, aimed at reducing the incidence of smoking and moderation in alcohol consumption among the adult population in the region, will serve to reduce the risk factors during pregnancy associated with development of disability in the newborn among pregnant women in the Mid-West region.

#### **(f) Role of immunisation in disability prevention:-**

Immunisation remains a safe and effective way to prevent morbidity and mortality from many childhood illnesses. Current levels of immunisation uptake for children in the Board's area are unsatisfactory, with a rate of 72.29% for MMR, 79.49% for Hib and 80.19% for 3 in 1 / 2 in 1 in 1999. **(MWHB, 2000: 3)** It is important as a strategy for disability prevention that uptake levels of the Childhood Primary Immunisation Programme reach 95% of the child population as outlined in the Health Board's *Strategy Statement on Child Health* **(MWHB, 1999: 7)** The recent appointment of Senior Public Health Nurses, with responsibility for immunisation should facilitate increased local uptake of immunisation. Of particular importance in this matter are some groups, such as, children of the Travelling Community, who may not avail adequately of immunisation services. The establishment by the Health Board of the Traveller Health Unit in September, 1998, the appointment of a Primary Health Care Worker for Travellers in August, 1999 and the creation of two posts of Community Workers for Traveller Health will assist in the a gradual improvement in the uptake of immunisation among this client group. **(MWHB, 2000 : 4)**

#### **(g) Role of genetic counselling in disability prevention:-**

A Genetic Counselling Service has started at the Mid-Western Regional Hospital, which is serviced from the National Centre for Medical Genetics, Dublin. Four clinics per year are currently held at the hospital. Further development of this service will be encouraged.

### **4. Change Issues:**

- ◆ Reduction in smoking levels and improvement in dietary lifestyles in the region.
- ◆ Reduced incidence of parasuicide and accidental poisonings in the region



- ◆ Reduction in level of accidents in the region, including active promotion of sensible drinking attitudes.
- ◆ Enhancement of drug prevention, treatment, rehabilitation and maintenance programmes in the region.
- ◆ Greater emphasis on preventative strategies in pre-conception, antenatal and perinatal services.
- ◆ Encouragement of folic acid supplementation, particularly focused on the high-risk population.
- ◆ Maximised uptake of primary childhood immunisation programmes, particularly among low uptake groups in the population, in line with best practice.
- ◆ Further development of the local genetic counselling service

## **4.2. Anticipatory Support**

Services and structures are required which anticipate the needs of persons with a physical and sensory disability in the region. By anticipating their needs proactive supports, structures and organisational processes can be planned and implemented in the light of the individual's needs.

### **1. Stakeholder View:**

During the stakeholder consultation process the stakeholders identified a number of issues that needed to be addressed:

- ❑ The strategic intent of the Health Board's services (and those of the voluntary service providers it funds) should be focused on satisfying client's needs rather than on the management of disability services.
- ❑ The lack of an adequate physical and sensory disability database, which would provide a comprehensive picture of need in the region.
- ❑ The deficit in provision of information to clients on services.
- ❑ The need for the establishment of a multidisciplinary assessment team.
- ❑ The need to strengthen the 'voice' of persons with a physical or sensory disability and that need for appeals procedures.

- ❑ The need for the Health Board to be more pro-active in managing inter-agency relationships.
- ❑ The need for the Health Board to act as a catalyst, in terms of advocacy on disability-related issues, with other public bodies in the region.
- ❑ The provision of physical access to Health Board's premises
- ❑ The need for disability awareness training to ensure understanding by staff of disability issues.

## **2. *Position of 'Towards an Independent Future':***

The Report Group pointed out that accurate information on the numbers and service needs of persons with disabilities is an essential requirement for the efficient planning and provision of services. Consequently, the Report recommended the establishment by the Department of Health, the Health Boards and voluntary bodies of a database on the: health service needs of persons with physical and sensory disabilities. The database should relate to a five-year period regarding individuals who currently receive, require or will receive a service within that timeframe. **(DOH, 1996 : 12)**

The Report examined the current post-natal, pre-school and school medical services that are an integral part of anticipatory care for the person with physical and sensory disability. The Report felt that it was desirable that all babies should be assessed by a Paediatrician prior to discharge from hospital. It was felt that the public health nurse who visits all newborn babies and mothers within forty-eight hours of notification of the birth provides a vital link between the pre-school child and the health services by referring the child for expert opinion, if necessary. The role of the pre-school and school health services is to provide a comprehensive developmental examination and to detect at the earliest stage any defect or disorder which would interfere with normal developmental progress, especially vision, hearing, speech, posture and physical defects together with emotional difficulties and refer children to appropriate services. The *National Health Strategy* identified the need for a fundamental review of the child health services. **(DOH, 1996: 13)**

The Report pointed out that the linkages between those services involved in the identification, assessment and treatment of disability are loosely structured. Concern was also expressed at the effectiveness of communication structures between different services. To facilitate access and improve coordination of services the establishment of regional child health assessment teams in each health board was recommended. **(DOH, 1996: 14)**

## **3. *Mid-Western Health Board's Position:***

### **(a) Regional Database:-**

The development of the National Physical and Sensory Disability Database is continuing apace, as outlined in chapter 3 above. The National Database Committee has decided that the focus of the database will be on creating a database that would facilitate service planning, managing and monitoring. (HRB, 2000: 2) The development of the database in the years ahead will enable assessment of need and identification of gaps in service provision which will inform planning and development of future services. More so than with the existing intellectual disability database, the physical and sensory database will be utilised to evaluate the quality of service provision, as well as the content of provision. The focus of data collection will be on the quality of data. The data-collection structure to be organised for the database in facilitating continuous updating and evaluation should establish, over time, a dynamic rather than a static character to the database. Following successful evaluation of the pilot implementation of the database in early 2001 implementation of the database in the remaining health boards will occur. The Director of Disabilities has been designated as Regional Database Coordinator, with overall responsibility for the Regional Database. A Database Administrator has also been appointed, to whom day-to-day operations of the Database are being delegated, whose role includes the following functions :

- ❑ Facilitating the collection, review and update of information for the database
- ❑ Facilitating the inputting of data to the Database
- ❑ Working with the Regional Database Coordinator and the HRB to ensure the validity of the regional dataset

The Database Coordinator and Administrator are currently working closely with the National Database Committee in preparation for implementation of the Database in the Mid-West Region. The Health Board has established a Physical and Sensory Disability Database Committee whose functions include:

- ❑ Reviewing the operation of the Regional Database and ensuring compliance with the Protocol for the National Physical and Sensory Disability Database
- ❑ Agreeing arrangements for providing access to the Regional Database
- ❑ Advising the Regional Database Coordinator on operational issues and problems that may arise.

### **(b) Information Provision:-**

A 'Directory of Services for Persons with Disabilities' has been published by the Health Board as part of its commitment to provide more information on service availability to persons with a disability and their families. The Directory in Braille and audio versions will be regularly updated.

**(c) Child Health Services:-**

The Health Board's screening programmes of the newborn and of early-childhood are aimed at ensuring early detection and prevention of conditions that may give rise to physical and sensory disability, if undetected. In accordance with the Health Board's *Strategy Statement on Child Health*, enhanced integration of children's services across the region will occur. (MWHB, 1999 :8 )

**(d) Community Consultant Paediatricians:-**

A key component of anticipatory support services to this client group is the appointment of Community Consultant Paediatricians, working in both a hospital and community setting, one of whom will have a special interest in children with a disability. The need for Consultant Paediatricians, with a special interest in disability, is important from the point of view of diagnosis, integration of services and provision of the service in the most appropriate setting.

**(e) Regional Children's Diagnostic and Assessment Service:-**

The development of a Regional Children's Diagnostic and Assessment Service for young people with complex developmental, physical/sensory, intellectual and psycho-social problems is proposed. The multidisciplinary assessment of a child with a disability brings many benefits to the child, parents and professionals. Firstly, when the disability is established, the service enables early intervention and reduction of disability in some instances. From the point of view of parents, it offers a 'one stop shop' professional service, with optimum interprofessional treatment for their child. The development of this service will enable the mainstreaming of diagnostic and assessment services for children with physical/sensory and intellectual disabilities. The above service should be led by a Consultant Paediatrician, with a special interest in disability. (MWHB, 1999 :9 )

**(f) Paediatric Audiology Service:-**

As part of the development of the Health Board's diagnostic and assessment services for children with a disability the development of a dedicated Paediatric Audiology service for the purpose of the early identification of children with hearing impairment is required. The sooner children are diagnosed with deafness the better their outlook for acquisition of speech. At present children at about seven to nine months are screened for deafness in Developmental Clinics by a method known as the Distraction Test. However, this screening method at Developmental Clinics in England has been found to miss a considerable percentage of children with deafness. Children screened at these clinics in the Mid-West Region who do not have a satisfactory result are currently assessed by the Audiology Service which until recently was organised through the National Rehabilitation Board (NRB). (This service is currently managed by the ERHA on an interim basis pending the transfer of all audiology services to health boards in 2001-2002) Very young children may require further assessment known as objective audiometry that at present usually requires referral to a Dublin hospital. An EU

directive will shortly be implemented which will require the screening testing for deafness of all newborn children. This development would add further to the requirement for clinical facilities, equipment and audiology professionals. Deficits have already been identified in these areas in the context of the current transfer of audiology services.

