Katie Hendrix

TOWARDS AN INDEPENDENT FUTURE

REPORT OF THE REVIEW GROUP
ON HEALTH AND PERSONAL SOCIAL SERVICES FOR PEOPLE WITH PHYSICAL AND SENSORY DISABILITIES

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ON HEALTH AND PERSONAL SOCIAL SERVICES
FOR PEOPLE WITH PHYSICAL AND SENSORY DISABILITIES

December 1996

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(Teil: 01 - 6613111 — fo-líne 4040/4045; Fax: 01 - 4752760)
nó trí aon díoltóir leabhar.

DUBLIN
PUBLISHED BY THE STATIONERY OFFICE
To be purchased directly from the
GOVERNMENT PUBLICATIONS SALE OFFICE,
SUN ALLIANCE HOUSE, MOLESWORTH STREET, DUBLIN 2,
or by mail order from
GOVERNMENT PUBLICATIONS, POSTAL TRADE SECTION,
4 - 5 HARCOURT ROAD, DUBLIN 2,
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CHAIRPERSON'S FOREWORD

Michael Noonan T.D.
Minister for Health

Dear Minister

I have pleasure in submitting to you the Report of the Review Group on Health and Personal Social Services for People with Physical and Sensory Disabilities, ***Towards an Independent Future.***

The task of the Review Group was to examine the current provision of health services to people with physical or sensory disabilities and recommend how such services should be developed to meet more effectively their needs and those of their families. Our Report is the first detailed review of services for persons with physical and sensory disabilities since the publication of the Green Paper ***Towards a Full Life*** in 1984.

The main thrust of our Report is the development of services to enable people with a physical or sensory disability to live as independently as possible in the community. We recommend that priority be given 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 attaches great importance to integrating services for people with disabilities with mainstream services wherever possible.

The Report identifies the lack of reliable information on the numbers of people needing a service and their precise service needs as a major deficiency. We recommend that immediate attention be given to developing a database of information on the needs of people with physical and sensory disabilities to provide a firm basis for planning services. We also recommend new structures to encourage the co-ordination of service planning and delivery between the statutory and voluntary sectors. These new structures will enhance the already excellent working relationship between the health boards and the many voluntary organisations providing services for people with disabilities.

Towards an Independent Future provides a blueprint for the development of health services for people with a physical or sensory disability in the coming years. Our Report follows closely on the publication of the report of the Commission on the Status of People with Disabilities, ***A Strategy for Equality***. The Report of the Review Group builds on the recommendations of the Commission as they affect health services for people with physical and sensory disabilities. We hope that our recommendations will be accepted and implemented and that they will achieve the goal of a more independent future for citizens with a physical or sensory disability.

Yours sincerely

Ruth Barrington
Chairperson

SUMMARY OF MAIN RECOMMENDATIONS

Chapter 2 - Considerations underlying the Report

1. The objectives of health and personal social services for people with disabilities should be to enhance their health and quality of life. (2.8.2)

2. Research should be undertaken to develop measures of outcome for disability services so that their benefits can be evaluated. (2.3.5)

Chapter 3 - Information Requirements

3. The Department of Health, health boards and voluntary agencies should establish a database on the health service needs of persons with physical and sensory disabilities. (3.4.2)

4. The Directors of Public Health should play a key role in the development of the regional databases. (3.1.2)

5. The Department of Health should establish a Database Development Committee comprising representatives of appropriate State agencies and voluntary organisations to prepare detailed proposals for the development of the database. (3.4.4)

Chapter 4 - Early Assessment and Rehabilitation

6. Regional child assessment teams for disability should be established in each health board area. (4.2.16)

7. Each health board, in consultation with the regional co-ordinating committee (proposed in Chapter 8), should agree a strategy for developing services, providing support, information, advice and counselling to parents and families of children with disabilities. (4.2.7)

8. Each health board should make arrangements for a specialised rehabilitation service linked to an acute general hospital which would meet the rehabilitation needs of most types of disability, including traumatic disabilities and also visual and hearing loss. (4.3.4)

9. The National Rehabilitation Hospital (NRH) should continue as the national centre for specialist rehabilitation. (4.3.6)

10. The NRH and Cappagh Hospital should operate as national centres of excellence in relation to the provision of artificial limbs and the NRH as the centre of excellence in relation to the rehabilitation of amputees. (4.3.7)

11. The Department of Health should develop a policy on physical and sensory rehabilitation within the framework set out in this Report and in the Health Strategy. (4.3.9)

Chapter 5 - Community Services

Community Support Services

12. Specific provision should be made to ensure that, where possible, general practitioners' surgeries are accessible to people with disabilities. (5.2.3)

13. Relevant voluntary organisations and the Irish College of General Practitioners should address the problem of lack of expertise of general practitioners, among other health professionals, in communicating with non-speaking patients. (5.2.4)

14. Each health board should address urgently the capacity of the nursing service in the community to provide the requisite nursing care to persons with a disability. (5.2.7)

15. Pending this detailed examination, an additional 100 whole time equivalent nurses should be appointed to meet the needs of the increasing number of people with disabilities who can be cared for at home. (5.2.8)

16. The twilight nursing service should be extended to be uniformly available throughout the country to persons with disabilities. (5.2.9)

17. The review of the home help service should examine how the service should be developed and made more responsive to the needs of people with disabilities. (5.2.13)

18. An additional 1,600 places in day service facilities for people with disabilities should be provided. (5.2.9)

19. The regional co-ordinating committees should give urgent consideration to the rationalisation of transport to day services. (5.2.23)

20. A specialised day activity/resource centre should be established in Dublin providing appropriate counselling services, speech therapy, occupational therapy and physiotherapy services, clinical psychologist and neuro-psychologist services as well as suitable recreational facilities to people with head injuries. (5.2.29)

21. All health boards should examine and review the services available in their area for people with head injuries. (5.2.30)

22. The current provision and future requirements for pre-school services for children with disabilities should be examined by each health board, in consultation with the regional co-ordinating committee. (5.2.31)

23. The review of sheltered employment for people with disabilities currently being carried out by NRB should be completed as a matter of urgency. (5.2.34)

24. An additional 200 sheltered employment places should be provided for people with disabilities. (5.2.35)

25. The Employment Support Scheme allocation should be increased by 25 per cent (100 places) as an initial measure and should be reviewed on an ongoing basis. (5.2.36)

Personal Assistance Services (three levels)

26. In the medium to long term, a personal assistance allowance should be paid as an income maintenance allowance by the Department of Social Welfare to people with severe physical disabilities who meet the eligibility criteria for such an allowance. (5.3.13)

27. In the short term, the funding and administration of personal assistance services, should rest with the Department of Health through the health boards. An exception is made in the case of personal assistance for people in third level education which should be met by the Department of Education. (5.3.15)

28. Assessment procedures should be established for the provision of personal assistance services. (5.3.19)

29. An appeals procedure should be developed to deal with cases where the client disagrees with the assessment result. (5.3.22)

30. Preparatory training/peer counselling should be provided for prospective PAS users and, where necessary, their families. (5.3.25)

31. A training course of a minimum of three weeks should be provided to people providing alternative levels of personal assistance. This should be provided by the organisation or agency acting as service broker. (5.3.26)

32. We support implementation of the Advisory Group's recommendation that funding of £5 million should be phased in over a three-year period for the development of all personal assistance services for people with physical disabilities. (5.3.27)

33. A flexi-care service providing nursing, respite or home help services to deal with emergency situations should be established in each health board area. (5.3.28)

Community Therapy Services

34. Health boards should plan an annual increase in speech and language therapists of fifteen over the next decade. (5.4.10)

35. Additional funding should be provided to enable the intake of students into the School of Clinical Speech and Language Studies to be increased by 20 per annum over a five-year period. (5.4.9)

36. Provision should be made for a further 80 occupational therapists to develop services for people with disabilities. (5.4.18)

37. To meet these requirements, the Department of Health should take the necessary steps to increase the number of occupational therapy students in training by 20 per annum for a five-year period. (5.4.18)

38. An additional 85 physiotherapists should be recruited to meet the identified needs of people with disabilities. (5.4.21)

39. Additional funding should be provided to enable the intake of students into the Schools of Physiotherapy to be increased by 12 per annum to meet the recommended staffing levels. (5.4.22)

40. The health boards should increase the number of social workers providing support services to people with disabilities and their families in the community by 40 over the next five years. (5.4.25)

41. Health boards should support the development of voluntary help lines, peer counselling and other family support services as an integral part of the community support services available to people with disabilities. (5.4.27)

42. While the Group supports the mainstreaming of psychological services for children with disabilities, we recognise the specialist nature of the work, and recommend that whatever arrangements are made, the personnel providing the service have adequate training and experience. (5.4.30)

43. Health boards should increase psychologist posts by 10 over the next three years to develop effective psychology services for adults and to further develop services for children. (5.4.32)

Technical Aids and Appliances

44. The Department of Health should develop guidelines on the supply of aids and appliances to ensure that there is equity in access to them across the country. (5.5.6)

45. The funding available for aids and appliances should be increased by £5 million over five years. (5.5.7)

46. The health boards and agencies providing resource centres for advice and information on technical aids should agree the most cost effective way of making similar services more widely available at local level. (5.5.9)

Chapter 6 - Respite and Residential Care Services

47. Two hundred dedicated respite places for people with disabilities should be provided in addition to existing services as a matter of urgency. (6.2.5)

48. Health boards, in consultation with the co-ordinating committees, should provide appropriate respite facilities for children with disabilities. (6.2.6)

49. While a certain degree of flexibility is required, each centre should put in place a proper admission/discharge policy for respite services. (6.2.8)

50. Each health board should undertake a planned programme of refurbishment of residential homes over the next five years in consultation with the co-ordinating committee and the agencies responsible for the homes. (6.3.2)

51. New developments of residential care should be modelled on the recent semi-independent and independent living accommodation and supported step down facilities for people with disabilities developed by the Cheshire Foundation and Irish Wheelchair Association. (6.3.3)

52. Developments of new homes and independent living units should be located in urban areas or easily accessible to retail and leisure facilities. (6.3.4)

53. Each health board, in consultation with the co-ordinating committee, should examine the viability of establishing in its area small independent domestic dwellings with support as recently established by the Irish Wheelchair Association in Galway. Health boards and voluntary bodies providing services to people with disabilities should liaise closely with social housing organisations and local authorities to ensure that an adequate number of accessible houses is available to people with disabilities who wish to pursue this option. (6.3.6)

54. Health boards, in consultation with the co-ordinating committees, should assess the likely requirement for residential care over the next five years, on the basis that the necessary community-based supports and respite care services will be put in place. (6.3.8)

55. An additional 100 residential places in dedicated facilities for people with disabilities should be provided as soon as possible. (6.3.9)

56. Health boards, in consultation with the co-ordinating committees, should examine the need for suitable residential services for young persons with a hearing impairment. (6.3.10)

57. Health boards should arrange for the provision of an additional 200 places for persons with long term disabilities requiring constant nursing care. (6.3.13)

58. The Departments of Health and Education, as part of the consultation recommended by the Special Education Review Committee, as a matter of urgency and in consultation with the schools, should consider the likely future demand for residential care for children attending schools for the deaf and blind and take appropriate steps to reduce the need for residential places as far as possible. (6.3.15)

59. In the interim, we recommend that no child should attend a residential school for the deaf unless the local School Inspector and a senior health professional certify that it is in the child's best interests that he or she so attends. (6.3.16)

60. Statutory residential care standards, similar to those applying to children's residential homes under the Child Care Act, 1991, should apply to the residences attached to schools. (6.3.17)

61. Each organisation providing services for children should have a set of guidelines for investigating complaints of abuse in conformity with the 1987 Department of Health published Child Abuse Guidelines and all statutory requirements. (6.4.1)

62. Agencies which do not yet have them should put in place, following discussion with health boards, procedures for the investigation of complaints of abuse in relation to vulnerable adults. (6.4.2)

63. The Department of Health should give consideration to introducing registration of residential homes for people with disabilities. (6.4.3)

Chapter 7 - Special Services for People with Sensory Disabilities

Visual Impairment

64. The child assessment teams provided for in paragraph 4.2.16 should include a specialist in motor movement development of visually-impaired children and a specialist family support worker for families with visually-impaired members when visually-impaired children are being assessed. (7.2.2)

65. The Departments of Health and Education should identify clear lines of responsibility for the supply of low vision devices and technical aids required in and out of the classroom setting. (7.2.3)

66. A once-off sum of £250,000 should be set aside to develop a pool of suitable aids and to help defray the routine costs of maintenance, the funding to be reviewed after three years. (7.2.4)

67. Rehabilitation services for visually-impaired persons should be improved and towards this end, each community care area should have available to it the services of a rehabilitation worker with an expertise in visual impairment. (7.2.6)

68. The Department of Health should ensure that publications of the Health Promotion Unit are accessible to people with visual impairments. (7.2.8)

69. Health boards, in consultation with the National Council for the Blind of Ireland (NCBI), should develop a comprehensive low vision service providing equipment prescribed in respect of visual impairments. (7.2.12)

70. The Department of Health, in consultation with the NCBI, should draw up a list of technical non-medical equipment needed for independent living which would be approved for health board funding. (7.2.13)

Hearing Impairment

71. The Department of Health should ensure that publications of the Health Promotion Unit are accessible to deaf and hearing-impaired persons through subtitling of videotapes and through sign language where feasible. (7.3.3)

72. When children with hearing loss are being assessed, the proposed regional child assessment teams should include a psychologist and speech therapist with specialist knowledge and expertise with deaf children and a specialist family support worker for deaf families. (7.3.5)

73. Radio aids or appropriate technical equipment should be provided for hearing-impaired children attending local schools without any time delay and this matter should be monitored by the Inter-departmental Committee of the Departments of Health and Education. (7.3.6)

74. Audiological rehabilitation should incorporate lip-reading classes in addition to the provision of hearing aids. (7.3.8)

75. NRB, in consultation with the National Association for the Deaf (NAD), should examine the provision of lip-reading classes and the training of further lip-reading teachers. (7.3.9)

76. Vocational training centres, where appropriate, should make specific provision for the communication needs of deaf trainees in the delivery of training. (7.3.10)

77. Each health board should arrange for communication support services, such as sign interpreters, lip speakers and deaf/blind communicators, to be available to it. (7.3.11)

78. Health boards, in consultation with the NAD, should arrange for the provision of adequate social work and counselling services for people with hearing impairments and their families. An additional 10 posts are required. (7.3.14)

79. Each health board should take steps to develop a specialist mental health service to cater for the needs of profoundly-deaf service users. (7.3.16)

80. The Department of Health, in consultation with the NAD, should draw up a list of non-medical technical equipment necessary for independent living which would be approved for health board funding. (7.3.17)

81. Each health board should support the provision of trained peer counsellors for the deaf to work with the NAD Family Support Team in each region, with a particular role in mental health services. (7.3.19)

82. Health boards, in consultation with the co-ordinating committees, should examine as a matter of urgency the need for suitable residential services staffed by both deaf and hearing staff fluent in sign language for young deaf persons with additional difficulties. (7.3.20)

Chapter 8 - Organisation and Co-ordination of Services

83. An appropriate and clear reallocation of non-health related responsibility among government departments should be made in line with mainstreaming services for people with disabilities. (8.2.2)

84. The Department of Health should publish national guidelines on eligibility for community services as soon as possible. (8.3.3)

85. The Chief Executive Officer of each health board should establish a regional co-ordinating committee for services for people with physical and sensory disabilities. (8.4.2)

86. The Department of Health should put in place a process for the ongoing evaluation of health services for people with disabilities. (8.4.6)

87. Each health boards should appoint a Director of Services for people with a physical or sensory disability. (8.4.7)

88. Appropriate base levels of funding must be developed to counter the funding uncertainties facing individual agencies. (8.5.4)

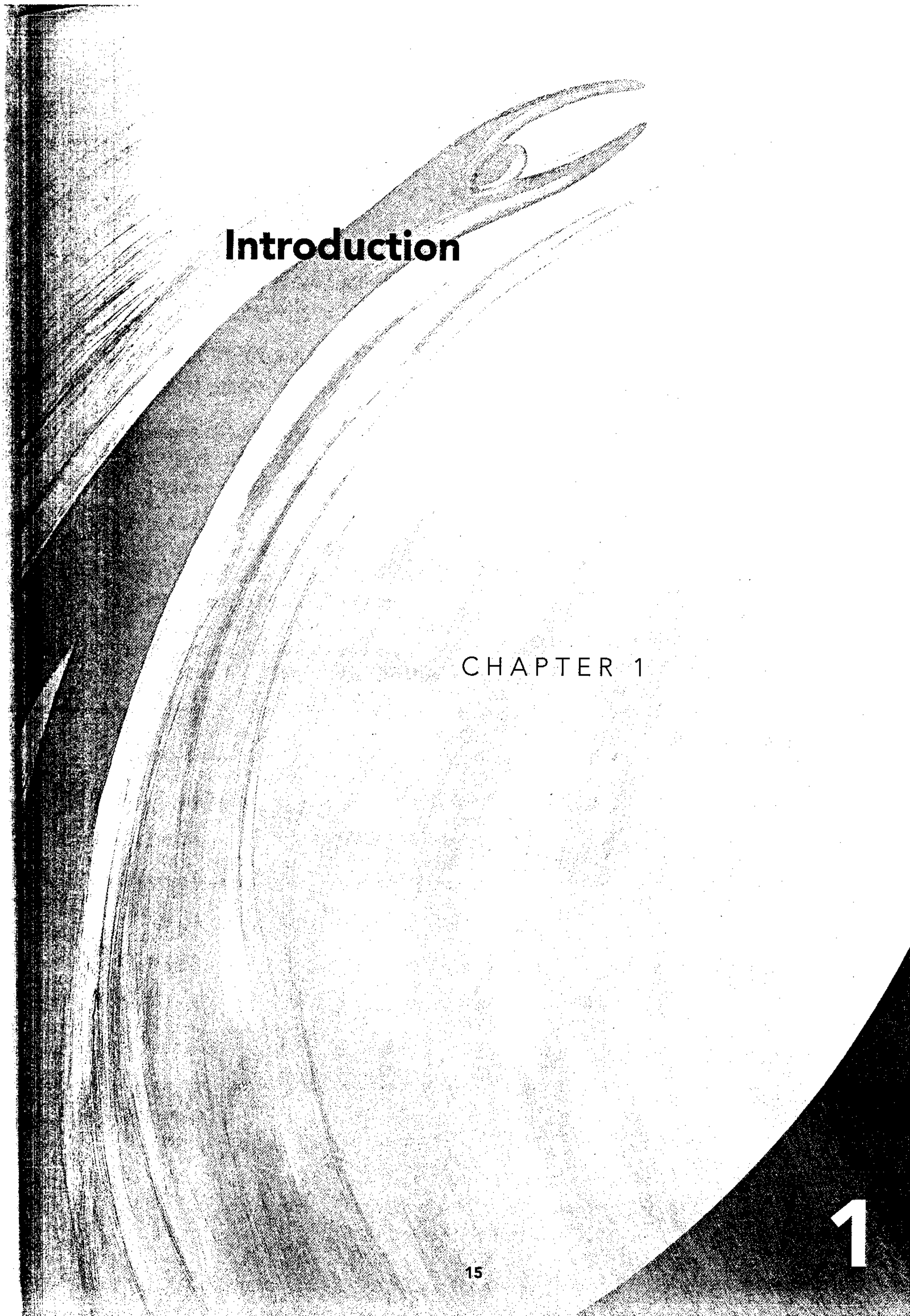
89. Health boards, in consultation with the relevant organisations, should make every effort to reduce the financial deficits of the organisations so as not to hamper the development and operation of new services. (8.5.6)

90. Health boards should take a lead role in developing a coherent information service in their region for people with disabilities. (8.6.4)

Chapter 9 - Health Promotion and Disability Prevention

91. Urgent attention should be given to the need to expand and develop the Genetic Counselling Service both in Dublin and other centres such as Cork and Galway. (9.5.1)

92. The Department of Health, in consultation with the Health Research Board, should develop a strategy for promoting medical/scientific research into conditions causing physical and sensory disabilities. (9.6.1)



Introduction

CHAPTER 1

1

1.1 Establishment and terms of reference

1.1.1 The Group was established by the Minister for Health on 30th June 1992 with the following terms of reference:

> *To examine the current provision of health care services to people with physical or sensory disabilities and to consider how they should be developed to meet more effectively their needs and specifically to make recommendations for service developments in accordance with the commitment contained in Section IV, Paragraph 33 of the Programme for Economic and Social Progress.*

1.1.2 Section IV, Paragraph 33 of the Programme for Economic and Social Progress states that:

> *"Services for people with physical disabilities will continue to be expanded by the provision of community-based support services. Priority support services will be:*
>
> - *provision of additional paramedical services, i.e. physiotherapy, speech therapy, occupational therapy;*
> - *provision of additional day care centres;*
> - *provision of respite care facilities;*
> - *provision of additional home support services; and*
> - *new training workshops and improvement of existing facilities.*
> - *A number of additional residential places for physically disabled people will also be provided."*

1.1.3 The Group welcomes the Government commitment contained in the Programme for Competitiveness and Work to enable the implementation of this Report's recommendations.

1.2 Membership

1.2.1 The following were appointed members of the Review Group:-

Chairperson

Dr Ruth Barrington	(from 1995) Director Continuing Care, Department of Health
Mr Tom Mooney	(to 1995) Director Continuing Care, Department of Health

Members

Mr Michael Bruton	Community Care Programme Manager, Western Health Board (subsequently Management Consultant)
Mr John Collins	(from 1996) Principal Officer, Department of Health
Mr PJ Fitzpatrick	Community Care Programme Manager, Eastern Health Board
Dr Thomas Gregg	Chairman, Cerebral Palsy Ireland
Mr Brendan Ingoldsby	Director, Multiple Sclerosis Society of Ireland (subsequently Assistant Principal Officer, Department of Health)
Mr Niall Keane	Chief Executive Officer, National Association for the Deaf
Mr Des Kenny	Chief Executive, National Council for the Blind of Ireland
Ms Angela Kerins	Director of Public Affairs and Care Services, Rehab Group
Dr Jim Kiely	Deputy Chief Medical Officer, Department of Health
Ms Mary Murphy	Trim, Co. Meath
Dr Arthur O'Reilly	Chief Executive, National Rehabilitation Board
Mr Matthew Ryan	(from 1995) Assistant Principal Officer, Department of Education
Ms Anne Winslow	Director of Services, Irish Wheelchair Association
Mr Pat Wylie	(from January 1994) Secretary to the Commission on the Status of People with Disabilities

Secretariat

Mr Brian Mullen	(to February 1996) Assistant Principal Officer, Department of Health
Ms Siobhán Kennan	(from October 1993) Higher Executive Officer, Department of Health

Mr Collins replaced Ms Frances Spillane in 1996.

Mr Ryan replaced Mr Liam Hughes in 1995.

Ms Kennan replaced Ms Christina McCarthy in 1993.

Dr Pauline Faughnan, Social Science Research Centre, UCD, resigned from the Group in December 1995.

Mr Donal Toolan, Forum of People with Disabilities, resigned from the Group in February 1993.

1.2.2 The Commission on the Status of People with Disabilities was established in December 1993. Dr O'Reilly and Ms Spillane became members of the Commission.

1.3 Preparation of the Report

1.3.1 The Group held 19 meetings. Four subcommittees were formed to examine specific issues: the development of a database; the organisation and co-ordination of services; services for adults; and services for children.

1.3.2 A wide range of bodies, including health boards, voluntary organisations and professional organisations representing medical and paramedical staff, was asked to make submissions. Fifty-six bodies sent submissions. These are listed in Appendix 1. We found these submissions most helpful in our task of preparing the report.

1.3.3 A questionnaire was issued to each health board to elicit up-to-date information on the number of people with disabilities as well as current health service provision and future service needs. A further questionnaire was issued to health boards in 1995, confined to questions on existing service provision and service developments required to deal with the known demand for such services. The Group's Secretariat visited all health boards in December 1995 to discuss the returns. The information gained was used in the preparation of the service chapters of the Report.

1.3.4 Following preparation of the first draft of the Report, a consultative seminar was held in February 1996 with interested bodies providing services for people with disabilities on foot of a commitment by the Minister for Health to consult them prior to the publication of the Report. A list of the organisations which participated is given in Appendix 2. This Report has taken account of the points made at the seminar and the Review Group wishes to thank all those participants for their contributions.

1.3.5 The Review Group wishes to express its appreciation of the invaluable assistance it received from Mr Michael Bruton during the drafting of this Report.

1.4 Interim report

1.4.1 In his address at the inaugural meeting of the Review Group, the Minister for Health requested us to prepare an interim report on the most urgent service needs so that these could be considered in the context of developments under the Programme for Economic and Social Progress in 1993. We presented this interim report to the Minister in December 1992. The interim report's recommendations are summarised in Appendix 3. *They do not form part of this Report's recommendations.*

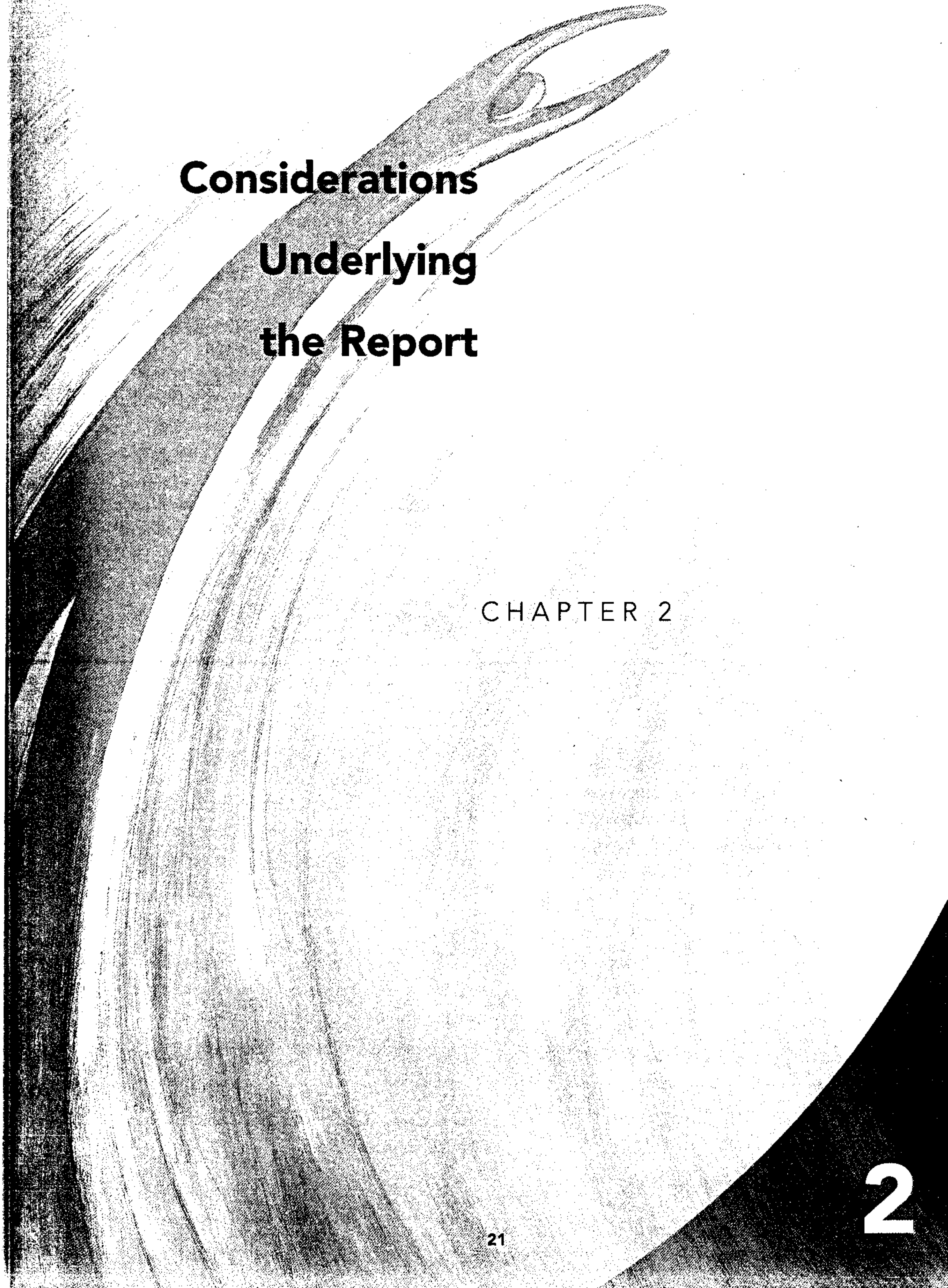
1.4.2 Following submission of the interim report, additional revenue funding of £1.5m in 1993 and 1994, of £2m in 1995 and of £1m in 1996 was made available for the development of services for people with disabilities. These additional resources have been built into the base funding for these services. This means that £6m more is available in 1996 for services than there was prior to 1993. Services developed with this additional funding include day care, residential and respite care, and therapy services provided by health boards and voluntary organisations. In the same period, capital funding was made available to build and refurbish facilities for services for people with disabilities, such as day care services and residential homes.

1.5 Terminology

1.5.1 In order to help the reader, the term *people with disabilities* is used throughout the Report to mean *people with physical and sensory disabilities* unless otherwise specified. The term *services* is used to refer to *health and personal social services* except where otherwise specified.

1.6 Secretariat support

1.6.1 The Review Group wishes to express its deep appreciation of the contribution of three people who acted as Secretary to the Group since its establishment in 1992 - Mr Brian Mullen, Ms Christina McCarthy and Ms Siobhán Kennan. A special word of thanks is due to Ms Kennan who, as the person responsible for the final draft, responded to our constant demand for changes with great efficiency, patience and good humour.



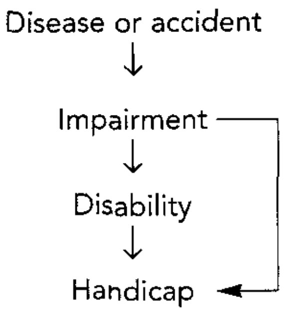
Considerations Underlying the Report

CHAPTER 2

2.1 Understanding disability

2.1 In addressing our remit, we became aware of the existence of considerable confusion in the use of language to describe "disability". Terms such as "*disability*", "*impairment*" and "*handicap*" are often used interchangeably. We considered that a common understanding of these terms is useful in terms of analysing and recording the health status of an individual or population, thereby providing a sharper focus for service provision. The approach we have adopted for the purposes of this report is the *International Classification of Impairments, Disabilities and Handicaps* (ICIDH), a theoretical framework of disability developed by the World Health Organisation (WHO) in 1980.