A Working Group on Audiology Services in the Mid-West is being convened with provisional Terms of Reference as outlined below:

1. To examine the current arrangements for the provision of audiology services in the Mid-West
2. To quantify the level of need for audiology services within the region taking into account potential developments in audiology (incl. neonatal screening)
3. To explore models of best practice in providing audiology services
4. To seek consumer and professional views
5. To make recommendations for the development of a locally based audiology service to meet the needs of the population that takes into account training requirements, clinical pathways, patient accessibility, support and management infrastructure.

#### **(g) Counselling Nurses for Persons with Disabilities:-**

A central role in the acquisition of relevant information in relation to persons with a physical or sensory disability who require or who, in the future, will require service provision is played by the Counselling Nurses for Persons with Disabilities. The objective of the counseling Nurse Service is to enhance the quality of life of children and adults with a disability and their families. A Review of the role and functions of the Counselling Nurses will be undertaken as part of the initial implementation phase of the Strategy Statements on Physical and Sensory Disability and Intellectual Disability. The Counselling Midwife, based at the Regional Maternity Hospital, offers immediate, continuous psychological and practical support to parents of babies, born with a disability and their families, while in the hospital and following discharge.

#### **(h) Anticipatory Organisational Structures:-**

A direct response, on the part of the Health Board, to recognition of the need for adequate anticipatory support structures, both within the Health Board's services and across agency-provided services, has been the recent appointment of Area Managers for Disabilities and the development of Area Disability Care Groups in each Catchment Area. Area Physical and Sensory Disability Advisory Committees will also be established within each Catchment Area. The consolidation of such structures and their enhanced liaison with the voluntary sector will be augmented to enhance coordination of services, including services to the families of this client group.

#### **(i) Regional Advocacy Structures:-**

A formal method of exchanging information, enhancing co-operation and defining roles and responsibilities between the Health Board and other statutory bodies in the

region is required as many persons with physical and sensory disability receive services from bodies not directly linked to the Board during their lifetimes. These bodies include the Department of Education and Science, the Department of the Environment and Local Government, the Department of Enterprise, Trade and Employment, the Department of Social, Community and Family Affairs and the Department of Justice, Equality and Law Reform, and their agencies. As the recognition of the civil right of persons with disabilities to inclusion in all mainstream activities of our society develops the need for these formal linkages will become ever more acute. Disability advocacy structures will be established, involving the Director of Disabilities, the Area Managers, representatives of the voluntary sector and regional representatives from other government Departments and local bodies, which will address advocacy-related issues.

#### **(j) Appeals Procedures:-**

The Health Board acknowledges the right of persons with a physical and sensory disability to redress on its services. In any organisation it is critical that an independent and impartial voice exists to adjudicate on appeals, for quite often these are requested by the most disadvantaged in society. The Health Board's Appeals Office was established to enable realisation of this right. The hallmarks of the Appeals Office are accessibility, promptness, privacy, equity, appropriateness and loyalty. In February 2000 the remit of the Appeal's Office was extended to cover appeals in relation to (among others) Blind Welfare Allowance, Domiciliary Care Allowance, Motorised Transport Grant, Disabled Persons Rehabilitation Allowance and Mobility Allowance. Within the specialised services for this client group, schemes currently being developed, such as the Home Support Services Scheme, have an appeals/complaints procedure incorporated as an integral element of the scheme.

#### **(k) Disability Awareness Training:-**

Misinformed perceptions of persons with a disability and their needs can be altered by provision of disability awareness training. A planned phased programme of physical/sensory disability awareness training that addresses basic customer service issues and promotes enhanced skills in dealing with this client group is being implemented for all relevant staff.

#### **(l) Accessibility of Facilities:-**

The issue of physical access for persons with a disability to Health Board buildings and facilities is being progressively addressed by the Health Board. The Health Board has stipulated in its contract with all new practitioners entering the General Practitioners Scheme that their surgeries must be physically accessible to persons with a disability and Health Centres in the region are progressively being adapted for

access. The Disabilities Directorate recently commissioned a major survey of the accessibility of the Mid-Western Regional Hospital and the recommendations of the survey will be fully implemented. The Technical Services Department is engaged in an ongoing programme of surveying the built environment of the Health Board and progressively adapting it for physical access. Much of this adaptation of Health Board premises will be accomplished over the five-year timeframe of the Strategy Statement.

#### **(m) Research Function:-**

Research is an important element, not only in assisting the prevention of disability, but also in ensuring the development of quality-based services that limit the effects of disability. The Health Board will be proactive in disseminating international and national research-based information on disability and, where appropriate encouraging dedicated local research into physical and sensory disability. Research-based analysis of regional data from the Regional Physical and Sensory Disability Database, when established, will provide valuable targeted data for planning purposes. The disabilities research function will be developed in collaboration with the development of the National Institute for Health Sciences and Management.

#### **4. Change Issues:**

- ◆ Implementation of Regional Physical and Sensory Disability Database.
- ◆ Provision of continuously updated accessible information.
- ◆ Enhanced coordination of Child Health Services.
- ◆ Appointment of Consultant Community Paediatricians.
- ◆ Development of Regional Children's Diagnostic and Assessment Service.
- ◆ Development of Paediatric Audiology Service.
- ◆ Review of role of Counselling Nurses.
- ◆ Enhanced consolidation of disability management and coordination structures.
- ◆ Creation of regional inter-departmental and inter-agency advocacy structures.
- ◆ Provision of programme of physical and sensory disability awareness training.

- ◆ Incorporation of right of appeal by consumers of services in all future service development.
- ◆ Progressive implementation of policy of adapting the Board's buildings and premises for physical access.
- ◆ Development of research function.

### **4.3 Home and Community Support**

The fundamental objective of health and personal social services for persons with a physical or sensory disability is to enhance their health and quality of life through enabling them live as independently as possible in the community. Provision of effective home and community services that can be adapted to individual needs is central to this objective.

#### **1. Stakeholder View:**

Stakeholders highlighted the following issues in the course of the consultation process:

- The absence of a comprehensive multidisciplinary early intervention service.
- The importance of developing pre-school services for children with physical or sensory disabilities.
- Geographic inequalities in service provision.
- The valuable role of Personal Assistants in enabling independent living.
- The need for significant expansion of day place provision.
- Inadequate provision and access to transport services.
- The important contribution that therapy services play for persons with physical or sensory disabilities.



- ❑ The central role of adequate provision of aids and appliances, together with the need to provide for the seating requirements of wheelchair users.
- ❑ The need to develop rehabilitation services in the region.

## **2. *Position of ‘Towards an Independent Future’:***

‘Towards an Independent Future’ emphasises that the objectives of home and community support to persons with a physical and sensory disability are twofold:

- To provide the support needed to enable people with disabilities to live independently in the community, either with their family or on their own, and
- To provide respite and support to carers.

The Report categorised the home and community services as follows: community support services, personal assistance services, community therapy services and technical aids & appliances. The related area of Rehabilitation can also be included.

**Community Support Services:** These include general practitioner service, community nursing service, home help service, day service, training and sheltered work. The Report recommended that, where possible, provision be made for ensuring that general practitioner's surgeries be made accessible to persons with disabilities. The Report pointed out that the number of persons with a disability living at home who need full-time nursing care is increasing, thus increasing the demand on the already stretched nursing service. A significant increase in the number of public health nurses providing a service to persons with a disability was recommended. Particular emphasis was placed on extension of the twilight nursing service for those with chronic nursing care needs. Criticisms of the existing home help scheme in meeting the needs of people with disabilities include the low level of service, uneven geographic availability and lack of flexibility.

Day services play an essential role in the spectrum of community services by offering stimulation, activation and therapy for the person with a disability as well as respite for the carer. The Report identified three broad categories of day service:

- specialised clinic facilities which offer a combination of medical and vocational rehabilitation facilities
- centres which provide day activation such as, recreational and sports pursuits to adults with disabilities
- community- based resource centres which deliver client-focused programmes in independent living, training, education, social and leisure and part-time employment.

The Report identified four core problems with current day services:

- a shortage of dedicated day places for people with disabilities
- services are not operating at full capacity

- uneven geographic distribution
- transport problems

The Report recommended that an additional 1,600 day places be provided nationally. Additional funding was advised to enable existing day care centres open in the evenings and at weekends. Health boards were urged to examine the possibility of adapting other community premises such as, community centres, youth clubs and sports halls for use as day centres for persons with physical and sensory disability. The need for each health board to rationalise transport services for people with disabilities, in consultation with other groups such as, intellectual disability services was emphasised. The Report recommended that each health board should examine pre-school service provision for children with disabilities. **(DOH, 1996: 15)**

**Personal Assistance Services:** The Report expressed the belief that personal assistance services enable people with disabilities to integrate more into their local community and significantly improve their quality of life, to move out of residential care, etc. Three different levels of personal assistance were identified:

- a comprehensive service whereby a person with a severe disability might employ (or be provided with) a personal assistant on an ongoing basis;
- assistance services such as, care attendants whereby assistance is provided for specific tasks or at specific times, primarily to offer respite to the carer, e.g. washing, dressing, etc.;
- other forms of assistance that provide respite to the carer and enable people with disabilities to engage in social and recreational activities such as, going to the cinema, participating in sports etc.

As an interim measure, the Report felt there should be an integrated source of funding for the three categories of assistance that should be administered by the health boards. (Medium to long-term funding would be through a personal assistance allowance paid by the Department of Social, Community and Family Affairs). The Report recommended the establishment of assessment procedures for personal assistance services which would focus on (a) a functional assessment to determine dependency and levels of dependency and (b) an interview to determine whether the individual has the capacity to manage personal assistance services. **(DOH, 1996: 16)**

**Community Therapy Services:** The Report stated that the main community therapy services i.e. occupational therapy, physiotherapy and speech & language remain significantly underdeveloped and inadequate for people with disabilities. The availability of community therapy services varies between health boards and community care areas. Centralisation of services can mean that some rural clients are unable to take up services. The Report considered that, generally, therapists should be appointed to provide a generic service to all sections of the community rather than be appointed with a specific focus on people with disabilities. There was a considerable need for health boards to appoint 15 speech & language therapists per year over the next decade, an additional 80 occupational therapists over the next five years and 85 physiotherapists.

**Family Support Services**, including social workers, offer support to patients and their families following discharge from hospital, including counselling to the client and information and advocacy to families. An increase of 40 over the next five years in the number of social workers providing support services to people with disabilities was recommended. The Report recommended that health boards support the development of the related service of help lines and peer counselling whereby people with a disability can provide individual assistance and support to others in coping with disability and helping them to bridge the gap between inactivity and participation. Psychology services for people with disabilities are offered largely by specialised centres such as, medical rehabilitation centres. When discharged home there is an absence of such services to enable them continue their personal adjustment and social integration. The Report recommended that health boards increase psychologist posts by 10 over the next three years. **(DOH, 1996: 17)**

**Aids & Appliances:** By increasing their independence and expanding the range of activities available suitable technical aids and appliances can make a significant contribution to the quality of life of people with disabilities. The Report points out that budgetary constraints and under-resourced occupational therapy services restrict health board's ability to supply, repair and replace necessary equipment quickly. It was felt that priority should be given to the supply of basic medical and surgical appliances and the establishment of an effective repair service (which should include communication devices for people with combined physical and communication disabilities). It was considered that Health Boards should also earmark some funding from their overall aids and appliances budget for provision of expensive technical or computer aids which can enhance people's quality of living. The Report recommended that the total aids and appliances budget of health boards be increased by £5m over five years. **(DOH, 1996 : 18)**

**Rehabilitation:** With respect to the related area of Rehabilitation, the Report acknowledged the need to provide expanded rehabilitation services for patients no longer in need of the services of tertiary referral hospitals. It was recommended that each health board make arrangements for a specialised rehabilitation service associated with an acute general hospital to meet the rehabilitation needs of most forms of disability (to include traumatic disabilities and visual hearing loss). Appropriate liaison with the National Rehabilitation Centre should also be part of any such arrangements). It was also felt that limb-fitting services required a full rehabilitation services to ensure that all patients received the support and back up to allow them return to their homes and existing lifestyles, as far as possible. **(DOH, 1996: 19)**

### **3. *Mid- Western Health Board's Position:***

#### **(a) Community Support and Personal Assistance Services**

**(i) Primary Care Services:-**

The Health Board's *Strategy for Primary Health Care in the Mid-West Region* will develop enhanced models of care, which will result in delivery of enhanced primary care services to persons with physical or sensory disabilities. Contracts between the Health Board and all new practitioners entering the General Medical Services Scheme stipulate that their surgeries must be accessible to persons with disabilities. The need for disability awareness training in the education process of general practitioners is also of importance.

**(ii) Community Nursing Service:-**

An increase in the staffing levels of the public health nursing service, which together with the Counselling Nurse Service, provides ongoing support to persons with a disability and their families, is required to cope with the increased demand placed on this service. In addition, the expansion of the twilight nursing service, particularly with respect to persons with a significant physical disability, would provide valuable out-of-hours nursing care to this client group and support carers. **(MWHB, 1999 : 10)**

**(iii) Day Services:-**

The Health Board will pursue a policy of developing the full spectrum of the three forms of day centre advocated by '*Towards and independent Future*'. Three models of day centre will be developed:

- centres with specialised facilities
- centres that provide day activation
- community-based multi-purpose resource centres

The adaptation of existing community centres throughout the region for use as day centres will be actively pursued. Increased funding to voluntary agencies in the region for collaborative provision of day services will be required to enable development of a spectrum of day activation, stimulation and therapy services for this client group. Funding will be spread across the region, as far as possible, to redress geographic inequalities in this form of service provision.

**(iv) Pre-School Services:-**

The Health Board advocates the integration of children with a physical or sensory disability into the mainstream pre-school services, where possible. The needs of the individual child with a disability will determine the precise form of service provision, whether mainstream or special pre-school. With new planning regulations, all purpose-built pre-schools will be required to be wheelchair accessible. With the funding available under the National Development Plan, pre-school providers can access funding to adapt their premises for suitability to children with a disability. The Health Board will actively encourage such adaption of premises. The Health Board's

Pre-School Unit will collaborate and work more closely with the disability services in improving service provision to children with a disability. The Health Board will continue to provide funding to specific voluntary agencies who provide pre-school services to discrete groups within the general population of persons with a physical or sensory disability such as, children with a hearing impairment.

**(v) Home Support Services:-**

The Health Board's Home Support Services to persons with a physical or sensory disability include three elements: (1) Personal Assistance Services; (2) Home Care Attendants Service; (3) Socialisation/Transport Services.

Personal Assistants (PAs) facilitate an individual with a disability in all aspect of their life. PAs provide the bridge between the individual's autonomy and citizenship by allowing the individual " to make a full contribution, as a citizen and a worker, rather than remaining passive recipients of state welfare and charity" **(NC, 1999:1)** The Board commissioned an evaluation report, '*Strengthening the Autonomy of Citizens with Disabilities*' on the operation of the 'Pilot Personal Assistants' scheme it had initiated, in partnership with voluntary agencies such as, the Centres for Independent Living and the Irish Wheelchair Association. The relevant implications of the findings and recommendations of the report will be implemented in the Mid-West Region to enable the development of a coherent and responsive personal assistance scheme to our consumers. The *Report of the Working Party on Services to the Young Chronic Sick in the Mid-West: 'Promoting Independent Living'*, recommended the making available of personal assistants to this client group as structures for the recruitment and employment of PAs were instituted in the region. **(MWHB, 1999:11)** Continued expansion to a full personal assistance service in the region that focuses on maximising health and social gain will occur and planning and provision of this service will be developed in partnership with relevant voluntary provider agencies.

Home Care Attendants perform a role for persons with physical or sensory disabilities that is an extension of the traditional role of the Home Help, involving the provision of personal care to the individual. The valuable role that Home Helps/Home Care Attendants can play in catering for the needs of persons with a significant physical disability and their carers was highlighted in the Health Board's report on services to this client group, '*Promoting Independent Living*'. **(MWHB, 1999: 12)** Provision of this service is effected on a partnership basis with voluntary agencies in the region and additional funding will be provided to enable further expansion of this service.

The requirement to meet the socialisation and transport needs of person with physical or sensory disabilities in the region has been recognised by the Health Board and funding has been provided to voluntary agencies for this purpose. Additional funding will be provided to meet the further needs of this service. The Health Board acknowledges the need for a rationalisation of transport services provided by the Health Board and the voluntary sector in the region and will establish a joint working group consisting of representatives of the Regional Coordinating Committee on Physical and Sensory Disabilities and the Intellectual Disability Services Consultative Committee to examine and report on the range of issues involved. The Health Board

welcomes the initiatives taken by the Department of Public Enterprise and the Department of the Environment and Local Government to ensure that public transport services such as, rail, bus and taxi services are made accessible to persons with a disability. Through its public advocacy role, the Health Board will strive to ensure the maximum accessibility to public transport services for this client group.

The Regional Coordinating Committee on Physical and Sensory Disabilities established a sub-committee to examine the Home Support Services in the region. The sub-committee issued a series of recommendations, including those relating to:

- ❑ Assessment of the person applying for home support services by the Health Board's Occupational Therapists
- ❑ Criteria for prioritisation of applicants
- ❑ Appeals/complaints procedures
- ❑ Monitoring/evaluation
- ❑ Recruitment, training and rates of pay of support workers.