2.1.2 The relationship between the ICIDH concepts can be shown as follows:



2.1.3 *Impairment* is defined as *any loss or abnormality of psychological, physiological or anatomical structures or function*, such as loss of a limb or poor vision. The identification of an impairment is carried out objectively by person(s) qualified to judge physical and mental functioning according to generally-accepted standards, such as an eye specialist will determine the level of sight loss.

2.1.4 *Disability* is defined as *any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.* Disability, therefore, relates to the activities which people can or cannot do, such as inability to walk or to see.

2.1.5 *Handicap* is defined as a *disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, social and cultural factors) for that individual*, for example not being independently mobile or not being able to work. Handicap is sometimes referred to as "social disadvantage". "Handicap" is a social phenomenon created by social and environmental factors which act as barriers to integration into the life of the community for people with disabilities. In many cases, it cannot be dealt with by the health services alone.

2.2 Target group

2.2.1 On the basis of the definition of disability outlined above, we considered that this Report's target group would include only those people who currently require health or personal social services or who are likely to need them in the future because of their disability in order to improve health or social status. This includes people with congenital or acquired disabilities such as stroke patients, people who are paralysed or blind as well as people with progressive conditions such as arthritis which might require them to avail of specialised services. This Report does not address the needs of people with impairments who do not have a disability.

2.3 Health Strategy "Shaping a Healthier Future"

2.3.1 In April 1994, the Minister for Health published the **Health Strategy**, *Shaping a Healthier Future*. The **Strategy** is underpinned by three principles - equity, quality of service and accountability. These are described in greater detail in Appendix 4. A direct implication of the accountability principle is the requirement that voluntary organisations demonstrate the health and social benefits derived from the provision of their services in order to secure future funding.

2.3.2 The Group considered that the following objectives of the **Strategy** are of particular relevance to disability services:

(a) *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.*

(b) *The management and organisational structures will provide for more decision-making and accountability at regional level, allied to better methods of performance measurement.*

(c) *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 which responds to his or her needs in an equitable and quality-driven manner and in an appropriate setting.*

Health and Social Gain

2.3.3 The **Health Strategy** identifies two objectives or outcomes of health care intervention - health gain and social gain.

2.3.4 *Health gain* is concerned with health status - in terms both of increase in life expectancy and of improvements in quality of life through the cure or alleviation of an illness or disability or through any other general improvement in the health of the individual or the population at whom the service is directed.

2.3.5 *Social gain* is concerned with improving people's quality of life by minimising the disability and social disadvantage resulting from an impairment. It includes, for example, the quality added to the lives of people with disabilities and their carers by the provision of support services, or the benefit to people with a sensory disability of a social environment which assists independence. The Group considers that the concept of social gain is of particular relevance to people with disabilities, especially those with sensory disabilities. **We recommend that research should be undertaken to develop measures of outcome for disability services.**

Health Strategy Four-Year Action Plan

2.3.6 The **Health Strategy** also contains a Four-Year Action Plan for physical and sensory disability services. This includes a commitment to further develop services on the basis of locally-assessed need, with specific reference to the provision of extra facilities for day care, respite care, home care and personal support services, and residential care/independent living. In addition, it refers to the amelioration of the organisation and co-ordination of services, establishment of a national database, improvement of therapy and psychological support services, vocational training standards and facilities, funding of voluntary organisations and availability of technical aids and appliances. Finally, it states that steps will be taken to help reduce the incidence of neural tube defects by increasing awareness of the need for folic acid in the diet of women at least three months prior to pregnancy.

2.4 Key issues in submissions

2.4.1 In addition to the issues arising directly from the **Health Strategy**, our deliberations took account of issues raised in the submissions we received. The key issues are summarised below and examined in detail in the relevant chapters of the Report. They are:

- lack of comprehensive data on the numbers and service needs of people with physical and sensory disabilities;

- inadequate access to information on service provision and entitlements (particular note should be taken of 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.

2.5 Other groups reviewing needs of people with disabilities

2.5.1 Our remit relates to health care services only. However, health and personal social services are only one of many concerns of people with disabilities. This Report draws attention to barriers which limit access to health services but which are not the responsibility of health authorities, such as inaccessible public transport. It also draws attention to deficiencies in other services, such as inadequate housing, which create additional demands on health care services.

2.5.2 We are aware that services generally for people with disabilities have been or are being examined by other groups, in particular by the Commission on the Status of People with Disabilities. The Commission was established at the end of 1993 to report to the Government on practical measures necessary to ensure that people with a disability can exercise their right to participate, to the fullest extent of their potential, in economic, social and cultural life. It was also charged with examining the adequacy of existing public and voluntary services to meet the needs of people with disabilities and making recommendations to ensure that these are met in a cohesive, comprehensive and cost effective way. Its Report was published in November 1996.

2.5.3 Other groups examining issues of relevance to general services for people with disabilities are:

- Inter-Departmental Committee on Transport for Mobility Impaired Persons;
- National Rehabilitation Board's (NRB) Advisory Committee on Training and Employment of People with Disabilities;
- National Advisory Committee on Medical Rehabilitation established by NRB.

2.5.4 Recent reports referred to in this Report are:

- Report of the Special Education Review Committee, Department of Education, October 1993;
- Report of the Advisory Group on Personal Assistance Services for People with Physical Disabilities, Department of Health, March 1995;
- *Shut up at Home?* - Disability Federation of Ireland, May 1994 (J. Kiernan and B. Harvey);
- *People First* - Irish Wheelchair Association Survey, 1994 ;
- NESF Report No. 5, National Economic and Social Forum 1995.

2.5.5 The Group welcomed the publication of the discussion document *"Developing a Policy for Women's Health"* and the nation-wide consultative process that followed at seminars organised by the health boards. The Group understands that women with disabilities raised many issues at these seminars regarding their particular needs in accessing health services, such as family planning, childbirth and motherhood.

2.6 United Nations Standard Rules

2.6.1 The Review Group, in considering the development of services for people with disabilities, took account of the United Nations Standard Rules on the Equalisation of Opportunities for Persons with a Disability adopted by the United Nations in December 1993. These rules were drawn up in consultation with organisations representing people with disabilities and, although not yet legally binding, are intended by the UN to provide the basic international legal standard for programmes, laws and policies on disability in the coming years. The rules set out a list of preconditions for equal participation including the raising of awareness and support services. They also set out specific targets for equal participation including access to the physical environment, access to information and communication, education, employment, income maintenance, family life and personal integrity, culture, recreation, sports and religion.

2.7 WHO - Health for all Targets

2.7.1 The Group framed its recommendations in the light of the "*Health for all Targets*" policy of the World Health Organisation and, in particular, the recommended target for people with a disability. This target advocates better opportunities for people with disabilities.

2.8 Objectives of health services for people with disabilities

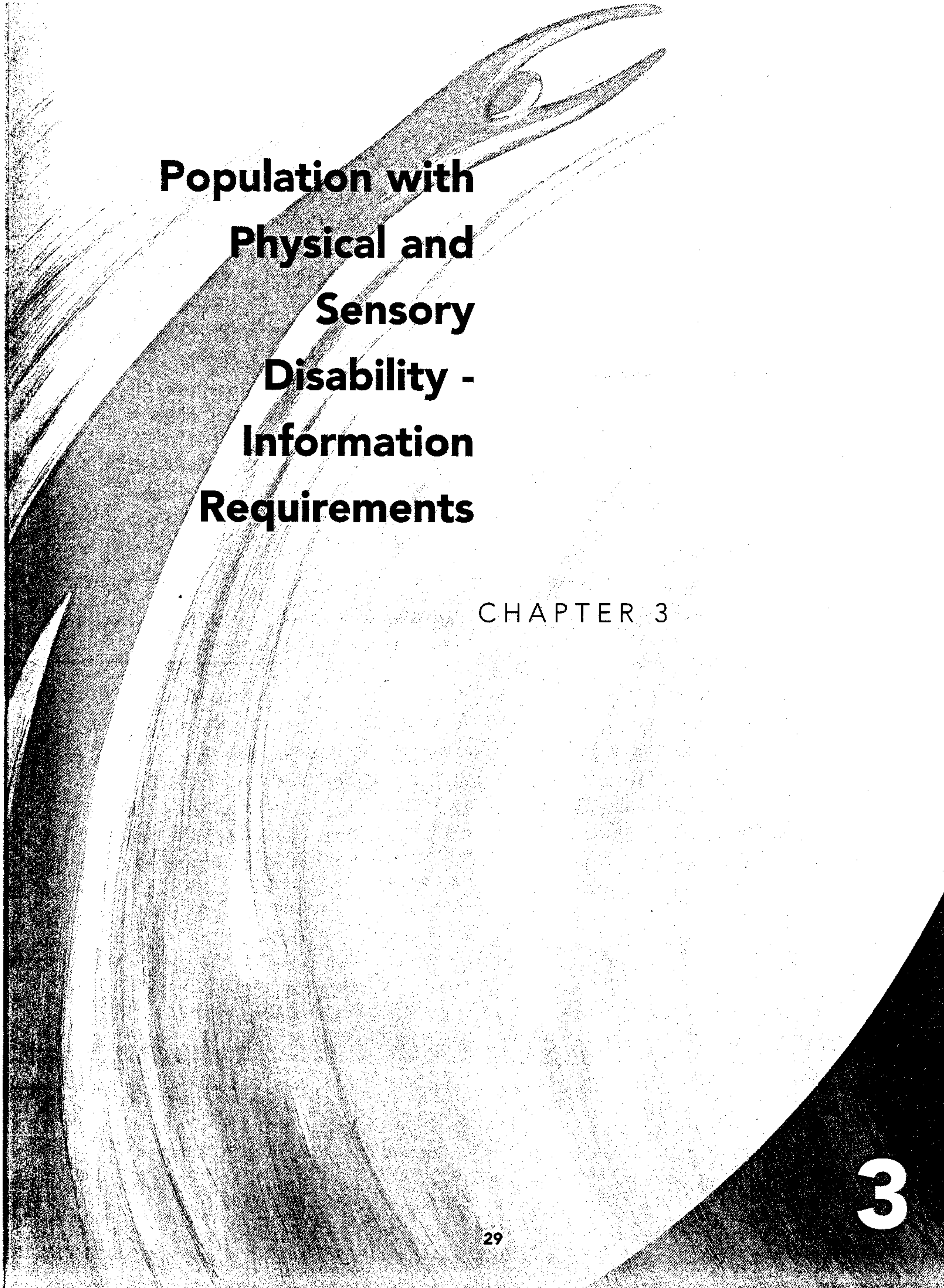
2.8.1. People with disabilities are increasingly asserting their right to control their own lives and to be involved in decision making in relation to their care. Their views must be sought and taken into account in planning services.

2.8.2 We consider that the objectives of health and personal social services for people 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.

2.9 Conclusions

2.9.1 In view of the wide range of disabilities included in the term "physical and sensory disability" and the complexity inherent in providing services to a wide range of people whose service needs differ according to their personal circumstances, we decided to make recommendations for the development of generic services which would be used also by people with disabilities. We make specific recommendations in cases where specialised services are required for a particular disability. Because of their range and diversity, it has not been possible to refer to and make recommendations regarding every individual disability. However, the general philosophy and approach we propose are relevant to all disabilities.



Population with Physical and Sensory Disability - Information Requirements

CHAPTER 3

3.1 Introduction

3.1.1 The efficient planning and provision of services are dependent on reliable information on the numbers and service needs of people with disabilities. Our interim report referred to the absence of such information. The Irish Census of Population does not include a question on disability and, unlike a number of other European countries, Ireland has never undertaken a national survey of physical disability. Information is not collected on a national basis on the incidence of physical and sensory disabilities. The Group considers that there is a need to identify service user needs on a regional and national basis in a consistent manner for planning purposes.

3.1.2 The Departments of Public Health are playing an important role in identifying service user needs in each health board area. **The Group recommends that the Directors of Public Health should play a key role in the development of regional databases on the needs of people with a disability.**

3.2 Statistical information

3.2.1 In the absence of a database, we sought to estimate the number of people with disabilities who have current or future health care service needs by examining a number of sources of information. These included administrative statistics on recipients of Department of Social Welfare benefits or of health allowances, health board data held under the physical handicap record system and voluntary organisations' data. We also examined national and international studies and issued two questionnaires to health boards.

Benefits statistics

3.2.2 The number of recipients of Department of Social Welfare and health board allowances for people with disabilities in 1994 was nearly 139,000. However, there are problems with using these statistics for the purposes of determining the prevalence of disability. Firstly, there is an element of double counting since one person could be in receipt of a number of allowances. Secondly, the present system of collecting data does not allow figures relating specifically to recipients with a physical or sensory disability to be extracted from the total, which includes people with a mental handicap or a mental illness. Thirdly, the definitions of disability which are used in determining eligibility for benefits encompass people who, although entitled to a benefit, do not require a specialised health service.

Long Term Illness Scheme

3.2.3 The Long Term Illness Scheme entitles persons suffering from any of nine specific conditions to obtain free drugs and medicines for the treatment of that condition. In 1994, over 29,000 people were registered under this scheme. However, many of these do not have a disability which requires them to avail of specialised health services. For example, the availability of appropriate medication helps the majority of people with epilepsy (22,000 of the total) to lead fully independent lives without recourse to other support services.

Health board data - Physical Handicap Record System

3.2.4 In 1981, the health boards introduced a physical handicap record system to identify the population receiving and requiring health services. The system has been only partially successful in producing complete data. In 1993, the record system held data on 12,390 persons with a sensory or physical disability receiving services.

Review Group questionnaires

3.2.5 We issued two questionnaires to health boards seeking information on current service provision and future service needs as well as the number of persons with disabilities by disability or impairment type. The data received were not consistent between health boards. There appeared to be large variations in the prevalence of certain conditions between boards. We considered that these inconsistencies were probably due to better records being kept in some areas rather than to actual differences in prevalence.

Voluntary organisation data

3.2.6 Voluntary organisations maintain registers of membership and clients. However, not all people with disabilities are members of voluntary organisations and not all members of organisations are service users. A census of the member organisations of the Disability Federation of Ireland (DFI) undertaken in 1992 revealed that 100,000 people were in receipt of direct services from those organisations. However, a third of DFI member organisations represent people who have disabilities other than physical or sensory.

National reports and studies

3.2.7 The 1991 Census of Population gives a figure of 80,435 persons unable to work due to permanent sickness or disability.

3.2.8 The 1994 Labour Force Survey on people aged 15 years and over unable to work due to permanent sickness or disability gives a total figure of 65,000, or 4.6 per cent of the total workforce. However, the figures include people with mental illness and mental handicap.

3.2.9 Other studies, mainly by post-graduate students, undertaken on the prevalence of disability in Ireland have identified prevalence rates ranging from 1.1 to 4.7 per 1,000 population. Notwithstanding this variation, all studies suggest that the incidence and severity of disability rise with age and that more females than males are likely to have a disability. These findings are consistent with UK and Spanish studies.

International studies

EC Data: Eurostat study

3.2.10 The Statistical Office of the European Communities and Directorate-General V commissioned the Centre de Politique Sociale et Économique Européene to collect and compare existing statistics on the socio-economic situation of people with disabilities in the European Community. The study favoured the national survey carried out in Spain in 1986-1987 which used the World Health Organisation International Classification of Impairment, Disability and Handicap. It found that 20 per cent of the population had some kind of impairment resulting in a disability for 14.9 per cent of the population, and handicap for 6 per cent of the population. A higher percentage of women than men had impairments, disabilities and handicaps.

British Data: Office of Population Censuses and Surveys Study

3.2.11 A survey of disability in 1988 by the British Office of Population Censuses and Surveys (OPCS) distinguished thirteen different types of disability relating to locomotion, reaching and stretching, dexterity, seeing, hearing, personal care, continence, communication and consciousness. Ten categories of disability were used based on the extent to which an individual's performance of activities is limited by impairments, ranging from very slight to very severe. Discounting the first two levels, the survey estimated that within disability severity categories 3-10, there were 27 per 1,000 children (ie persons aged under 16), 34 per 1,000 men and 44 per 1,000 women.

3.3 Estimate of prevalence of disability

3.3.1 We considered that the OPCS research represented a good attempt at estimating the prevalence of disability and, given the similarities in lifestyles between Ireland and Britain, might be the best means of estimating the prevalence of disability in this country. Applying the OPCS rates to the Irish population based on the 1991 Census would give an estimate of 27,000 children, 38,800 men and 43,300 women with a physical or sensory disability, giving a total of 109,300 people. However, the OPCS survey does not allow an accurate assessment to be made of actual health service needs. There are people with disabilities who do not require specialised health services.

3.3.2 We are satisfied that an urgent need exists for the establishment of a national database on the numbers and requirements of persons with physical and sensory disabilities. While the recommendations in this Report for the development of services are made on the best available data, we believe that it is only following the establishment of this database, or at least a detailed review of health service needs by the co-ordinating committees recommended in Chapter 8, that service needs can be definitively assessed.

3.4 Database

3.4.1 We examined the database on mental handicap established in 1995 on foot of the recommendations of the Review Group on Mental Handicap Services 1990 report "*Needs and Abilities*". The report stated that all agencies should "contribute to the *establishment and maintenance of a core database on clients using accurate and detailed information based on standard terminology, clear classifications and a specific coding system*". Essential prerequisites for its establishment were the provision of specific financial and personnel resources and commitment by health boards and the agencies involved to its implementation. The mental handicap database has proved to be extremely valuable in planning services at national and regional levels.

3.4.2 We recommend the establishment by the Department of Health, health boards and voluntary bodies of a database on the health service needs of persons with physical and sensory disabilities as a matter of priority. The database should provide a picture of need over a five-year period. Individuals who currently receive, require or will require a service within that time frame should be included on the database. As the database is intended for planning purposes, a person should only be included on the database where there is a service need. The operation of the database must comply with the terms of the Data Protection Act, 1988.

3.4.3 We consider that the database on physical and sensory disabilities should be designed to provide reliable and up-to-date information for a number of separate but related purposes:

- for epidemiological purposes at national level, to describe the prevalence and, where possible, annual incidence of the various types of disability and to provide a base line from which trends can be monitored over time;

- for planning service developments at national, regional and sub-regional level including prioritising service needs and assisting in resource allocation decisions;

- individual health boards and other service providers may maintain, at their discretion, data for their own purposes such as the development of group or individual care plans;

- for research purposes.

3.4.4 The issue of a database has been the subject of much discussion by the Group and also at the consultative seminar referred to in paragraph 1.3.4. It is considered that further discussion is necessary to develop detailed proposals for the establishment of a database, in particular to advise on which categories of disability should be included on the database. **We recommend the establishment by the Department of Health of a Database Development Committee comprising representatives of appropriate State agencies and voluntary organisations to prepare detailed proposals for the development of the database.**

3.4.5 In preparing its proposals, the Development Committee should have regard to the following:

(a) data should be collected only in respect of persons with disabilities requiring specialised health services with the aim of improving their health and social status and a list of categories of such persons should be developed;

(b) a national database should be established based on a sub-set of data from regional databases;

(c) each health board should be assigned the responsibility for the establishment and maintenance of a regional database for people with physical and sensory disabilities;

(d) data should be collected in a standardised manner to ensure cross-regional comparability;

(e) a database committee should be established in each health board area and a database co-ordinator appointed. The committee should be representative of data suppliers and should have an overall management role in relation to the regional database;

(f) the necessary technical and financial resources must be provided to establish and maintain the database;

(g) software provided should be user friendly and ensure easy retrieval of information relating to service needs in formats which meet the requirements of users;

(h) individual agencies may need to maintain additional specific data for their own particular purposes. Such data should not form part of the proposed national database;

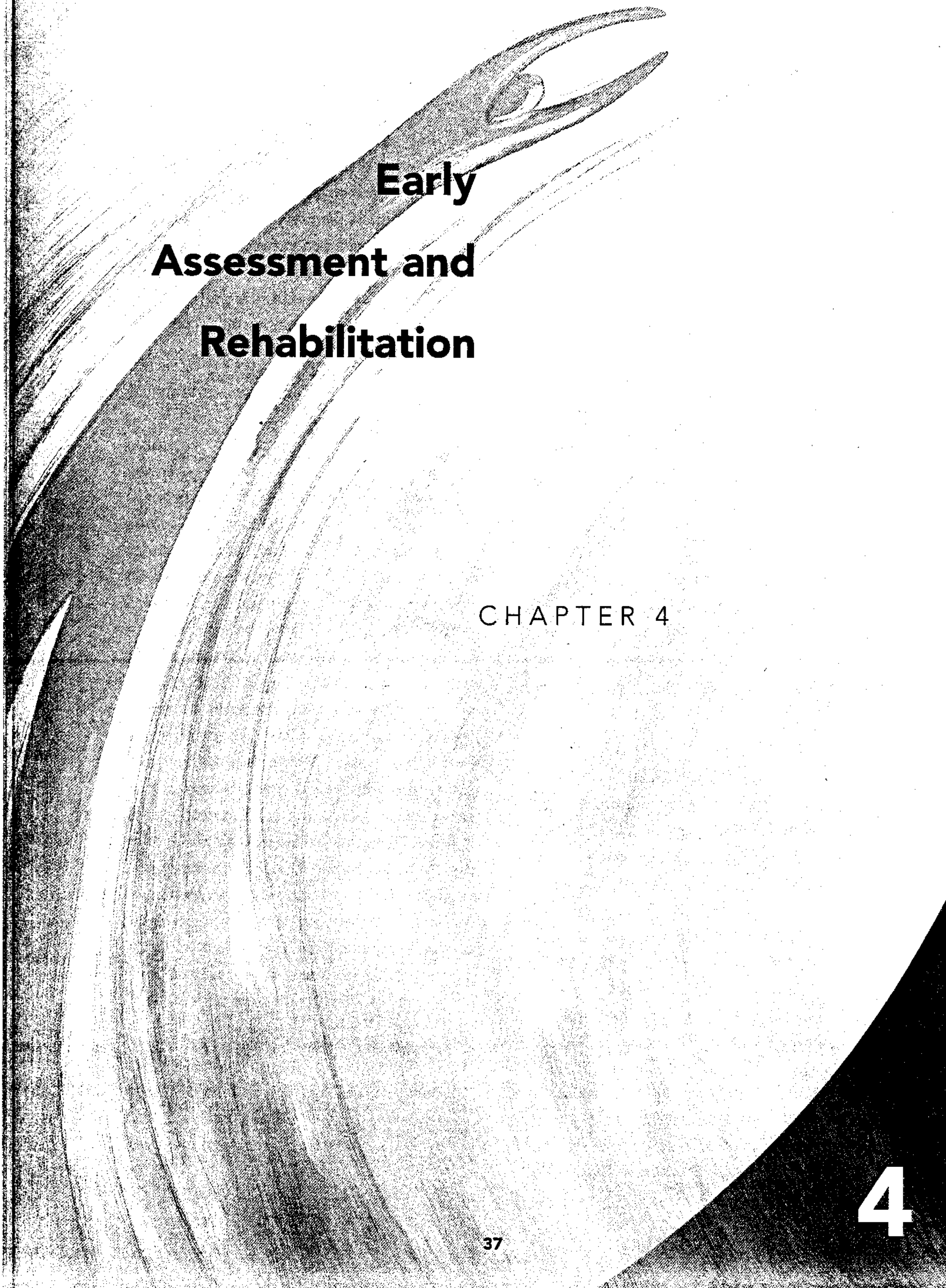
(i) each service user should have an individual personal identification number which is transferable as he/she moves between services or regions;

(j) the operation of the proposed database must comply with the terms of the Data Protection Act, 1988. Responsibility at each level under the Act should be clearly identified;

(k) systems must be put in place to audit the quality and accuracy of the data;

(l) such information from the database as is compatible with the requirements of individual confidentiality should be available to organisations working in the field of disability to aid them in planning their own activities;

(m) a national committee should be established by the Department of Health to undertake the ongoing development of the database and to approve access to the database for third parties.



Early Assessment and Rehabilitation

CHAPTER 4

4.1 Introduction

4.1.1 While the number of children born with a disability is decreasing, a significantly higher proportion of those born with disability have severe and multiple disabilities which require higher levels of input at an early stage and continuing higher levels of service provision throughout childhood. Early intervention programmes in the first years of a child's life can afford greater opportunity for the child to reach his/her potential and may reduce the demands for services in later life. Similarly, early assessment and treatment of adults with an impairment or disability may play a significant role in helping them to achieve optimal rehabilitation.

4.2 Assessment

4.2.1 Parents are often the first to notice that their child may not be reaching appropriate milestones for his/her age. Professional staff should ensure that they are sensitive to concerns expressed by parents about the development of the child to ensure that he/she receives appropriate and prompt assessment and treatment. The value to parents of good quality information on the expected achievements of milestones in a child's development is extensively recognised in the many publications devoted to child health and development. Good information is a prerequisite to effective action. The Health Promotion Unit of the Department of Health has produced publications in this area which should be readily available through all maternity departments and general practitioner surgeries. However, written material is not accessible to people with reading difficulties or visual impairments. **The Group recommends that professional staff involved in the assessment of disability should be particularly sensitive to the information needs of parents who cannot access the written word and, where necessary, have interpreters available to them.**

4.2.2 The Group is of the view that the current post-natal, pre-school and school medical services offer ample opportunity for the promotion of health as well as early detection of disability and for prompt referral to the relevant profession for a specialised opinion. These services include the maternity and infant care scheme/service, public health nursing service, national primary childhood immunisation programme, and child health pre-school and school services. We consider that there should be a systematic gathering and analysis of information between the various services involved in screening children for possible disabilities.

Maternity and Infant Care Scheme

4.2.3 Services under the Maternity and Infant Care Scheme are provided free of charge to all women. These include the services of the family doctor during pregnancy and for both mother and baby for up to six weeks after the birth. Women may also avail of outpatient antenatal services provided free of charge at public maternity hospitals.

4.2.4 The Group welcomes the continuous decline in the neonatal and perinatal mortality rates and considers that emphasis must continue to be placed on encouraging mothers to attend hospitals for their confinement where services are immediately available to ensure their safety. There is some evidence that low birth-weight babies have an increased risk of developing disabilities such as cerebral palsy. Early and frequent attendance by women at pre-natal clinics has been shown to be related to good outcomes in relation to birth weight. However, there is a worrying trend of attendance only late in pregnancy among certain mothers, in particular teenage mothers. Special efforts are required to reverse this trend. In addition, we consider that particular emphasis should be placed on monitoring the needs of those most at risk in pregnancy - teenage mothers, travellers, women at the extremes of their reproductive life and women with intercurrent chronic illnesses such as heart disease or diabetes.

4.2.5 It is desirable that paediatricians assess all babies prior to discharge from hospital. Information relating to the child's health, including the possible presence or development of an impairment or disability, is incorporated in the birth notification form sent by the maternity hospital to the health board on the birth of each child in order to ensure maximum co-ordination of services from the outset. This helps those involved in planning and delivering services to be better informed and responsive to needs. Each maternity unit should ensure that the birth notification form is forwarded as soon as possible to the health board area where the mother resides.

4.2.6 We recommend that relevant information pertaining to a child's disability be incorporated in the database recommended in Chapter 3 to enable the planning process to be better informed.

4.2.7 The Report of the Maternity and Infant Care Scheme Review Group will be published shortly. We hope that it will give recognition to the special needs of women with disabilities in accessing maternity and infant services and that these needs should be dealt with as flexibly as possible, including the provision of support services.

Public Health Nursing Service

4.2.8 Within forty-eight hours of notification of the birth to the public health nurse, mother and infant are visited at home by the nurse. The purpose of the visit is to offer support and guidance on the management of the baby. A series of developmental checks is also carried out in the home and in the local clinic. The level of home visiting is left to the professional discretion of the public health nurse and visits are made in accordance with assessed need. Public health nurses provide a vital link between the pre-school child and the health services by referring the child for expert opinion.

Child Health Services

Pre-school Service

4.2.9 This service is based on a comprehensive developmental examination of children at the approximate ages of 6-9 months, 12-15 months and 2 years and takes place at the local health centre.

School Service

4.2.10 The aim of the school service is to detect at the earliest stage any defect or disorder which would interfere with normal developmental progress, in particular vision, hearing, speech, posture and physical defects as well as emotional difficulties and to refer children to the appropriate services. The service is based on a comprehensive medical examination of school entrants and further examinations of older children selected on the basis of information furnished by their parents and public health nurses, other health professionals and teachers. The service is free to all children in national schools or other designated schools.

4.2.11 The **Health Strategy** identified the need for a fundamental review of the child health services. This review has recently been carried out and the report is currently being considered in the Department of Health. We hope that the issue of ensuring that adequate resources are provided and used as efficiently as possible to screen children effectively will be addressed in any changes to the service.

Other services

4.2.12 Assessment services to determine the precise nature and extent of disability are provided by the acute hospital sector, NRB and voluntary bodies such as Cerebral Palsy Ireland and the Central Remedial Clinic.

4.2.13 It is recognised that the opportunity for early detection of disability exists within the current post-natal and child medical services. However, once a problem is suspected, it is important that children can be referred without delay to a specialised assessment centre where they can be assessed more intensively and their future service requirements identified.

4.2.14 Specialised assessment centres/procedures are located principally in the major urban areas. For people living outside these areas, assessments for specific disabilities such as hearing or sight disability may involve lengthy travel, additional costs and disruption of family and work arrangements. The Group considers that it may be necessary for health boards to provide specific assistance with travel costs and make specific arrangements to ensure attendance with the necessary specialists. This assistance to enable parents to avail of all services may be particularly important for those for whom attendance at services might be a source of hardship, or whose family may have social or emotional difficulties which might militate against them availing of the services.

4.2.15 A number of submissions suggested that the links between services involved in the identification, assessment and treatment of disability were loosely structured. They expressed concern that communication systems between different services do not always ensure that key personnel receive the necessary information on an individual's diagnosis. Consideration should be given also to ensuring speedy access to confirmatory diagnostic facilities through hospital outpatient appointments.

4.2.16 We consider that dedicated assessment services are required in each region to facilitate access and improve co-ordination. **We recommend the establishment of regional child assessment teams in each health board area**. Each team should be headed by a professional with special competence in disability. The teams should be multi-disciplinary and include a consultant paediatrician, physiotherapist, speech and language therapist, psychologist, family support worker or therapist and social worker with appropriate skills.

4.2.17 The information on future service requirements identified in the assessment centres must be included on the national database. **We recommend that health boards establish formal links between assessment services and the regional database committees recommended in Chapter 3.**

4.2.18 There is a lack of practical support available to the parents and families of children with significant disabilities, particularly those aged under two. Families require support services, information, advice and counselling. **The Group recommends that each co-ordinating committee should agree a strategy for developing such services in their area.**

4.3 Rehabilitation

National Rehabilitation Hospital (NRH)

4.3.1 The National Rehabilitation Hospital is a 123-bed specialised voluntary hospital providing treatment and rehabilitation for people with spinal injuries, head injuries, strokes, multiple sclerosis and spina bifida. A national limb-fitting, repair and manufacturing unit is located on the site of the NRH.