The recommendations of the report will be progressively implemented and, as an initial response, a significant investment will be made in providing accredited training to home support service providers.

**(vi) Rehabilitative Training Service:-**

The *Report of the Commission on the Status of People with Disabilities* and the subsequent dissolution of the National Rehabilitation Board have directed the provision of vocational training and employment to mainstream service providers. Vocational training and employment services for people with a disability will be the remit of the Department of Enterprise, Trade and Employment through FÁS. Within this new framework the emphasis will be on progression pathways to employment for persons with disabilities. Consistent with the national policy on mainstreaming, the Health Board will formally disengage from the provision of training for open employment.

A specialised training service will remain for persons with physical or sensory disabilities who do not have the skills or ability to access mainstream training or employment. This training will be rehabilitative/life skills focused which will give a foundation for further employment skills training and other options, including sheltered and supported employment. In collaboration with other agencies, the Health Board will develop standards for the Rehabilitative Training service, together with the development of an accreditation process. The Health Board will produce a Policy Document in 2001 on the provision of Rehabilitative Training in the Mid-West Region.

**(vii) Communication Services for Hearing Impaired:-**

When dealing with hearing impaired persons professional health care staff may require access to sign language interpreters/lip speakers. The Health Board will employ interpreters, on a contract basis to meet this need. Funding will also be contributed for the provision of sign language classes in the region.

## **(b) Community Therapy Services**

### **(i) General Service Provision:-**

The community therapy services, particularly occupational therapy, physiotherapy and speech and language therapy, play a key role in service provision and enhancement of the health and social gain for this client group. The Health Board's Department of Public Health completed a review of these three therapies in the region and issued a series of specific recommendations on development of the services that are being progressively implemented, as funding is made available. **(MWHB, 1999: 13)** *The Report of the Working Party on Services to the Young Chronic Sick in the Mid-West* identified the important contribution that these community services make in addressing the needs of this client group. The Report emphasised that therapeutic services also require to be in place in the acute hospital settings to enable an adequate follow-up service to clients discharged home from hospitals. The Report recommended the establishment of occupational therapy and speech and language therapy departments at the Mid-Western Regional Hospital, Ennis General and Nenagh General Hospitals and the appointment of additional staff to the physiotherapy department of acute hospitals in the region. **(MWHB, 1999: 14)** The Health Board will actively strive to realise the implementation of this recommendation.

### **(i) Early Intervention and Therapy Service:-**

As emphasised in the *Strategy Statement on Intellectual Disability*, the Health Board recognises the critical role that early intervention services can play in limiting the effects of congenital and early-acquired disabilities. A comprehensive multidisciplinary team will be developed in each Catchment Area to deliver early intervention and therapy services to over 250 children. The proposed service will include a psychological service for children with physical/multiple disabilities, as there is currently no provision for this client group within the region. Each team will consist of: a Coordinator; a Physiotherapist; an Occupational Therapist; 2 Speech and Language Therapists; a Social Worker; a Psychologist; 2 Therapy and Nursing Assistants; and Administrative Support. This service will be developed from the pilot Early Intervention Service for children with an intellectual disability, established by the Brothers of Charity Services in West Limerick. The early intervention services for children with an intellectual disability and children with a physical or sensory disability will be integrated and, following evaluation, the model of service will be extended to the three County Catchment Areas of the region.

### **(iii) Family Support Services:-**

The range of family support services such as, psychology, social work and community welfare services, provided to this client group are currently insufficiently developed. The

Board will facilitate development of a counselling service to persons with a physical or sensory disability. A Social Work service will be provided to children in this client group as an integral part of the multidisciplinary Early Intervention and Therapy Teams, being established in each Catchment Area. '*Towards an Independent Future*', pointed out that "a number of studies have revealed a close relationship between disability and poverty. There are many reasons for this, including the fact that many people with a disability are unemployed, working at the lowest level of remuneration or frequently out of work, due to illness. In addition, it has been shown that most people with disabilities have to meet additional costs, due to their disability." (DOH, 1996: 20) In recognition of this relationship between disability and poverty, the Health Board will pilot a Community Welfare Service within the Disability Directorate to disability proof the Community Welfare Service and to work with persons with physical or sensory disabilities. The functions of the Community Welfare Officer will include an information provision role and provision of client-focussed work in accessing entitlements.

**(iv) General Strategic Intent:-**

The Health Board intends to significantly develop the level of these services in the region over the timescale of implementation of this Strategy Statement, both in terms of Health Board provision and provision by the voluntary sector, involving partnership with appropriate voluntary agencies in the region.

### **(c) Aids and Appliances**

**(i) General Provision:-**

Once-off funding for provision of aids and appliances (additional to core funding) has been provided over the last two years - £500,000 in 1999 and £700,000 in 2000 -, where eligibility was extended to all persons with a disability, irrespective of income. This has resulted in increased expectations among our consumers. For as long as supplementary funding is provided the Health Board will continue to strive to eliminate the board's annual waiting list for aids and appliances.

**(ii) Integrated Regional System:-**

In recognition of the paramount role played by the provision of aids and appliances in enabling persons with a physical and sensory disability to live their lives as independently as possible, the Health Board has established a sub-committee of the Regional Coordinating Committee to pilot a project focusing on the provision, maintenance, cleaning and tracking of aids and appliances in the Mid-West Region. The purpose of the project is to establish a system to ensure that the use of aids and



appliances is maximised and their 'recycling' (which encompasses the three aspects: maintenance, cleaning and tracking) occurs quickly and efficiently back to the community and persons with disabilities. Following evaluation, the pilot project will be implemented on a regional basis, which will enable development of an integrated, centralised system for providing and recycling aids and appliances. The development of standardised regional policies and protocols for the aids and appliances service will be an additional aspect of the project. The *Report of the Working Party on Services to the Young Chronic Sick in the Mid-West* pointed out that this client group are costly in terms of equipment provision (wheelchairs, communication aids, beds etc) due to specialised equipment requirements and a low mortality rate. (MWHB, 1999: 15) The development of such an integrated system is in accordance with the recommendations of the Report and will bring obvious benefits to this client group.

**(iii) Information Technology for Visually Impaired:-**

Within the overall provision of aids and appliances, specialist requirements relating to discrete groups such as, the visually impaired, the hearing impaired and persons with a speech and language disorder exist. The Health Board, in partnership with the National Council for the Blind, will explore the appointment of a regional specialist who will examine the theoretical and practical issues surrounding the use of information technology for persons with a visual impairment. The functions of the specialist would include (among others):

- ❑ Developing an awareness of the needs of visually impaired people, the role that technology can play in meeting their needs and applying this knowledge in the training process.
- ❑ Assisting and instructing visually impaired people in the use of personal computer systems.

**(iv) Aids and Appliances for Hearing Impaired:-**

The need for a locally accessible technical aids service for persons with a hearing impairment is recognised and the Health Board will explore with the National Association for the Deaf (NAD) the feasibility of developing a service in the Mid-West Region similar to the 'Deaftech' service currently operated by NAD.

**(v) Aids and Appliances for Persons with a Speech and Language Disorder:-**

Specialised technical aids and appliances are required to assist in the support of persons with a speech and language disorder in the region. Resources will be made available for provision of this equipment, on the basis of assessed need, as funding becomes available.

**(vi) Regional Seating Clinic:-**

A significant number of persons with a physical disability have difficulty in achieving and maintaining a seated position that is vital for effective functioning in everyday life. A Regional Seating Clinic would provide an efficient resource for the assessment and treatment of this client group. The Health Board will establish a seating clinic in the region that will provide a focus for seating and a centre of excellence. The Regional Seating Clinic will provide the following benefits to users:

- ❑ maximisation of functional abilities
- ❑ good posture control and anatomical positioning
- ❑ physiological benefits
- ❑ psychological benefits **(MWHB, 1999: 16)**

#### **(d) Rehabilitation Services**

##### **(i) General Service Provision:-**

The National Rehabilitation Hospital (NRH), Dun Laoghaire, is the national centre for specialist rehabilitation. There is a need to enhance rehabilitation services in the Mid-West Region for persons discharged from the NRH and acute hospitals. The Consultant in Rehabilitation Medicine, recommended in the *Report on Services to the Young Chronic Sick in the Mid-West*, will have an expanded remit to manage the rehabilitation of all persons with a physical or sensory disability in the region. **(MWHB, 1999: 17)** Section 5.1 of this Strategy Statement outlines the proposed development of rehabilitation services to Adults with an Acquired Brain Injury from this region, including the development of a Transitional Living Unit. The proposed development in acute hospitals in the region of occupational therapy and speech and language therapy departments and enhancement of physiotherapy staffing levels (as already outlined) will augment the rehabilitation service provided to this client group. The progressive implementation of the recommendations of the '*Review of Physiotherapy, Occupational Therapy and Speech and Language Therapy Services in the Mid-Western Health Board*' will strengthen the community therapy services provided to this group.