4.3.2 On foot of the Comhairle na nOspidéal 1990 report on spinal cord injuries, the Mater Hospital was designated as the national centre for the acute management of spinal cord injuries. The NRH's national role as the rehabilitation centre for patients with spinal cord damage has continued. Special links were put in place to provide for integration of services between the NRH and the Mater Hospital.

4.3.3 In recent years, the NRH has been catering for increasing numbers of patients with brain injuries. These patients require intensive care, often on a one-to-one basis. The Group welcomes the recent expansion of the brain injury services at the NRH which has enabled the provision of separate and more efficient services for children and adults. Notwithstanding these improvements, the Group considers that existing services are inadequate to meet the rehabilitation needs of the increasing number of people who survive severe head injuries and strokes.

4.3.4 The reports of the Dublin Hospital Initiative Group recognised the need to provide expanded rehabilitation services for patients who no longer required the services of tertiary referral hospitals and recommended additional research in this regard. **We recommend that each health board make arrangements for a specialised rehabilitation service linked to an acute general hospital which would meet the rehabilitation needs of most types of disability, including traumatic disabilities and also visual and hearing loss.** Arrangements must also involve liaison as appropriate with the NRH which is the national centre of excellence in this field The development of regional services is in line with the **Health Strategy** policy that each health board should be self-sufficient in acute hospital and physical disability services.

4.3.5 The Group recognises the existence of a range of disabilities and impairments which could be ameliorated through rehabilitation, such as cardiac, oncological and orthopaedic conditions. The National Advisory Committee on Medical Rehabilitation established under the auspices of NRB is currently examining the role of medical rehabilitation across the whole spectrum of medical and surgical specialties with particular reference to the role of consultants in medical rehabilitation. It is expected that this report will be finalised in the near future.

4.3.6 **The Group recommends that the NRH should continue as the national centre for specialist rehabilitation**. It should pilot new therapies and support the development of good practice nationally. It should provide support to the network of regional rehabilitation services recommended in paragraph 4.3.4.

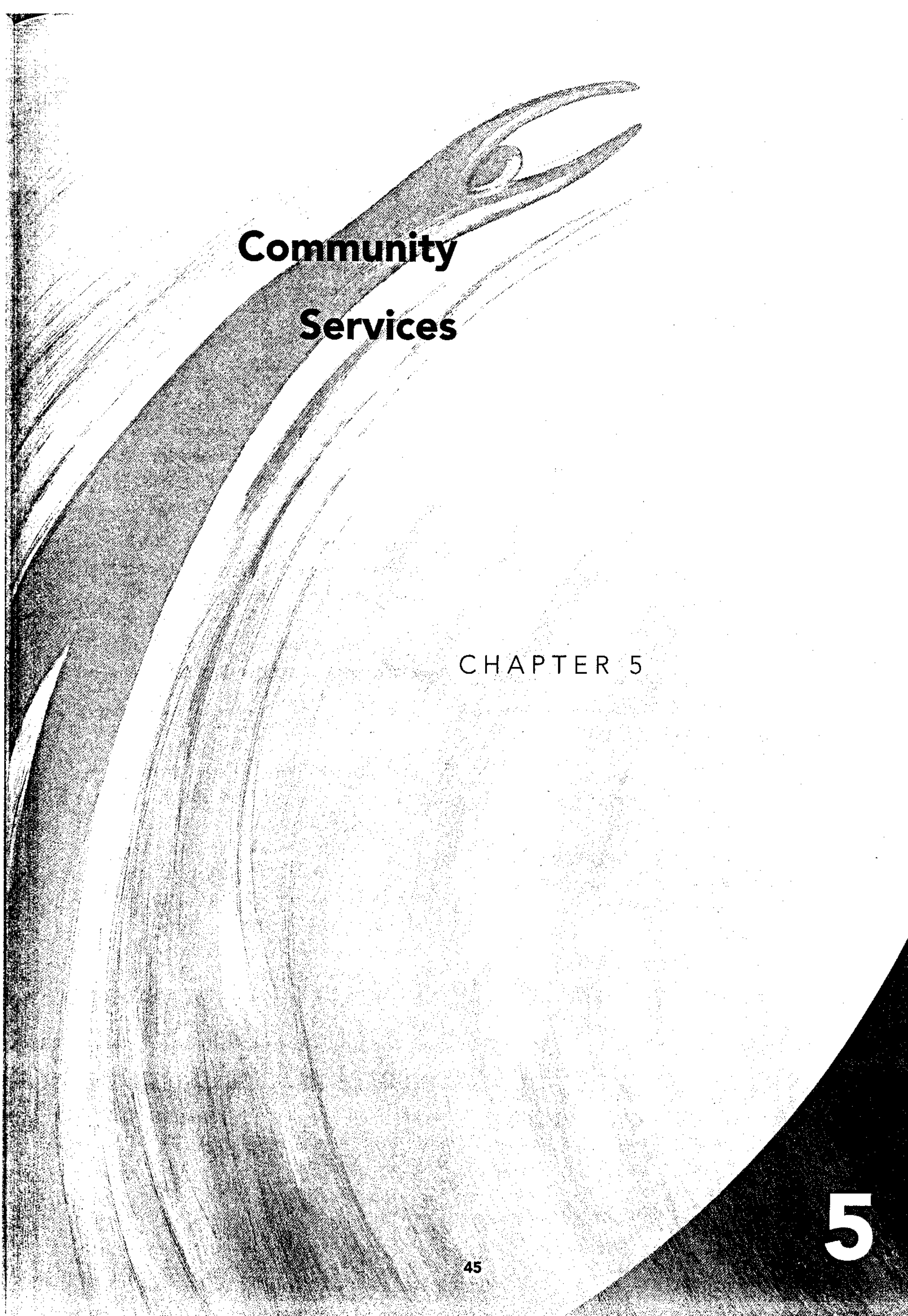
Limb fitting

4.3.7 Limb-fitting services are provided largely by the NRH in clinics in Dublin, Cork, Galway, Sligo and Letterkenny and by Cappagh Orthopaedic Hospital, Finglas. Approximately two hundred new amputees are seen every year at the NRH, 76 per cent of whom are aged 51 and over. The Group is of the view that limb-fitting services require a full rehabilitation service to ensure that all patients receive the back-up necessary to enable them to return to their home and existing lifestyle in so far as is possible. **Given the small number of cases per year, the Group recommends that the NRH and Cappagh Hospital should operate as national centres of excellence in relation to the provision of artificial limbs and the NRH as the centre of excellence in the rehabilitation of amputees.**

4.3.8 The Group is aware of complaints made by people seeking artificial limbs regarding delays, sometimes lasting months, in assessment, provision and replacement of limbs and of the lack of financial support for persons not holding medical cards. We consider that additional resources are needed to ensure that assistance is given in respect of people requiring limb fittings, for example children who may need a new limb every year, who do not come within the guidelines set down for medical cards. **We recommend that an additional £800,000 be phased in over the next five years to meet the demand for artificial limbs/prostheses under the existing scheme.**

Rehabilitation policy

4.3.9 Policy on the rehabilitation needs of people with different disabilities should be developed in more detail. **The Group therefore recommends that the Department of Health should develop a detailed policy on physical and sensory rehabilitation within the framework set out in our Report and in the Health Strategy.** Particular attention should be paid to the health service needs, including rehabilitation, of people with head injuries, stroke patients and people with spinal cord injuries and the care of those patients exhibiting challenging behaviour.



Community Services

CHAPTER 5

5

5.1 Introduction

5.1.1 As set out in paragraph 2.8.2, the Group considers that the fundamental objective of health services for people with disabilities is to enhance their health and quality of life through enabling them to live as independently as possible in the community. Effective community services are central to achieving this objective.

5.1.2 People with physical and sensory disabilities do not form a homogenous group. For example, a person using a wheelchair and a blind person who is able to walk will have different service needs. Health service needs vary according to the severity of the person's disability, personal circumstances, desires and aspirations as well as to the needs of their carer. Accordingly, community services must be comprehensive, flexible, and easily accessible. The vast majority of submissions we received stressed the inadequacy of existing community health service provision and the need to enhance it substantially.

5.1.3 Community services have two main aims: to provide the support necessary 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. A comprehensive community support service includes home support services, counselling and family support, day services, therapy services and the supply of appropriate aids and appliances.

5.1.4 While the Group's philosophy emphasises the importance of community services, we recognise that they cannot meet all needs and that specialised residential care services are also required. These services are examined in Chapter 6.

5.1.5 The community services are examined under the following main headings:

(i) Community Support Services

(ii) Personal Assistance Services

(iii) Therapy Services

(iv) Aids and Appliances.

5.2 Community support services

5.2.1 These include the general practitioner service, nursing service in the community, home help service, day services and sheltered employment.

General practitioner service

5.2.2 General practitioners are very often the first point of contact people with a disability have with the health services and play a crucial role in the diagnosis of impairment or disability as well as a significant advisory and referral role to other services. The availability of general practitioners throughout the country and the tradition of house calls are valuable features of this service for people with disabilities. We welcome the initiatives which have been taken in recent years to strengthen the role of general practitioners in the provision of health services. The advent of the Health Board General Practice Units has provided an interface between general practitioner services and health boards to improve co-ordination of service provision.

5.2.3 Since 1993, substantial investment has resulted in improved practice premises, better equipment, more support staff including paramedical staff and better arrangements between general practitioners in relation to cross cover. Linkages with other health services including the hospital services have also been improved. These developments have enabled general practitioners to expand the range of services provided in their surgeries. **We recommend that specific provision be made for ensuring that, where possible, general practitioners' surgeries are accessible to people with disabilities.**

5.2.4 It has been brought to our attention that general practitioners, among other health care professionals, frequently lack the expertise needed to communicate with non-speaking patients. **The Group recommends that the relevant voluntary organisations and the Irish College of General Practitioners address this problem.**

Nursing service in the community

5.2.5 Under Section 60 of the Health Act, 1970, health boards are obliged to provide a nursing service for persons with a medical card and such other groups as the Minister may specify. This service is provided by public health nurses. Services provided by public health nurses to persons with disabilities range from the provision of information and advice to nursing heavily dependent persons. As with general practitioners, public health nurses are often the initial point of contact a child may have with the health services. They also make referrals to the appropriate services.

Nursing at home

5.2.6 The number of persons with a disability living at home who require full nursing care is increasing, creating a greater demand on a service already stretched. There are many conditions, such as muscular dystrophy and cystic fibrosis, which used to require intensive hospital-based treatment and care. Developments in technology have enabled people with cystic fibrosis and emphysema to live at home on ventilators supported by their general practitioner and public health nurse in a planned care programme with their consultant. Similarly, trained nurses can provide the necessary care in the home to a person with cystic fibrosis which previously could be provided only in hospital.

5.2.7 The Group considers that there is a need to expand the capacity of the service generally and provide more nurses with the training necessary to meet the needs of people with disabilities and their carers. **The Group recommends that each health board should address urgently the capacity of the nursing service in the community to provide the requisite nursing care to persons with a disability.**

5.2.8 Pending this detailed examination, the Group recommends that the nursing service be strengthened by the appointment of an additional 100 whole time equivalent nurses to meet the needs of the increasing number of people with disabilities who can be cared for at home.

Twilight nursing

5.2.9 General trained nurses provide nursing care and assistance out of hours and at weekends to people identified by the district public health nurse. This service, known as the twilight nursing service, is particularly important to persons with chronic nursing care needs and has proved very effective. However, the service is not uniformly available throughout the country. **The Group recommends that the twilight nursing service be extended so that it is uniformly available throughout the country to persons with disabilities.**

Home help service

5.2.10 After family and friends, the home help service provides the main source of support to people with disabilities in their own home. The service is provided either by the health boards, or on their behalf by voluntary organisations, to give domestic assistance such as cooking, cleaning, and laundry to people who need it. The service is provided under Section 61 of the Health Act, 1970, which empowers health boards to make arrangements to assist in the maintenance at home of persons who, but for the provision of such a service, would require to be maintained otherwise than at home. In 1993, the public expenditure on home help services was £14 million approximately, representing 1 per cent of the total non-capital exchequer expenditure on health in that year. Aimed primarily at elderly people, the home help service is provided to a relatively small number of people with disabilities - in 1993, an estimated 1,800 people with disabilities received a home help service out of a total figure of 17,000.

5.2.11 Many of the submissions complained of the limitations in the present scheme in meeting the needs of people with disabilities, in particular uneven geographic availability, lack of flexibility and low level of service. The average number of hours provided per week is 10 with many people receiving far fewer hours' service than they need. However, the provision of personal care by home helps on extended duties under the direction of the public health nurse has occurred in an ad hoc way in some health boards in response to the identified need of individual clients to whom they were already providing a home help service. Thus, a limited assistance is provided by the home help service with the daily living needs of people with disabilities such as washing, dressing and toileting.

5.2.12 However, the service is not geared to providing the constant and comprehensive personal care needs of many people with disabilities and is not provided outside ordinary working hours when a person with a disability and their family may need assistance most. In addition, submissions were concerned at the strict means testing for the service and the level of contribution expected from recipients of the service whose means exceed the income guidelines. They also stated that the ages of children living in the house may be taken into account when eligibility is being assessed, so some families are forced into allocating children domestic duties inappropriate to their age.

5.2.13 We are aware that the home help service for elderly people is to be reviewed. We understand that many of the issues referred to in the preceding paragraphs will be examined during the course of that review. **The Group recommends that the review of the home help service should examine how the service should be developed and made more responsive to the needs of people with disabilities.**

Day services

5.2.14 Day services, by providing stimulation, activation and therapy for the person with the disability as well as respite for the carer, are an essential component of an effective community care service for people with disabilities. Attendance at a day centre may make the difference between a person with a disability being able to live at home and enjoy day services and having to seek residential accommodation because the strain of caring is too great.

5.2.15 Day services fall into three broad categories:

(i) specialised clinic facilities which offer a combination of medical and vocational rehabilitation services. They provide an assessment service and a wide range of therapies such as physiotherapy, occupational and speech and language therapy. Most of these clinics which work closely with the local consultant paediatricians are operated by Cerebral Palsy Ireland at centres around the country and by the Central Remedial Clinic.

(ii) centres which provide day activation, such as recreational and sport pursuits to adults with disabilities. Some may provide a limited occupational and physiotherapy service to their clients. On average, a person would attend a day care service two to three days a week.

(iii) community-based resource centres which deliver client-focused programmes in independent living training, education, social and leisure and part-time employment. These services provide clients with the lifeskills, opportunities and supports to achieve their full potential and to live as independently as possible in their local community.

5.2.16 People with a primary physical and sensory disability can have a dual or multiple disability. They often have difficulty in accessing services because they do not meet the admission criteria of service providers. People with dual disabilities have special needs which must be accounted for when providing a service.

5.2.17 We examined the role of day services and suggest that they adopt the following objectives:

(a) to identify tasks to suit the skills and abilities of each service user;

(b) to maintain and/or improve the level of personal independence, mobility and communication skills of each person attending;

(c) to enable people with disabilities to integrate into community life.

5.2.18 We identified four main problems with current day services:

(a) a shortage of dedicated day places for people with disabilities;

(b) services are not operating at full capacity;

(c) uneven geographic distribution;

(d) transport problems.

Shortage of dedicated places

5.2.19 It is estimated that there are currently 1,480 day service places availed of by people with disabilities. In many cases, adults with disabilities are inappropriately placed in day centres for the elderly or for people with mental handicap rather than in day services established specifically for them. Approximately 40 per cent of the existing service is provided by the voluntary sector. **The Group recommends that additional day service facilities should be established specifically for adults with disabilities and estimate that an additional 1,600 places are required.**

5.2.20 We also consider that, where possible, persons who have been availing of a particular day service should be allowed to continue to attend after they reach their sixty-fifth birthday if they so wish.

Capacity

5.2.21 In many cases, existing day care centres are not operating at full capacity through lack of adequate resources. Additional funding would enable these to open in the evenings and at weekends and so provide a more flexible response to the needs of service users.

Uneven geographic distribution

5.2.22 Day services are inadequate particularly in rural areas and in parts of Dublin, especially in Dublin South-West and North-West. There are other premises in the community such as community centres, youth clubs and sports halls which, with minimal adaptation, could be used as day care/social centres. Locating day services at such premises should be examined as a matter of urgency by the health boards in consultation with the co-ordinating committees.

Transport problems

5.2.23 Many submissions complained about difficulties in getting to and from day services. We consider that inadequate transport prevents or severely limits people with disabilities from attending day services. The almost total lack of accessible public transport, particularly in rural areas, means that specialised transport has to be provided by health boards and voluntary organisations. People living furthest away may have to travel for up to two hours to and from a day service. **We have already referred to the need to rationalise transport services for people with disabilities and we recommend that urgent consideration to this issue be given by the co-ordinating committees.** This could be carried out in consultation with other groups such as the mental handicap services providing similar transport services to day facilities. All vehicles used to transport persons to any service should be fitted with a tail lift and equipped with safety harnesses so that they can be used by people with a physical disability.

5.2.24 Access to public transport is crucially important to people with disabilities in achieving independence and integration. Without it, initiatives such as the provision of personal assistants (discussed in Section 5.3) will be hindered from providing the maximum level of independence possible to service users. The Group considers that the right of access of all citizens to public services, including public transport, needs to be emphasised. For people with disabilities, the lack of accessible public transport can increase the level of handicap they suffer as a consequence of their disability. **Accordingly, the Group recommends that immediate steps be taken to provide public transport which is accessible to all people with disabilities.**

Specialised day activity centres for people with head injuries

5.2.25 As a general principle, we consider that day services provided for people with disabilities should be accessible to all, regardless of the type or severity of the disability. However, we believe that existing services do not cater adequately for the needs of people with head injuries and that provision of specialised day centres for these service users is required.

5.2.26 It is estimated that each year, in Ireland, 850 people acquire a moderate/severe head injury. Constant improvements in post accident/stroke care ensure an increase in the survival rate of people with very severe injuries and consequently more people living with severe disabilities. This increase has not been matched by an increase in service provision. People with head injuries can experience complex physical, psychological and/or social problems such as impairment of intellect, memory, concentration as well as changes in mood and behaviour. It has been represented to the Group that while acute hospital surgical services for people with head injuries are generally very good, psychological and social work assistance at the immediate post trauma stage need development.

5.2.27 There is a lack of suitable community services, including counselling, neuro-psychological assessment and therapy services to provide the necessary support to people with head injuries and their families. The physical, cognitive, social and emotional problems associated with head injury can make it difficult for people with this type of injury to fit into "generic" services such as ordinary day centres. The experiences of Headway

Ireland, the national head injuries association, show that the programmes on offer in existing day centres are unsuitable for the special needs of people with head injuries and can cause difficulty in coping for the staff. In a number of cases, people with head injury have been placed in psychiatric hospitals because of the unavailability of appropriate facilities.

5.2.28 Families and carers of people with head injuries often require regular and planned respite, because of the difficulty and stress of caring for a person with multiple problems. It is often the behavioural and emotional deficits which cause the most problems in the home for the person with the head injury and the family. Respite care which is flexible and meets the needs of the service users and carers is required.

5.2.29 We recognise a need also for meaningful daily activities for people with head injuries to enable them to reintegrate into society or to develop their social and other skills to the highest level possible. **Accordingly, and given the concentration of people with head injuries in the Dublin area, we recommend that a specialised day activation/resource service be established in Dublin providing appropriate counselling services, speech therapy, occupational therapy and physiotherapy services, clinical psychologist and neuro-psychologist services for people with head injuries as well as suitable recreational facilities.** This service should be linked to the National Rehabilitation Hospital.

5.2.30 Pending the development by the Department of Health of a detailed policy on rehabilitation recommended in paragraph 4.3.9, we recommend that all health boards examine and review the services available in their area for people with head injuries. The Group welcomes the recent allocation of funds by the Eastern Health Board to Headway Ireland for the provision of a day centre facility in Dublin for people with head injuries.

Centres for pre-school children

5.2.31 Playgroup facilities are a valuable asset in the therapeutic and social context of the development of pre-school children with disabilities. As stated in the last chapter, the Group considers that early intervention is invaluable in maximising the developmental potential of children with disabilities. There is a need for additional pre-school services to be provided in convenient and accessible locations. Such services would provide intensive early therapy services for children and, by involving parents in the continuing treatment at home, would be an invaluable support to families caring for children with disabilities in the home. Consideration might be given to attaching these pre-school facilities to local health centres or other health facilities. **The Group recommends that the current provision and future requirements for pre-school services for children with disabilities should be examined by each health board in consultation with the regional co-ordinating committee.** A number of local pre-schools could be designated and provided with support to facilitate attendance by children with special needs.

Sheltered employment

5.2.32 Sheltered employment places are an integral part of an overall day service provision for people with disabilities. Places are currently available in long-term training centres, sheltered employment, and in the industrial therapy and occupational therapy units of psychiatric hospitals. It is generally agreed that these facilities do not meet current need, in terms of either the number of places available or the type of work options offered.

5.2.33 Apart from the need for, and the costs associated with, sheltered employment, there are a number of fundamental issues in regard to its provision which need to be addressed. These include the following:

(i) where should responsibility for sheltered employment lie? There is a strong view among people with disabilities and the organisations representing them that responsibility for policy in relation to the employment of people with disabilities should rest with the Department of Enterprise and Employment. The Irish Congress of Trade Unions shares this view and maintains that sheltered employment should be part of mainstream labour market policy and strategies designed to integrate all categories of workers into the labour market.

(ii) how many sheltered places are required? The development of a database on service needs of people who have a disability will help to resolve this problem.

(iii) is sheltered employment the most appropriate form of rehabilitation or should policy emphasise integration with mainstream employment? Should policy for people with significant physical, sensory or mental disabilities concentrate more on the provision of day care or recreational facilities?

(iv) is there a need for a more structured system of sheltered employment?

5.2.34 The provision of sheltered employment concerns all categories of disability and is a subject which we consider warrants a separate, detailed examination. **Accordingly, we recommend that the review of sheltered employment for people with disabilities currently being carried out by NRB be completed as a matter of urgency.**

5.2.35 The Group acknowledges that, in the meantime, there is an urgent need for additional sheltered employment for people with a physical disability. **The Group recommends the provision of funding for an additional 200 sheltered employment places for people with disabilities.** This is in advance of the completion of NRB's review.

Employment Support Scheme

5.2.36 The Employment Support Scheme was introduced in 1990. It is administered by NRB on behalf of the Department of Health and it operates on the basis that employers receive a subsidy towards the cost of reduced productivity by employees with a disability. This is a very successful scheme. In February 1996, there were 383 people employed under this scheme. **The Group recommends that the Employment Support Scheme allocation should be increased by 25 per cent (100 places) as an initial measure and be the subject of ongoing review.**

Income support

5.2.37 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 disabilities 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. These costs depend on the nature and severity of the disability and range from the need for aids and appliances, extra heating and clothing, special food, laundry services and medication to extensive adaptations to the home or personal transport.

5.2.38 There is a growing recognition of the special financial hardships faced by people with disabilities and their carers. The submissions highlighted the inadequacy of the allowances for people with disabilities, in particular the Mobility Allowance, carers' allowances and Disability Allowance (formerly Disabled Persons Maintenance Allowance) as well as the strict eligibility guidelines governing these and other schemes such as the Disabled Drivers and Disabled Passengers (Tax Concessions) Regulations. In addition, the Department of the Environment Disabled Persons Grant, through which local authorities may pay a grant for the provision of additional accommodation or necessary work to adapt the home to meet the needs of a person with a disability, is considered inadequate. Many submissions complained at the lack of information about entitlements, the complicated application procedures and the annual review of eligibility for an allowance paid in respect of a disability which is clearly permanent, such as paraplegia.

5.2.39 We consider that the provision of adequate income support is an integral part of an overall community support service to people with disabilities and is vital to their integration as full and equal members of society. We welcome and commend the recommendations contained in the report of the National Economic and Social Forum (No 5) and the recent report of the Commission on the Status of People with Disabilities regarding a Disability Living Allowance or Cost of Living Allowance for people with disabilities.

5.3 Personal assistance services

5.3.1 In many cases, people with disabilities living at home receive assistance with the tasks of daily living from their relatives, friends or neighbours. Depending on the severity of the disability, a person may require assistance with some or all of the following activities - dressing, washing, toileting, eating, communication and mobility. In many cases, responsibility for the care rests with one person principally. This constant requirement for assistance can put considerable physical, mental and emotional strain on the person with the disability and their carer. The Carers' Association of Ireland estimates there are almost 100,000 carers in Ireland, 25,000 of whom provide care on a full-time basis. Although the majority of these care for an elderly person, a sizeable proportion provide care for people with disabilities.

5.3.2 The Group is satisfied that there is a need to expand and develop different levels of home/personal support services for people with disabilities and their carers. These services should be flexible and sensitive to the needs of the person with the disability and the carer and enable them to lead as independent a life as possible.

Current personal support services

5.3.3 The current personal support services provided under home care attendant schemes and personal assistance services are described briefly below.

Home Care Attendant Scheme

5.3.4 The home care attendant scheme provided by a number of voluntary organisations such as the Irish Wheelchair Association and Muscular Dystrophy Ireland is aimed at offering temporary relief to the carer by providing a trained reliable care attendant to look after the needs of the person with the disability. Although it is primarily a respite service for the carer, it has been provided on occasion to people who live on their own. In many cases, these services have received financial assistance from the local health board.

5.3.5 The home care attendant scheme operates more flexibly than the home help service referred to at 5.2.10 by providing assistance in the evenings and at weekends as well as a more intensive service if the carer is under stress. The scheme is also more focused on providing assistance with daily living needs of the person with a disability, for example, in limited cases ongoing care is provided to persons in full-time education. The Group considers that an overnight service would offer welcome short term respite without the need for the person with the disability to move to a residential respite facility.

Personal Assistance Service

5.3.6 Pioneered by the Centre for Independent Living as the EU-funded research programme INCARE, the personal assistance service involves the employment of personal assistants (PAs) by people with physical disabilities to enable them to live as independent a life as possible. The PA provides assistance at the discretion and direction of the person with the disability and may involve providing assistance with tasks of everyday living such as personal care, household tasks and outside the home, whether in a work or social situation, thus promoting choice and independence for the person with the disability.

5.3.7 The independent living philosophy underpinning the personal assistance service concurs with the Group's view that people with a disability should be empowered to live independently. The philosophy of independent living espouses living like everyone else, that is having the right to self determination, to exert control over one's life, to have opportunities to make decisions, take responsibility and to pursue activities of one's own choosing, regardless of disability.

5.3.8 For clarity, the comprehensive personal assistance service described above is referred to as a PAS (personal assistance service) in this Report.

Development of personal assistance services

5.3.9 We examined the report of the Advisory Group on Personal Assistance Services for People with Physical Disabilities (hereafter referred to as the Advisory Group). We agree with their view that a significant proportion of people with disabilities would be interested in availing of personal assistance services to enable them to integrate more in their local community and greatly improve their quality of life, to pursue further education, to work and/or to move out of residential care, thus promoting significant social gain to people with disabilities and their carers.

Advisory Group's proposed organisation of services

5.3.10 The Advisory Group identified three different levels of personal assistance:

(i) *a comprehensive service whereby a person with a severe disability might employ (or be provided with) a personal assistant on an ongoing basis to enable him/her to live and pursue education and/or employment i.e. the PAS;*

(ii) *assistance services such as care attendants whereby assistance is provided for specific tasks or at specific times, primarily to offer respite to the carer, eg washing, dressing, limited assistance with education, etc;*

(iii) *other forms of assistance which 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.*

5.3.11 The Advisory Group estimated that there are approximately 200 people who would require a PAS and a further 1,500-2,000 who would benefit from categories (ii) and (iii) above.

Funding of personal assistance services

Medium to long-term funding

5.3.12 While the personal assistant or home care attendant might assist with specific medical problems of the person with the disability, his/her main role is to carry out the tasks of daily living which the service user cannot carry out for him/herself. In this way, the assessment of suitability for personal assistance is primarily a functional assessment of the type and levels of dependency of an individual.

5.3.13 Accordingly, we consider that the provision of funding for the three types of personal assistance services described in paragraph 5.3.10 is primarily a matter of income support rather than the provision of a health/social service. **We recommend that in the medium to long term, a personal assistance allowance should be paid as an income maintenance allowance by the Department of Social Welfare to**

people with severe physical disabilities who meet the eligibility criteria for such an allowance. The level of payment should be on a sliding scale depending on the number of hours' personal assistance required and could form part of a general costs of disability allowance.

Short term/interim funding arrangements

5.3.14 The funding currently provided for PAS needs to be placed on a firm footing. We consider also that the level of the funding currently available for home care attendant services is inadequate. The Advisory Group considered that there should be an integrated source of funding for the three categories of assistance services described in paragraph 5.3.10. This would require an assessment of people's needs and personal circumstances with a view to determining the level and type of service they require, ranging from the comprehensive PAS to a few hours' assistance a week.

5.3.15 In the short term, the Group recommends that the funding and administration of personal assistance services, including the PAS, should rest with the Department of Health through the health boards. An exception is made in the case of personal assistance for people in third level education, which should be met by the Department of Education.

5.3.16 From the point of view of equity, it is essential that additional funding for the lesser levels of assistance should be provided in parallel with, and at least at the same rate as, funding for PAS.

Organisation of service provision

5.3.17 In order to ensure that the high cost PAS are targeted to ensure maximum benefit and accepting that demand will inevitably exceed funding available, the Group recommends that PAS be allocated on the basis of national guidelines concerning eligibility criteria. In general terms, we feel that priority should be given to people who need a PA to undertake third level education, training, employment or as an alternative to residential care. The Group recommends that any development in relation to PAS should be subject to periodic reviews and evaluation. This evaluation should involve the personal assistant users themselves.

Means testing

5.3.18 We agree with the Advisory Group's recommendation that criteria for a means test should be established. These will have to ensure that they do not penalise people or deny them access to the level of assistance they require to become active contributors to and participators in society.

Assessment

5.3.19 We recommend the establishment of assessment procedures for personal assistance services. Two principal areas of assessment to determine the level of service are recommended:

(i) functional assessment to determine dependency and levels of dependency;

(ii) interview to determine whether the individual has the capacity to manage a PA or alternative forms of assistance services.