##### **(ii) Prosthetic and Orthotic Services:-**

Prosthetic and Orthotic Services are currently provided by Independent Disabilities Services, on a visiting basis, to the Regional Orthopaedic Hospital, Croom. In addition, some patients avail of care at other centres, including the National Rehabilitation Centre in Dublin. The Health Board is currently examining a proposal to enhance the existing service at Croom which will greatly improve the quality of care offered to this client group and which would negate their need to seek services outside the Mid-West Region. In addition, the need for comprehensive Physiotherapeutic Rehabilitation is also being explored. This will enable patients who have undergone amputations to

achieve maximum independence and an improved quality of life by providing access to an improved model of in-patient and outpatient care. The Health Board will also work closely with voluntary agencies in the community who provide orthotic services to children to ensure timely provision of these services.

#### **4. *Change Issues:***

##### **(a) Community Support and Personal Assistance Services:-**

- ◆ Enhanced development of primary care services to this client group.
- ◆ Enhancement of twilight nursing service to persons with a significant physical disability.
- ◆ Development of full spectrum of day services.
- ◆ Further development of pre-school services to facilitate mainstreaming of services for children with a physical or sensory disability.
- ◆ Continued expansion to a full personal assistance service, which maximises health and social gain, on a partnership basis.
- ◆ Further expansion of the Home Care Attendant Service, on a partnership basis with voluntary agencies in the region.
- ◆ Provision of additional funding for socialisation/transport services.
- ◆ Establishment of joint Working Party to examine and report on the rationalisation of transport provided by the Health Board and voluntary agencies to persons with a physical or sensory disability and persons with an intellectual disability in the region.
- ◆ Development of policy document on Rehabilitative Training Service.
- ◆ Development of communication services for hearing impaired.

##### **(b) Community Therapy Services:-**

- ◆ Progressive implementation of the recommendations of the review of therapy services in the Mid-West Region.
- ◆ Development of occupational therapy and speech and language therapy departments in specific acute hospitals in the region.
- ◆ Development of comprehensive multidisciplinary Early Intervention and Therapy Teams in each County Catchment Area.

- ◆ Piloting of employment of Community Welfare Officer within the Disability Directorate.

**(c ) Aids and Appliances:-**

- ◆ Development of a regional integrated, centralised system for provision and recycling of aids and appliances.
- ◆ Encouragement of information technology provision for visually impaired.
- ◆ Exploration of feasibility of developing locally accessible technical aids service for persons with a hearing impairment.
- ◆ Development of a Regional Seating Clinic.

**(d) Rehabilitation Services:-**

- ◆ Appointment of Consultant in Rehabilitation Medicine.
- ◆ Development of Transitional Living Unit for Adults with an Acquired Brain Injury.
- ◆ Enhancement of Prosthetic and Orthotic Services at Regional Orthopaedic Hospital and orthotic service provision for children by voluntary sector in region.
- ◆ Development of comprehensive Physiotherapeutic Rehabilitation service.

## 4.4. Respite/Residential Support

There is a need for adequate provision of respite support, whether residential, in-home, weekday, weekend or holiday which offer valuable respite to the individual with a disability and their carers. Despite the provision of enhanced community support services and structures there will continue to be a need for residential support facilities for persons with a physical or sensory disability, either for temporary periods or on a long-term basis.

### 1. *Stakeholder View:*

The stakeholder consultation process identified the following issues:

- ❑ Significant expansion of respite support, together with a requirement for innovative provision.
- ❑ The urgent requirement to address the respite and residential needs of persons with a significant physical disability the region, in order to support carers.
- ❑ The need for innovative provision of independent living accommodation.

### 2. *'Position of Towards an Independent Future':*

**Respite Support:** The Report identified three categories of respite support provision: (1) 'crisis' respite (2) 'planned' respite - short breaks or holidays (3) 'planned repeated' respite multiple breaks from routine caring arrangements during the year. The provision of an additional 200 dedicated respite places that would be provided either as specialist respite facilities or as dedicated respite places in appropriate long-term residential facilities for people with disabilities was recommended. Appropriate respite facilities for children should also be developed.

**Residential Support:** The Report envisaged a range of residential support services for people with disabilities that include:

- (1) respite support - short temporary periods of residential support
- (2) long-term residential support which could be provided in:
  - a) independent living facilities, with appropriate supports from community-based services;

- b) independent or semi-independent living facilities with the required support services for people who, although they need significant assistance with daily living, do not require much nursing support;
- c) facilities that provide high levels of paramedical and nursing support for people with very significant disabilities.

The Report also considered that many residential buildings are unsuited to the purpose they are currently serving. A planned programme of refurbishment of residential homes over the next five years should be undertaken by health boards, in consultation with the co-ordinating committee and the agencies responsible for the homes.

Independent living arrangements offer people with disabilities the opportunity to live in a domestic dwelling with the support of the necessary health and social services. Health boards and voluntary bodies providing services to people with disabilities were advised to liaise closely with social housing organisations and local authorities to ensure the provision of a sufficient number of accessible houses. The Report recommended that health boards, in consultation with the co-ordinating committee arrange for the provision of 100 additional residential places in dedicated facilities for people with disabilities. The Report highlighted a noticeable shortfall of appropriate places for persons with long-term disabilities needing constant nursing support. Consideration of the issue suggested that there was a need for at least one young chronic sick unit per health board area. A recommendation that health boards arrange for the provision of an additional 200 places for persons with long-term disabilities requiring constant nursing care was made. **(DOH, 1996: 21)**

### **3.: *Mid-Western Health Board's Position:***

#### **(a) General Respite Support:-**

In respect of 'crisis respite support', the Health Board will negotiate with voluntary organisations for the provision of residential respite accommodation in each catchment area, which will incorporate appropriate support from outreach therapeutic teams. 'Planned respite support' and 'multiple-planned respite support' provision by voluntary agencies will also be supported. The Health Board will also facilitate the principle of choice among this client group with respect to respite support by providing financial assistance towards the form of respite of their choice.

#### **(b) Respite Support for Persons with a Significant Physical Disability:-**

In respect of respite support for persons with a significant physical disability, the Board will develop a community-based residential respite facility in conjunction with

Rehab Care in the Limerick area. The facility will provide a holiday break for the client in a community setting, an opportunity to avail of community-based facilities, an opportunity for socialisation and an opportunity to live away from home in an environment that fosters independent living. Further provision of respite support for this client group will be effected through the development of a six-bed facility in West Limerick and one each in the Clare and Tipperary Catchment Areas.

**(c) Independent Living Units:-**

The gradual provision of independent living units for persons with a physical or sensory disability in each County Catchment Area will be facilitated through the advocacy role of the Board with local authorities and social housing authorities in the region. The models of independent living units developed by the Cheshire Foundation and the IWA with assistance of funding from the Department of the Environment and Local Government's Capital Assistance Scheme will be examined and reported on by a subcommittee of the Co-ordinating Committee with respect to their adaption and translation to the Mid-West Region. Of particular value are accessible independent living units accompanied by the necessary supports and training for persons with a disability in all aspects of independent living that facilitate the move to fully independent living.

**(d) Residential Accommodation for Persons with a Significant Physical Disability:-**

The Health Board is of the opinion that the optimal arrangement for provision of the residential needs of persons with a significant physical disability is the development of appropriate community residential facilities, with access to community supports, in each County Catchment Area.

**(e) Future Residential Requirements:-**

The implementation of the provisions contained in the Home and Community section and Respite section of this Strategy Statement will steadily reduce the need for provision of residential care for persons with physical or sensory disability. A sub-committee of the Regional Coordinating Committee will be established to examine and report on the need for any further development of residential facilities in the region. The deliberations of this sub-committee will be informed by the research project, recently completed by Rathfredagh Cheshire Home, which identified the residential/respite needs of persons with a physical or sensory disability in the Mid-West Region.

#### **4.      *Change Issues:***

- ◆ Further development of crisis, planned and multiple-planned respite support.
- ◆ Development of community-based residential respite facilities for persons with a significant physical disability in each County Catchment Area.
- ◆ Establishment of a sub-committee of the Regional Coordinating Committee to examine models of independent living units for this client group and issue recommendations for their translation to the Mid-West Region.
- ◆ Development of appropriate community residential facilities for persons with a significant physical disability in each County Catchment Area.
- ◆ Establishment of a sub-committee of the Regional Coordinating Committee to examine future residential requirements in the region.