5.3.20 In assessing service need, a functional assessment should be carried out including an assessment of the safety of the individual in his/her environment, and dependency in all or some of their daily living habits. Functional assessment should preferably be carried out by a multi-disciplinary team of professionals with expertise in this area and include an occupational therapist, physiotherapist and public health nurse. A standardised assessment to define disability in terms of low, moderate and severe should be developed to ensure uniformity of service provision. Occupational therapists should have significant input in devising this instrument. Procedures to deal with borderline cases and appeals should also be developed. The relevant professionals should be involved in the development and piloting of this assessment procedure, as should representatives of voluntary organisations.

5.3.21 In assessing an individual's entitlement to existing personal assistant services, such as home care attendant services, factors such as the availability of family members to provide assistance are taken into account. This should also be taken into account by health boards in the case of assessment for PAS.

5.3.22 The results of the assessment procedures, such as the number of hours of assistance to be provided, should be discussed with the service applicant. In certain cases, the assessment team might recommend that an alternative, more cost-effective, form of assistance might be as beneficial as personal assistance to the client such as appliances or a home help service or that such a provision would reduce the requirement for personal assistant hours. **The Group recommends that an appeals procedure be developed to deal with cases where the client disagrees with the assessment result.** The appeals board might include relevant professionals and voluntary organisation representatives.

5.3.23 The determination of a person's capacity to handle a PAS would require a detailed interview exploring the relevant skills such as mental state, maturity, assertiveness, communication and understanding of what the service entails. It would be important to try to standardise this as much as possible as this type of assessment would involve a significant subjective component. The assessment should be carried out by one or more trained professionals, such as a member of the functional assessment team or a social worker, and individuals involved in the training and recruitment of PAs and leaders.

Service brokerage

5.3.24 The Group recommends the establishment of service brokerage which would effectively act as the employer and take care of the necessary administrative arrangements, such as making the necessary tax deductions and returns, and arranging insurance. Voluntary agencies currently providing personal assistance/home care schemes could fulfil this role and the necessary funding for the provision of personal assistance services should be channelled by the health boards through these agencies. It would be essential, however, that the person with a disability be directly involved in the selection of the assistant.

Training

5.3.25 Training is a key element in ensuring the success of a PAS. It involves both the training of the person with a disability in managing a personal assistant and of the assistant. As presently structured, the person with the disability is the main trainer of the PA. It is important therefore that people with disabilities considering a PAS are adequately informed in advance of what is involved in managing a PAS and are provided with the necessary training in this regard. In addition, the transition from dependent to independent living may require significant adjustment for the service user. People who move out of home or residential care to live independently may experience psychological and practical difficulties, e.g. they may experience difficulties in handling money or may make inappropriate friendships. **The Group recommends that preparatory training/peer counselling should be provided for prospective PAS users and, where necessary, their families.**

5.3.26 The Advisory Group considered that training should be provided also for people providing alternative levels of personal assistance, particularly for home care attendants. **We recommend that a three-week training course should be provided as a minimum and that training should be the responsibility of the organisation acting as service broker.** The course should cover lifting techniques, personal care, domestic duties and disability awareness. In view of concerns expressed about ethical issues, guidelines on personal care and relationships should form part of training courses.

Estimated cost of developing personal assistance services

5.3.27 In the absence of an assessment of the levels of assistance required, the Advisory Group estimated that there are 100 people requiring 50 hours of assistance a week, 60 requiring 100 hours a week and 40 requiring 150 hours a week at an estimated cost of between £2 million and £3.5 million. The Group further estimated that the provision of 15 hours a week of personal assistance service at a lower level to 1,500 people would require an additional allocation of £3.5 million. For reasons of equity already outlined, the Advisory Group considered that introduction of a PAS should be accompanied by a parallel development of alternative or lesser levels of personal assistance services. **We support implementation of the Advisory Group's recommendation that funding of £5 million should be phased in over a three-year period for the development of all personal assistance services for people with physical disabilities.**

Flexi-care

5.3.28 In addition to the structured personal assistance services described above, we consider that a "flexi-care" service should be available. Its main aim would be to respond promptly to the home care service needs of people with disabilities, in particular those who are on waiting lists for home help or respite service and who are receiving either no service or one which does not meet their needs. The assistance provided would depend on the individual needs of the person with a disability or his/her family, and would range from home care and nursing assistance to a more concentrated service during, for example, periods of domestic crisis. The mental handicap services Home Support Scheme indicates that this type of care is very important in providing support to carers in a user-friendly manner. **The Group recommends the establishment in each health board area of a flexi-care service providing nursing, respite or home-help services to deal with emergency situations.** The board could provide the service itself or through a voluntary body.

Special needs assistants in classrooms

5.3.29 The Report of the Special Education Review Committee drew attention to the need for Special Needs Assistants. We received submissions indicating that there are children with physical disabilities who are unable to attend school because of the lack of a special needs assistant in the classroom. As the Review Committee pointed out, such assistants are likely to be in continuous contact with pupils for the whole of the school day, just as teachers are. The absence or shortage of such a service has meant that many children must be assisted in the school setting by a parent or indeed by classmates. The Review Committee also criticised the ad-hoc approach to funding Special Needs Assistants and particularly the lack of continuity and professional experience which inevitably arises from the use of FAS training schemes in this context. We fully endorse the recommendations at paragraph 7.2.4 of the Special Education Review Committee report in regard to the appointment of additional Special Needs Assistants funded by the Department of Education in both special and ordinary primary schools and in secondary schools. Specific training in communication and technology for non-verbal children is essential if such assistants are to function efficiently.

5.4 Community therapy services

5.4.1 The main community therapy services are occupational therapy, physiotherapy and speech and language therapy. Health board therapists are generally assigned to community services, acute hospital services, psychiatric services and residential services. They are an essential element in meeting the health service needs of people with physical and sensory disabilities.

5.4.2 Notwithstanding recent improvements in the provision of therapy services through the provision of additional therapists and funding for equipment, the Group is of the view that therapy services for people with disabilities remain significantly underdeveloped and inadequate to meet the demand. The organisation and availability of community therapy services vary between health boards and between community care areas of the same board. Even where therapists are available, the therapy time available to people with disabilities, particularly adults, seldom matches their need. Understaffing results in limited services being provided, in terms of both the type of client groups treated and the effectiveness of the treatment provided. Centralisation of services may result in rural clients being unable to avail of the services. Furthermore, the pressure of large case loads means that primary prevention work has to be given low priority which can often exacerbate a condition leading to a need for long term therapy. A study commissioned by the South Eastern Health Board in 1995 on children with disabilities confirmed a large unmet need for occupational therapy (60 per cent of children needed more occupational therapy), physiotherapy (19 per cent), speech and language therapy (18 per cent) and psychology services (10 per cent). The other main areas of unmet needs are poor provision of equipment and aids, including assessment, supply and maintenance.

5.4.3 We recommend that the health boards should address the understaffing and under-resourcing of therapy services for people with disabilities as a matter of urgency.

5.4.4 Our approach to the development of therapy services is that in general therapists should be appointed to provide a "generic" service to all sectors of the community rather than being assigned specifically to cater for people with disabilities. We are satisfied that, in the main, the most effective and efficient therapy service from the viewpoint of both the service users and therapists is one which deals with the broad range of people and impairments. Accordingly, our recommendations in the following paragraphs regarding the appointment of additional therapists refer to the number of wholetime equivalent posts required for services for people with disabilities.

5.4.5 Notwithstanding this, it is vital that specialist training in disability awareness be given to some therapists in recognition of the need for specialist services, for example speech and language therapy services for people with hearing or visual impairments. Such therapists could continue to maintain a generic caseload as currently operates informally in many health boards. This arrangement provides a framework for consultation and support with colleagues where needed and provides recognition of specialist skills. Each health board should give consideration to the co-ordination of specialist multi-disciplinary teams, including medical and paramedical services, in providing services to people with disabilities.

5.4.6 Health boards should examine their current community therapy services with a view to resolving problems of service delivery such as the provision of a co-ordinated service between hospital and community therapists, setting clear objectives for the service, introducing a team approach to reduce the sense of isolation of which some therapists have complained and provision of adequate equipment and accommodation. We also recognise the necessity for appropriate clerical support to enable therapists to spend more time with patients and less time on non-clinical duties such as photocopying, issuing of appointments or maintaining waiting lists. The provision of induction courses in a multi-disciplinary group should also be examined for newly appointed therapists. **We recommend that each regional co-ordinating**

committee examine the provision of therapy services to ensure liaison and co-ordination between the work of therapists employed by the health board and by voluntary organisations.

Speech and language therapy

5.4.7 Speech and language therapy services are provided mainly by health board community care programmes. The service is concerned with assessing, diagnosing, treating and contributing to the prevention of disorders of communication in children and adults. This includes assessment for, and recommendation of, communication devices for those with severe communication impairments. The nature of speech and language therapy is such that treatment is lengthy, necessitating regular attendance over a long period of time. The wealth of knowledge concerning human communication and the development of communication aids is constantly evolving which means that speech and language therapists are required to expand continually their knowledge. **We recommend that health boards facilitate therapists in doing so.**

5.4.8 Submissions have complained of long waiting periods for assessment for speech and language therapy services and delays in receiving a service following assessment. Adult services are particularly inadequate as the existing therapy services concentrate on providing services for children. The inadequacy of the service is due in part to the shortage of therapists and the fact that they are dealing with growing case loads as the general level of awareness of speech and language problems and their long term implications increases.

5.4.9 Shortages of speech and language therapists are partly due to the small number being trained each year, as well as health board limited resources and difficulties in recruiting and retaining experienced therapists in the public sector. The School of Clinical Speech and Language Studies in Trinity College Dublin is the only school in the country providing speech and language training. The action of the Department of Health in 1992 in securing an increase in the annual intake of students to the School from 20 to 26 has helped improve the availability of trained staff. **Nevertheless, in order to meet our recommended increases in recruitment of speech and language therapists, we recommend that the Department of Health take the necessary steps to enable the intake of students into the School of Clinical Speech and Language Studies to be increased by 20 per annum over a five-year period.**

5.4.10 We recommend that, to meet the needs of people with disabilities, health boards should increase speech and language therapists by fifteen per year over the next decade.

5.4.11 A number of health boards, in co-operation with the Department of Education, have developed speech and language therapy units attached to schools for children requiring intensive intervention. Typically, these units are developed so that 6-8 children with specific language disorders which would not respond to conventional therapy are given a service on a daily basis over a period of 2 years after which, ideally, they would be reintegrated into the local primary school with a follow-up service provided by a community therapist. **It is recommended that each health board examine the needs of pre-school and school-going children, including children in secondary school, with specific language impairments with a view to establishing special language units.**

5.4.12 An outreach team, to include a speech and language therapy service, should be a core feature of service delivery in each health board area to provide a service to people with severe disabilities.

Occupational therapy

5.4.13 The community occupational therapist is concerned primarily with facilitating people with disabilities to achieve as independent, productive and satisfying a lifestyle as possible and to become as fully integrated as possible in the community. Treatment provides opportunities for the client to explore and master the tasks essential to life roles at home, school, work and leisure.

5.4.14 Therapists also provide training to home carers including home helps, evaluate and make recommendations on appliances and housing adaptations, and continue treatment programmes initiated in hospital in order to effect a return to health or an adjustment to disability. They also devise therapeutic programmes for individual children attending special schools and advise teachers and other staff on specific problems, equipment, architectural needs and treatment role.

5.4.15 The availability of occupational therapy services is inadequate. A number of acute hospitals throughout the country have no service at all which means that people discharged from specialised centres back to their local area have no follow-up service at home. Submissions have complained of waiting periods of up to six months for an assessment for housing adaptations or for aids and appliances. This waiting period affects the independence of the user and imposes strain on the carer. The constant increase in the types of aids and appliances available, including new aids for everyday needs such as dressing or being able to turn on light switches, has put an added pressure on occupational therapists to keep up to date with developments as well as pressure on limited budgets. In addition, the policy of maintaining people at home wherever possible has led to great pressure on the occupational therapy service as therapists are required to carry out increasing numbers of examinations of houses for possible adaptation.

5.4.16 Submissions suggest that occupational therapists should provide a broader range of services including education to parents concerning feeding, play, self help skills and community leisure. We consider that they should also be part of a multi-disciplinary team, liaising with local schools to offer ongoing advice to teachers and provide therapy where appropriate.

5.4.17 It has been represented to us that there is sometimes a lack of communication between hospital and community occupational therapists. In some instances, a person may be assessed by a hospital occupational therapist who may make recommendations for aids and appliances which a community occupational therapist, familiar with the home situation, may not think suitable. In addition, lack of communication between the hospital occupational therapist and his/her community counterpart may mean that the hospital occupational therapist is not aware of what equipment the client has as home, leading to inefficiencies. Appropriate consultation between the hospital and the community occupational therapy services should be a feature of service delivery. In view of the emphasis on community care and provision of assistance to help service users integrate back into their community, the role of the occupational therapist is continually expanding and requires ongoing investment and training.

5.4.18 We recommend that health boards make provision over the next five years for a further 80 occupational therapists to meet the needs of people with a disability. To facilitate this increase, we recommend that the Department of Health take the necessary steps to increase the number of students in training by 20 per annum for a five-year period. A significant increase in the number of occupational therapists is needed to provide the current service at adequate levels as well as to service the proposed expansion of day care/activity services. Additional specialised centres with occupational therapists are also needed so that patients can avail of services nearer home.

Physiotherapy

5.4.19 The community physiotherapist's role is to facilitate optimum health and well-being through education, health promotion, preventive measures, training and manual techniques for individuals, carers and the community at large. The physiotherapist helps to achieve the functional potential of a person with a physical disability and to compensate for functional disorders. Typically, a physiotherapist would examine, chart, analyse and evaluate an individual's functional state and recommend and implement a course of therapy to prevent and overcome functional difficulties.

5.4.20 The requirement for specialised equipment, which sometimes is not transportable, means that in many cases clients are required to attend for therapy at health board centres or centres run by voluntary groups. People with disabilities have inequitable access to physiotherapy services by being dependent largely on the facilities available near them. As with other services, this varies widely across the country. Many patients, especially in rural areas, must travel long distances to services, often without access to public transport. While physiotherapy can be provided more efficiently in properly-equipped and locally-based therapy centres and hospitals, there is also a need for a domiciliary service. This would provide advice and guidance to carers on basic therapy for people with various disabilities, such as the care and management of people with cystic fibrosis. The availability of such domiciliary services is very limited in practice. Of crucial importance is an improved follow-up service between hospital and community services to ensure that people with disabilities continue to receive appropriate and adequate therapy after they are discharged from hospital. This is often not provided.

5.4.21 We recommend that health boards provide for an increase of 85 physiotherapists to meet the needs of people with disabilities. The Group considers that the focus in the work of these additional physiotherapists should be in daycare and activity centres, domiciliary services and outreach clinics.

5.4.22 We recommend that the Department of Health take the necessary steps to enable the intake of students into the Schools of Physiotherapy to be increased by 12 per annum to meet our recommended staffing increases.

Family support services

5.4.23 Individuals can live in extremely stressful situations where feelings of isolation coupled with an unwillingness to admit to an inability to cope can lead to physical or mental breakdown with consequential call for inpatient/outpatient treatment and re-admission to residential care. Family support services, including social workers, provide support to patients and their families following discharge from hospital, including counselling in relation to their emotional/psychological adjustment to disability and the practical impact on their lives. A social worker can provide a social assessment of the overall needs, and help mobilise the appropriate services in conjunction with other concerned community personnel.