# Chapter 5: Discrete Issues

## 5.1 Persons with Adult Acquired Brain Injury

Individuals with an acquired brain injury form part of the larger client group, known as the 'Young Chronic Sick'. Acquired brain injury, is an injury that results in damage to the brain as opposed to a developmental or neurological disorder. Those who present most often with this condition are young adults who sustain injuries in a traffic accident or a fall. Many head injuries are mild and, with assistance from the appropriate services, usually fade away over time but others are more severe, causing long-term disability and the necessity of ongoing support. More people with head injuries are surviving due to advances in microsurgery (NWHB, 1999: 1). The severity of the disability is ultimately dictated by the location and severity of the injury to the brain. Complications relating to movement, memory, intellect or sensation and social difficulties brought about by personality changes and regulatory disturbances are a number of the ways in which individuals may be affected.

This client group presents with significant treatment, caring and emotional needs because the conditions are acquired in adolescence or early adult years and occur within established relationships. Significant psychological strain is placed on the family, providing twenty-four hour support. Currently there is no specific dedicated service for persons with an Acquired Brain Injury within the Mid-West Region. Consequently services for these clients are being provided in ad-hoc manner, with some inappropriate placements and funding not being utilised in an effective and efficient manner. It is recognised, however, that there is a need for planned and coordinated service provision.

Clients with an Acquired Brain Injury generally have the following service needs:

- ❑ Acute Hospital Care
- ❑ Acute Rehabilitation
- ❑ Transitional Living Units
- ❑ Independent Community Living

Acute Hospital Care can be provided at the Mid-Western Regional Hospital, with Acute Rehabilitation generally provided at the National Rehabilitation Hospital, Dun Laoghaire. Development of a Transitional Living Unit (TLU) within the Mid-West Region is currently being explored to provide a service for:

1. Those who have completed an acute rehabilitation programme but whose needs are such that they are unable to return to, or remain at, home;
2. Those with cognitive impairment and psychosocial functioning problems, affecting areas such as poor motivation, social skills and interpersonal skills, limited insight into their impairment and the milder syndromes of inappropriate

behaviours. However, these clients would have the potential to improve through participation in therapeutic programmes.

Services could be provided to those who have been discharged from acute hospital inpatient care and, if appropriate, medical rehabilitation or, alternatively, clients could be referred directly from the Community or other continuing care settings

A multi-disciplinary team would provide the following intervention and rehabilitative training programme of intensive input:

- ❑ Cognitive and Behavioural Retraining
- ❑ Communication Skills
- ❑ Community Activities
- ❑ Physiotherapy
- ❑ Occupational Therapy
- ❑ Speech and Language Therapy
- ❑ Numeracy and Literacy, relevant to daily Living
- ❑ Independent Living Skills
- ❑ Future Planning

Liaison and joint working with relevant agencies would continue throughout each programme, as appropriate. The client's progress would be reviewed as frequently as necessary and the programme and the goals may be modified in the light of each review. Discharge planning would commence at, if not before, discharge. The maximum length of stay would be two years, with exceptions at the management's discretion. An initial six-bedded unit should be developed to provide services to this client group within the Mid-West Region, with Day Therapy and Out-Reach Services within an appropriate catchment area. Support structures within the Community would be required within areas that would be unable to avail of the service. This service could be provided solely by the Health Board or alternatively in conjunction with a service provider from the voluntary sector.

An effective and efficient system for the transition from hospital into the community is required so that the level of therapy and support continues. This client group and their families have identified a wide range of services to be provided following discharge including for example, social work, speech and language therapy, physiotherapy, occupational therapy, respite support, education/training and psychological support in order to enable adjustment to the persons changed status. (**NRH, 2000: 1**) Persons with adult acquired brain injury, on discharge from the Transitional Living Unit, would avail of the generic community support services put in place, as outlined in the 'Home and Community' and Respite/Residential Support' elements of the 'Continuum of Support'.

The National Rehabilitation Hospital is to establish provincial advocacy groups to involve the brain-injured and their families and other interested parties, in the hope that the needs of the brain injured will become more widely known and appropriate services developed. The Health Board will support this advocacy process.

(The needs of persons of age under 18 with an acquired brain injury fall within services to persons with an intellectual disability and are addressed under that Strategy Statement).

## **5.2 Persons with Dual Disabilities**

In many cases a person may have both a physical or sensory disability and an intellectual disability. In some cases there may also be multi-disabilities impacting on the full sphere of human functioning.

The basis for accessing a specialised service, whether physical/sensory or intellectual, is determined by the primary diagnosis - that is, the most predetermining condition of the disability. The setting most appropriate to the person's needs must also be considered. The primary diagnosis must therefore be used to inform the decision as to the most appropriate service.

In the case of those with an intellectual disability, in general, those that have a moderate to severe intellectual disability, with a physical or sensory disability, would access services through an intellectual disability service provider. In the case of people with a mild intellectual disability their preference would be for a generic or physically orientated service. Where a person does fall within the care of an intellectually disabled service the physical and sensory needs of the person will also be met by the same service. For example, seating management may be critical for some people with an intellectual disability and hence they would have their seating and posture requirements also met. This may include the provision of aids and appliances and physical therapies to support the personalised programme of the individual.

Clear protocols for management and referral will be developed, in conjunction with the voluntary sector, for persons with Dual Disabilities in the Mid-West Region.

# **Chapter 6: The Strategy**

## 6.1 Strategic Statement of Purpose and Intent

**Cognisant** of the need for development of services in accordance with the principles underpinning the *United Nations Standard Rules on the Equalisation of Opportunities for Persons with a Disability*;

**Mindful** of the three key principles underpinning the health services declared in the *National Health Strategy* of equity, quality of service and accountability and the concept of health and social gain;

**Recognising** the values underpinning service provision adopted in the Health Board's *Corporate Strategy* of Equity, Accessibility, Effectiveness, Efficiency, Appropriateness, Responsiveness, Dignity and Farsightedness;

**Reaffirming** the three guiding principles adopted by the *Commission on the Status of People with Disabilities* of Equality, Maximising Participation and Enabling Independence and Choice;

**Recalling** the core thrust of the deliberations of the *Review Group on Health and Personal Social Services for People with Physical and Sensory Disabilities* of developing services to enable persons with a physical or sensory disability to live as independently as possible in the community;

**Emphasising** that persons with a physical or sensory disability, and their families, guardians, advocates and organisations must be active partners with the Health Board in the planning and implementation of measures affecting their health and social wellbeing;

**Desiring** to facilitate the continued self-empowerment of persons with a physical or sensory disability in the Mid-West Region;

The Health Board affirms as its Strategic Statement of Purpose and Intent for persons with a physical or sensory disability in the region that:

The purpose of services for this client group is to facilitate the development of each individual to their full personal and social potential and to maximize their independence, choice and participation in society. This is achieved by advocating, promoting and developing 'person-centered' services.

The intent of services for this client group will be centered on responsiveness to consumer need and the focus of services will be pivotally placed on the individual person with a physical or sensory disability, their families and carers.

The objective of services is to effect a continuous lifecycle model of service and social support through the provision of an integral 'continuum of support'. The precise nature

and mix of the elements in the support continuum will be dictated by the impact on consumer's needs of changing internal and external environments.

The Health Board will focus on assessment of need, service planning/coordination, research, monitoring/evaluation and quality assurance. Service provision by the voluntary/community sector will be encouraged, wherever appropriate. Where a lack of expertise or capacity to provide a service exists within the voluntary/community sector the Health Board may become a direct service provider or invite other providers to deliver designated services. The Health Board will energise the contribution of related statutory bodies and agencies that have a direct impact on the lives of consumers in the region, through its public advocacy role.

The Disability Services of the Health Board will also be proactive in disability proofing other Health Board services and the services of related statutory bodies and their agencies. Particular focus will be directed to catalysing and enhancing the partnership with the voluntary and community sector to facilitate their enhanced provision of health-related services, including provision of information, advice and advocacy.

## **6.2 Strategic Objectives**

The Statement of Purpose and Intent is an expression of the strategic vision envisaged for the services to persons with a physical or sensory disability in the Mid-West Region. The Strategic Objectives of the Strategy, which bring a focus to the vision, are as follows:

### **Strategic Purpose and Intent:-**

- ❑ Promotion of 'person-centered' services of the highest quality that enable consumers to live the life of their choice within their desired community setting through the provision and facilitation of the appropriate supports and social resources.
- ❑ Delivery of a continuous lifecycle model of service and social support through the provision of an integral 'continuum of support'.
- ❑ Formalising of Health Board's relationship with the voluntary sector and enhancing organisational and operational capacity of the sector.
- ❑ Ensuring high standards and timeliness in service delivery.

### **Preventative Support:-**

- ❑ Promotion of preventative strategies to reduce incidence of physical and sensory disability in the region.

### **Anticipatory Support:-**

- ❑ Full implementation of the Regional Physical and Sensory Database.
- ❑ Development of Regional Children's Diagnostic and Assessment Service
- ❑ Development of internal and public advocacy role of Disabilities Directorate.
- ❑ Disability proofing of all Health Board services and facilities.
- ❑ Forging effective linkages, developing coherent coordination and defining areas of responsibility with other statutory bodies that interface with health and personal social service provision for persons with a physical or sensory disability.

**Home and Community Support:-**

- ❑ Development of full spectrum of Day Services.
- ❑ Enhancement of Personal Assistance, Home Care Attendant and Family Support Services.
- ❑ Expansion and development of therapy services.
- ❑ Development of Early Intervention/Therapy Teams and pre-school services for children.
- ❑ Development of comprehensive range of home and community services for persons with a significant physical disability.
- ❑ Enhancement of the quality of Rehabilitative Training service in the region.
- ❑ Development of an integrated regional system for provision and recycling of aids and appliances and development of a Regional Seating Clinic.
- ❑ Enhancement of Rehabilitation Services in the region, including provision for Adults with an Acquired Brain Injury.

**Respite/Residential Support:-**

- ❑ Development of respite support services in the region.
- ❑ Appropriate development of residential facilities, with particular emphasis on facilitation of independent living units.

**Human Resource Function:-**

- ❑ Development of effective staff recruitment and retention policies/structures and appropriate training programmes.

### 6.3 Values and Service Principles

The service principle, outlined in '*Towards an Independent Future*', of developing services to enable persons with a physical or sensory disability to live as independently as possible in the community and the principle of mainstreaming services for persons with disabilities, as far as possible, outlined in '*A Strategy for Equality*', will underpin the strategic action designed to achieve health and social gain for persons with a physical or sensory disability.

This principle will be buttressed by the principles of equity, quality of service and accountability enshrined in the National Health Strategy, '*Shaping a Healthier Future*'. The values espoused in the Health Board's *Corporate Strategy* of accessibility, appropriateness, responsiveness and dignity will vigorously motivate service planners, managers and service providers.

Affirmative action will be directed towards realising the broader principles adopted by the Commission on the Status of People with Disabilities of equality, maximising the participation and enabling the independence and choice of this client group in the region.

The design of services along the continuum of support will facilitate the development of an holistic, continuous lifecycle model of service delivery that is person-centered and appropriately supportive.

### 6.4 Organisation and Management

The Health Board values the significant complementary role played by voluntary agencies in addressing the needs of persons with a physical or sensory disability in the region. The Health Board and the voluntary agencies need to develop the inter- and intra-organisational and collaborative capacities of the agencies. **The Health Board appreciates the challenges this may place on voluntary agencies and is therefore committed to provision of the necessary support to ensure that they are equipped, both in managerial and operational terms, to carry out their role.** The Health Board has initiated a partnership project to give effect to this commitment and is appointing a Project Manager to coordinate the project. The Board has also commissioned research to identify, profile and assess the existing capacity of voluntary organizations providing services to this client group and also to identify the needs of these organisations. A Consultative Group, comprising representatives from the Board and the voluntary agencies has been established.

The role of the Health Board will be, primarily, one of assessment of need, service planning/coordination, appropriate direct service provision, research, monitoring/evaluation and quality assurance. The appointment of senior administrative, information and research and quality staff to the Disabilities Directorate will facilitate the development and enhancement of this role. Where a lack of expertise or capacity to

provide a service exists within the voluntary/community sector the Health Board will either provide the service or invite other providers to deliver designated services.

The Regional Coordinating Committee on Physical and Sensory Disability will continue to play a key partnership role in the overall management and planning of services in the region, involving representatives of the Board, voluntary organisations and consumers of the services in the region. Area Managers will enable effective local coordination of services. The Disability Care Groups in each County Catchment Area will enable the coordinated and planned delivery of services in each Area.

Area Physical and Sensory Disability Advisory Committees will provide a mechanism for the prioritised, planned and coordinated development of services and will facilitate appropriate and adequate representation of local views from service providers and advocates. The future direction of services will pivot around catchment area and sector-based coordination and delivery of services.

## **6.5 Supporting Strategies**

The implementation of this Strategy Statement will impact on staffing structures and levels, capital and revenue resources and information and communication policies. The pivotal supporting strategies are the People Strategy, the Resource Strategy and the Information Strategy.

### **The People Strategy:**

The People Strategy acknowledges the function of the people employed by the Health Board and its partner agencies in effecting the objectives of this Strategy. The purpose of the People Strategy is to ensure convergence between the culture, structures, policies and procedures of the Health Board and its partner agencies and the motivation, commitment, performance and striving of their staff towards achievement of their Corporate Objectives in a learning environment which is conducive to change.

The central elements of the People Strategy involve:

- ❑ Aligning the management of human resources with the objectives of the Board and its partner agencies
- ❑ Acknowledging that people, throughout the organisations, are the key strategic resource
- ❑ Developing appropriate structures, policies and procedures so that a constructive environment is created for staff of the Health Board and their partner organisations to contribute successfully to the attainment of Corporate Objectives
- ❑ Developing an equitable, caring organisational ethos for staff who are skilled at creating, acquiring and transferring new knowledge and changing and adapting their



behaviour to effect improvement in response to new knowledge and insights, in a continuous process. (MWHB, 1998: 1).

- Developing effective recruitment retention policies and structures in order to retain people.
- Structuring appropriate personal development programmes to continually develop the competencies and knowledge base of staff.

### **The Resource Strategy:**

The realisation of the central principles outlined in '*Towards an Independent Future*' and the developments outlined in this Strategy Statement will require significant capital and revenue investment to effect the desired improvement in the quality of life for this client group in the Mid-West Region. In order to address the issues arising within the Resource Strategy, the Board will compile a detailed costed Action Plan that will identify and outline the infrastructural, financial, staffing, training, information technology resources required to give effect to the objectives of the Strategy Statement. The Action Plan will embrace the developments prioritised in the National Development Plan over the period 2001 – 2006 for the region with respect to services for persons with a physical or sensory disability.

### **The Information Strategy:**

The Health Board needs information for a variety of reasons, to facilitate operational decision-making; to carry out needs assessment; to undertake research and evaluation; to measure performance; to inform service planning and review so that client groups receive a quality service. The Health Board also generates information in a variety of ways, as reports, as assessments, as activities, as statistics and other key data. This information needs to be managed in terms of its collection, storage and eventual retrieval.

A minimum dataset is currently being developed within the Disabilities Directorate to facilitate the collection, in a standard format, of appropriate, accurate and relevant data on activities across all disciplines. Activity data is used to inform the operational management and strategic planning of services. Therefore, it is important that protocols and procedures are put in place to ensure that data is collected, checked, monitored and validated.

A computerised, patient-centered information system will also be developed to record activity data. This system will be capable of integrating with similar systems within the Board and the voluntary agencies so as to provide a comprehensive overview of each client's use of services within the Mid-West Region.

The collection of appropriate, accurate and relevant activity data will ensure that the Health Board can make informed decisions in relation to service planning and policy formation. It will also facilitate more formal measures of performance based on activities and outcomes rather than waiting lists and waiting times.

Full implementation of the Regional Physical and Sensory Disability Database will receive priority within the Disabilities Directorate, as the database will be an essential tool in determining and assessing the extent of need among this client group and informing the orderly planning and development of services. The appointment of a Database Administrator and the establishment of the Regional Database Committee will facilitate the implementation of the database.

As the Health Board is driven into much tighter levels of accountability, it is becoming increasingly important that healthcare professionals have access to accurate, relevant and timely information in order to:

- ❑ Keep up-to-date with the latest developments in their field
- ❑ Facilitate assessments/diagnosis
- ❑ Undertake research
- ❑ Give advice and support

The recent appointment of an Information Scientist to the Health Board's Disability Directorate will ensure access to information on national and international best practice and alternative models of service delivery and facilitate the dissemination and exchange of information and ideas on disability services among healthcare professionals.

## Chapter 7: Strategy Implementation and Review

Effective implementation of the Strategy Statement will require managed change at three functional levels; strategic, tactical and operational, together with planned periodic review of the effectiveness of the Strategy's operationalisation.

At the strategic level, enhancement of the partnership structures that exist between the Health Board and the voluntary organisations who provide services to persons with a physical or sensory disability will be required. Significant importance will be placed on realisation of the objectives of the 'Partnership Project'. Emphasis will also be given to forging effective linkages, developing coherent coordination and defining areas of responsibility with other statutory bodies that interface with the health and personal social services in providing services to this client group. Development of the Health Board's public advocacy role will require collaboration and eliciting of cooperation with other statutory bodies in the region.

Tactical issues involve setting standards and monitoring their implementation. A suite of performance indicators will be developed for the services, based on the personal outcome measurement model and evidence-based approaches. Practices within the Board and its partner agencies, and at the interface between the Health Board and the agencies will be regularly reviewed to induce a seamless, comprehensive service to clients. Explicit criteria will be developed for entry to services in order to coherently define the boundaries of the services.

Operational issues are cited as 'change issues' in Chapter 4, the 'Continuum of Support'. Promotion of preventative strategies to reduce the incidence of physical and sensory disability. Implementation of the Regional Physical and Sensory Disability Database. Development of the Regional Children's Diagnostic and Assessment Service and the Early Intervention and Therapy Teams. Expansion of therapy services and development of comprehensive range of services for the Young Chronic Sick. Enhancement of Personal Assistance, Home Care Attendant and Family Support Services will be required. The development of an integrated regional system for the provision and recycling of aids and appliances will be a priority development. Provision of a Regional Seating Clinic will be needed in the region. Rehabilitation Services, particularly for Adults with an Acquired Brain Injury will require significant enhancement. Appropriate and adequate development of respite services and residential facilities will need to occur. The disability proofing and advocacy roles of the Disabilities Directorate will be emphasised.

A half-yearly Review of the progress in implementing of the Strategy Statement will be held, which will involve senior management of the disabilities services and representatives of the voluntary organizations. Prior to the holding of the half-yearly reviews submissions will be sought from all stakeholders on their perceptions of the implementation process and summarised feedback from these submissions will inform deliberations at the Reviews.

# References

**DOE&LR 1996: 1**, *'A Strategy for Equality': Report of Commission on the Status of People with Disabilities*, 1996, p.8.

**DOE&LR 1996:2**, *'A Strategy for Equality'*, *ibid*, pp. 12 – 13.

**DOE&LR 1996:3**, *'A Strategy for Equality'*: *ibid*, 1996, p. 161.

**DOH, 1994:1**, *'Shaping a healthier future' : A strategy for effective healthcare in the 1990s.*, Department of Health, 1994, pp. 10 –11.

**DOH, 1994:2**, *'Shaping a healthier future'* , *ibid*. p. 72.

**DOH, 1996:1**, *' Towards an Independent Future': Report of the Review Group on Health and Personal Social Services for People with a Physical and Sensory Disability*, Department of Health, 1996, p.23.

**DOH, 1996 : 2**, *' Towards an Independent Future'*, *ibid.*, p.27.

**DOH, 1996 : 3**, *' Towards an Independent Future'*, *ibid.*, pp.24 – 25.

**DOH, 1996 : 4**, *' Towards an Independent Future'*, *ibid.*, p.5.

**DOH, 1996 : 5**, *' Towards an Independent Future'*, *ibid.*, 1996, pp. 100 – 101.

**DOH, 1996 : 6**, *' Towards an Independent Future'*, *ibid.*, pp. 33 – 35.

**DOH, 1996 : 7**, *' Towards an Independent Future'*, *ibid.*, p. 108.

**DOH, 1996 : 8**, *' Towards an Independent Future'*, *ibid.*, p. 109.

**DOH, 1996 : 9**, *' Towards an Independent Future'*, *ibid.*, p. 39.

**DOH, 1996 : 10**, *' Towards an Independent Future'*, *ibid.*, p. 109 – 110.

**DOH, 1996 : 11**, *' Towards an Independent Future'*, *ibid.*, p. 109 – 110.

**DOH, 1996 :12**, *' Towards an Independent Future'*, *ibid.*, pp. 33 – 35.

**DOH, 1996 :13**, *' Towards an Independent Future'*, *ibid.*, pp. 39 – 40.

**DOH, 1996:14**, *'Towards an Independent Future'*, *ibid.*, pp. 41.

**DOH, 1996:15**, *'Towards an Independent Future'*, *ibid.*, pp. 47 – 55.

**DOH, 1996:16**, ‘*Towards an Independent Future*’, *ibid.*, pp. 56 - 62.

**DOH, 1996:17**, ‘*Towards an Independent Future*’, *ibid.*, pp. 63 – 70.

**DOH, 1996:18**, ‘*Towards an Independent Future*’, *ibid.*, pp. 71 - 73.

**DOH, 1996:19**, ‘*Towards an Independent Future*’, *ibid.*, pp. 42 -43.

**DOH, 1996:20**, ‘*Towards an Independent Future*’, *ibid.*, p. 55.

**DOH, 1996:21**, ‘*Towards an Independent Future*’, *ibid.*, pp. 76 – 81.

**DOHC, 2000:1**, *The National Health Promotion Strategy: 2000 – 2005*, Department of Health and Children, 2000, p.57.

**DOHC, 2000: 2**, *The National Health Promotion Strategy: 2000 –2005*, *ibid.* p.57

**DOHC, 2000: 3**, *The National Health Promotion Strategy: 2000 –2005*, *ibid.* p.58.

**DOJE&LR,1999:1**, ‘*Towards Equal Citizenship: Progress Report on the Implementation of the Recommendations of the Commission on the Status of People with Disabilities*’, Department of Justice, Equality and Law Reform, 1999, pp. 109 & 127.

**HRB, 1999:1**, ‘*National Physical and Sensory Disability Database: Information Pack*’, Health Research Board, 1999, pp.1 – 3.

**HRB, 2000:1**, ‘*A Guide to the Physical and Sensory Disability Database*’, Health Research Board, July 2000.

**HRB, 2000:2**, *National Physical and Sensory Disability Database: Newsletter, Issue No. 2 – July 2000*, Health Research Board, pp. 1 –2.

**HRB, 2000:3**, *National Physical and Sensory Disability Database: Newsletter, Issue No. 1 – January 2000*, Health Research Board, p. .

**MWHB, 1998: 1**, *People Strategy*, Mid-Western Health Board, 1998, p.4.

**MWHB, 1999:1**, ‘*Health and Social Wellbeing in the Midwest*’; *1<sup>st</sup> Report of the Director of Public Health*’, Mid-Western Health Board, 1999, p19.

**MWHB, 1999:2**, ‘*Health and Social Wellbeing in the Midwest*’; *1<sup>st</sup> Report of the Director of Public Health*’, *ibid.*, p. 47.

**MWHB, 1999:3**, ‘*Health and Social Wellbeing in the Midwest*’; *1<sup>st</sup> Report of the Director of Public Health*’, *ibid.*, p. 20

**MWHB, 1999:4**, *Action Plan: Response to the Report of the National Task Force on Suicide*, Mid-Western Health Board, 1999, pp. 7 – 15.

**MWHB, 1999:5**, *Health and Social Wellbeing in the Midwest*; 1<sup>st</sup> Report of the Director of Public Health, *ibid.*, pp. 48 - 52.

**MWHB, 1999:6**, *Health and Social Wellbeing in the Midwest*; 1<sup>st</sup> Report of the Director of Public Health, *ibid.*, p. 52

**MWHB, 1999:7**, *Strategy Statement on Child Health in the Mid-West Region*, Mid-Western Health Board, 1999, p.22.

**MWHB, 1999: 8**, *Strategy Statement on Child Health in the Mid-West Region*, *ibid.*, p. 21.

**MWHB, 1999: 9**, *Strategy Statement on Child Health in the Mid-West Region*, *ibid.*, p. 22.

**MWHB, 1999:10**, *'Promoting Independent Living': Report of the Working Party on Services to the Young Chronic Sick in the Mid-West*, Mid-Western Health Board, 1999, p. 10.

**MWHB, 1999:11**, *'Promoting Independent Living'*: *ibid*, pp. 11 – 12.

**MWHB, 1999:12**, *'Promoting Independent Living'*: *ibid*, p. 11.

**MWHB, 1999: 13**, *A Review of Physiotherapy, Occupational Therapy and Speech and Language Therapy Services in the Mid-Western Health Board*, Dept. of Public Health, Mid-Western Health Board, 1999, pp. 28-33.

**MWHB, 1999:14**, *'Promoting Independent Living'*: *ibid*, p. 15.

**MWHB, 1999:15**, *'Promoting Independent Living'*: *ibid*, p. 14.

**MWHB, 1999: 16**, *Proposal for Mid-West Seating Clinic*, Mid-Western Health Board, 1999, pp. 4 – 16.

**MWHB, 1999:17**, *'Promoting Independent Living'*: *ibid*, p. 16.

**MWHB, 2000: 1**, *Health and Wellbeing in the Mid-West: 2nd Report of the Director of Public Health*, Mid-Western Health Board, p.28.

**MWHB, 2000: 2**, *Health and Wellbeing in the Mid-West: 2nd Report of the Director of Public Health*, *ibid*, pp. 58 – 59.

**MWHB, 2000: 3**, *Health and Wellbeing in the Mid-West: 2nd Report of the Director of Public Health*, *ibid*, pp. 44 – 45.

**MWHB, 2000: 4**, *Traveller Health Unit : End of Year Report (1999)*, Mid-Western Health Board, pp. 1 – 3.

**NC, 1999:1**, *'Strengthening the Autonomy of Citizens with Disabilities': Personal Assistance Services, Mid-Western Health Board, Evaluation Report*, Neylon Consultants, 1999, p. 10.

**NRH, 2000: 1**, *Survey of People with Acquired Brain Injury*, NRH – National Rehabilitation Hospital, June 2000.

**NWHB, 1999 : 1**, Keenaghan, C., *Head Injury in the North West: Needs Assessment Briefing Paper*, Public Health Department, North Western Health Board, October 1999.