5.4.24 Family support services catering specifically for people with disabilities and their families and carers are extremely limited and are in the main provided by voluntary organisations. Some groups, notably the National Council for the Blind and the Irish Wheelchair Association, have a tradition of employing social workers. The Group welcomes the recent establishment by the National Association for the Deaf of a family support service for the deaf community in Ireland with funding received under the Child Care Act, 1991. These innovative methods of supporting persons with a disability within the community setting are to be welcomed.

5.4.25 In addition to client counselling, social workers should provide information and advocacy to families of people who have suffered a disability through accident, such as families of people with head injuries. A need exists for the development of links between individuals with a disability and the wider community. The Group recommends that health boards should increase the number of social workers providing support services to people with disabilities and their families by 40 over the next five years.

Help lines and peer counselling

5.4.26 Many voluntary organisations have established telephone advisory services for their members which fulfil a distinct but as yet unquantified need. A recent development by voluntary organisations such as the Irish Wheelchair Association and the National Council for the Blind has been the promotion of peer counselling. The underlying principle of peer counselling is that people with a disability can provide individual assistance and support to others in coping with disability and help them to bridge the gap between inactivity and participation.

5.4.27 The Group recommends that health boards support the development of help lines and peer counselling as an integral part of the community support services available to people with disabilities.

Psychology services

5.4.28 The provision of counselling, training in coping skills, and ongoing family support are some of the ways in which the psychologist can assist in improving the life situation of people with disabilities and their families. Psychologists can play a role in such key areas as social functioning and adjustment and family reactions to disability. Psychologists specialising in rehabilitation are employed by some of the voluntary bodies such as the Central Remedial Clinic and Cerebral Palsy Ireland as well as by NRB. Notwithstanding these services, the current provision of psychology services, particularly community-based services, for people with disabilities is inadequate. People with disabilities receive services largely from specialised centres, such as medical rehabilitation centres or special boarding schools, which are remote from their home community. When they are discharged from these centres to their homes, they find an absence of the psychological services necessary to continue their personal adjustment and social reintegration. Yet, ironically, the return home presents the greatest challenges and the greatest need for support, not only for the person with the disability, but for family and carers.

5.4.29 The Group also recognises that psychological services are needed by the school-going population and their families. Psychologists have a key role in assessing and making recommendations regarding appropriate educational provision and placement, supporting integrated education, and helping parents in developing their child's potential.

5.4.30 We welcome the recommendation of the **Report of the Special Education Review Committee** that the ratio of school psychologists be reduced from 1:12,000 to 1:5,000 as this should give further impetus to the concept of integrated education. We understand that the continuation of NRB's psychological service to schools for children with disabilities is currently the subject of discussion between the Departments of Health and Education. **While we would strongly support the mainstreaming of psychological services for disabled children, we recognise the specialist nature of the work, and recommend that whatever arrangements are made, the personnel providing the service have adequate training and experience.**

5.4.31 We consider that community-based psychological services for people with disabilities must be expanded. These will need to be geographically dispersed but provide specialised services. They will also need to maintain close links with existing medical, educational and vocational institutions. We consider the NRB to be well-positioned with its network of centres throughout the country and its existing services and linkages to provide a specialised community-based psychology service in close association with the health boards.

5.4.32 We recommend that the health boards increase psychologists posts by 10 over the next three years to develop effective psychology services for adults with disabilities and to develop further services for children with disabilities. These psychologists would liaise closely with existing statutory and voluntary services such as the National Rehabilitation Hospital, the National Association for the Deaf and the National Council for the Blind, and would deliver the agreed services directly and at community level.

5.5 Technical aids and appliances

5.5.1 Appropriate technical aids and appliances can contribute significantly to the quality of life of people with disabilities by increasing their independence and expanding the range of activities available to them. Innovations in technology provide an ever-increasing range of equipment to assist people with disabilities. For example, availability of simple aids may mean that a person with severe arthritis is no longer dependent on others for dressing. Bed or bath hoists may reduce the need for assistance from a carer or home help. The prompt provision and maintenance of the appropriate wheelchair can make a person independently mobile.

5.5.2 Health boards provide a range of aids and appliances to people with physical disabilities, including incontinence materials, wheelchairs, special beds, hoists, callipers as well as specialised items from time to time. The health boards' current budget for aids and appliances is estimated at £10 million, including aids and appliances for the elderly. Voluntary agencies also provide aids and appliances as well as seating clinics at which wheelchair seats are custom-made to enable maximum mobility for the user. However, in many instances, the range of aids provided is limited.

5.5.3 In the main, aids and appliances which have been recommended for a person with a disability are provided free of charge to medical card holders. People without medical cards may be assisted financially where the purchase of equipment constitutes financial hardship. Health boards may make a contribution to the cost of purchasing a powered wheelchair equivalent to the purchase price of an ordinary chair. Many submissions referred to a lack of clarity regarding entitlements under the General Medical Scheme, Long Term Illness Scheme and from health boards generally. In addition, they referred to differences in availability and policy regarding eligibility in relation to the provision of aids and appliances between health boards and even between different community care areas. The frequency with which wheelchairs or other appliances are replaced also varies between health boards. There is no uniform policy on refunds for aids and appliances for those not holding medical cards. In addition, the Group is aware of long waiting lists for assessment for aids and appliances due to the shortage of occupational therapists and subsequent waiting period before the provision of the appliances to the user. It should be noted that waiting lists for aids and appliances are kept artificially low due to waiting lists for occupational therapy services.

5.5.4 Budgetary constraints and under-resourced occupational therapy services limit health boards in their ability to provide, repair and replace necessary equipment promptly. Further demands on health board resources are caused by the provision of customised equipment such as wheelchairs which cannot be re-used when the client no longer needs it, for example when a child has outgrown his or her chair.

5.5.5 Lack of resources to purchase and repair essential appliances, such as wheelchairs, coupled with significant delays in the supply of such items, is causing much hardship. In our view priority should be given to the supply of basic medical and surgical appliances and the establishment of a properly-managed repair service. This should include communication devices for people with combined physical and communication disabilities. Expensive technical or computer aids which can enhance people's quality of independent living are increasingly available. It is considered that health boards should earmark some funding from their overall aids and appliances budget to provide such items.

5.5.6 The Group recommends that the Department of Health develop guidelines on the supply of aids and appliances by health boards to ensure that there is equity in access to them across the country. New aids and appliances should be added to the list of equipment available from health boards as soon as they have been properly evaluated.

5.5.7 In order to overcome the present deficiencies in the supply and repair of technical aids, we recommend that each health board, in consultation with the co-ordinating committee, assess the demand for technical aids and appliances in its area. In the interim, we recommend that the total aids and appliances budget of health boards be increased by £5 million over five years.

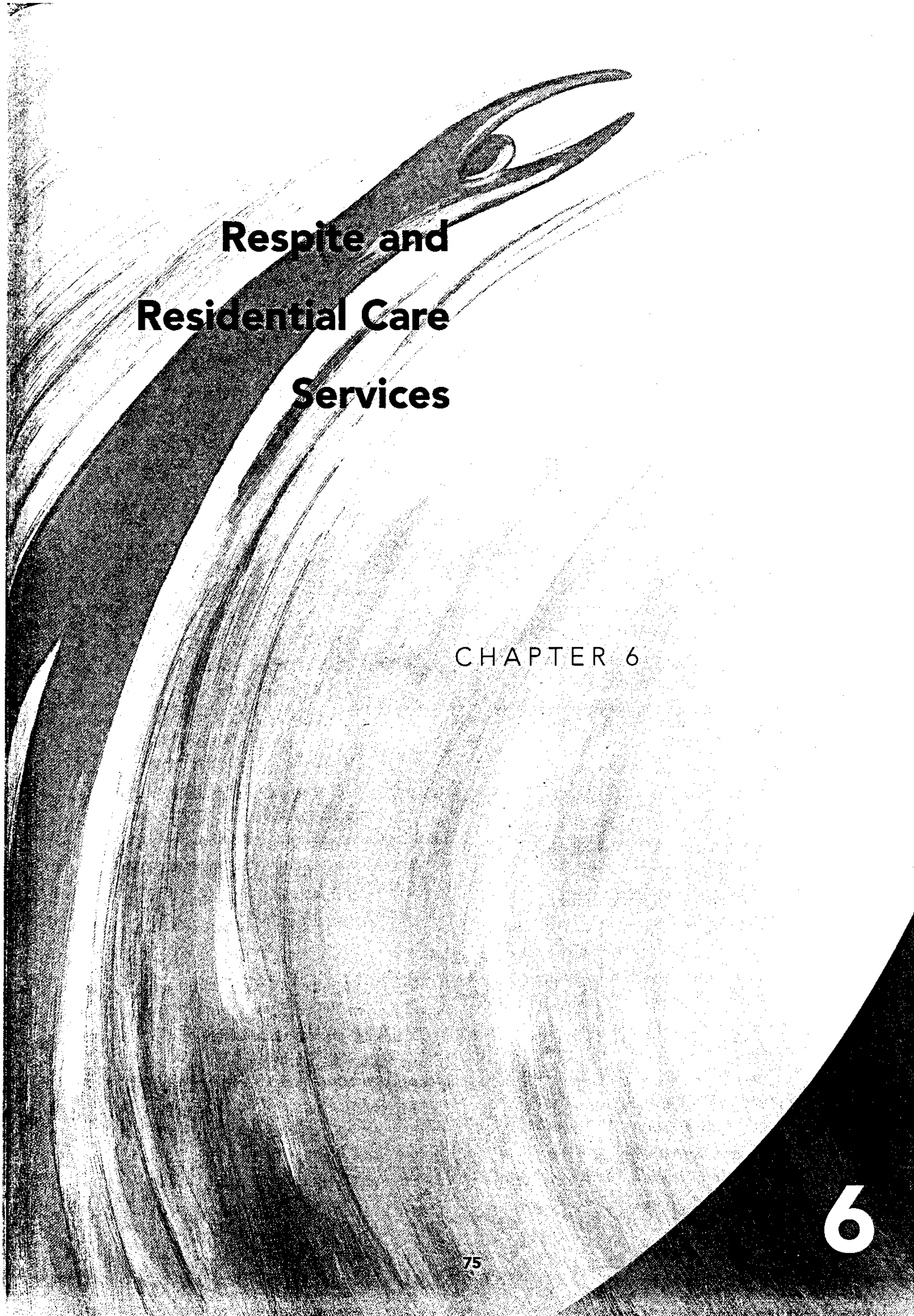
5.5.8 The difficulty we outlined above in relation to the provision of appliances and aids is a significant problem for children attending school who may need the same appliance at home and at school, such as computers and visual aids. For example, if a child requires a computer or other similar aid in school, he/she will invariably require the same equipment at home for study. In most cases such equipment is not provided in the home, thereby considerably impairing the child's educational development. **We consider that the Department of Education should make provision for the prompt supply of the necessary equipment both in school or college and in the home to children and young adults attending school or third level education.**

5.5.9 The Group recognises that a number of agencies provide resource centres for advice and information on technical aids, chiefly the NRB Disability Resource Centre, the National Council for the Blind technical service, the National

Association for the Deaf technical service - Deaftech, the Irish Wheelchair Association technical service and the Arthritis Foundation Resource Centre. ISAAC Ireland (International Society for Augmentative and Alternative Communication) plays an active role in providing information, advice and training about communication devices. **We consider that there is a need to make a similar service more locally accessible to those who need it. These agencies and the health boards should discuss and agree the most cost effective way of achieving this objective.**

5.6 Conclusions

5.6.1 In this Chapter, we have outlined the range of community services required by people with physical disabilities if they are to enjoy an independent future. It is clear there are significant shortfalls in the provision of community services. Existing services could be better organised to support people with disabilities in the community. Considerable input is required by the health boards and voluntary agencies if the services available to people with disabilities in the community are to meet the objectives of equity, quality and effectiveness that are fundamental principles of the **Health Strategy.**



Respite and Residential Care Services

CHAPTER 6

6

6.1 Introduction

6.1.1 Despite the many advances in medical care and allowing for the provision of community care support services recommended in the previous Chapter, there is, and will continue to be, a need for residential care facilities for people with disabilities on either a long term basis or for temporary periods. The Irish Wheelchair Association 1994 nation-wide survey of its members, *People First*, found that 58 per cent of members living in residential homes do so by choice. It is likely that some of these as well as the 42 per cent who do not live in residential homes by choice might choose to live in more independent accommodation or on their own if the necessary support services were provided.

6.1.2 The Group sees the need for a range of residential care services for people with disability. These include:

(i) Respite care - short temporary periods of residential care during which the person with a disability may receive medical, therapy and support services and which also affords the carer an opportunity for a break;

(ii) long-term residential care which provides appropriate support to people with disabilities who choose to live in residential care or who cannot be cared for in their home. These would include people with significant disabilities whose ageing families can no longer care for them. Such care could be provided:

(a) in independent living facilities with appropriate supports provided as required from the community based services described in Chapter 5,

(b) in independent or semi-independent living facilities with the necessary support services for people who, although they require significant assistance with daily living tasks, do not require a lot of nursing care, or

(c) in facilities which provide high levels of paramedical and nursing care, known as young chronic sick units, for people with very significant disabilities.

6.1.3 These options are described in detail in the following paragraphs. We also examine residential services for children attending schools for the deaf and blind.

6.2 Respite care

Definition

6.2.1 The Disability Federation of Ireland has defined respite care as "*temporary care, either community or centre based, which provides relief and personal development opportunities for the carer and the person requiring care within a variety of facilities. The need for care ranges from crisis intervention to planned regular breaks*". The Review Group considers this definition of respite care to be the most suitable.

6.2.2 Services such as the home care attendant scheme, home support and day placement services provide respite to carers of people with disabilities. These "non-residential" respite services have been examined in Chapter 5, and the reference in this Chapter to respite services refers to residential respite services only.

6.2.3 Residential respite care, by providing emergency and planned breaks for families and those caring for people with disabilities, is a vital support towards maintaining people with disabilities in their home. It is recognised that the availability of regular respite can reduce the number of people seeking long-term residential care. It is also accepted that, at certain times, people with disabilities need to be apart from those who routinely care for them. The 1994 DFI study of respite care for people with physical disabilities undertaken in the Eastern Health Board area, *Shut up at Home?*, identified three categories of respite care provision that ideally should be provided. These are:

(i) "*crisis*" respite when the carer becomes temporarily and suddenly unable to continue to provide care, eg due to illness or other emergency situations.

(ii) "*planned*" respite to enable the person with a disability and the carer to take a short "break" or holiday. This is the most often sought respite service.

(iii) "*planned repeated*" respite placement involving multiple breaks from the routine caring arrangements during the year. Such situations arise where the person with disability requires significant care putting considerable strain on the carer which can only be relieved through the provision of regular breaks.

Current respite care provision

6.2.4 It is estimated that there is currently a total of 140 respite places available to people with disabilities. However, most of these are not located in respite places dedicated for people with disabilities. Respite facilities tend to be located in nursing homes, geriatric homes, district hospitals or units for the young chronic sick which are used as required for people with disabilities. Submissions highlighted the unsuitability of such facilities for people with disabilities. It is clear to us that the number of dedicated, or even suitable, respite beds for people with disabilities is wholly inadequate.

6.2.5 **On the basis of information received from health boards we recommend that 200 dedicated respite places for people with disabilities, in addition to the existing number of places, be provided as a matter of urgency.** These places could be provided either as specialist respite facilities or as dedicated respite places in suitable long-term residential facilities for people with disabilities. The precise location and the appropriate provider of these places would be a matter for consideration by the co-ordinating committees. These facilities should be attractive and adjacent to social facilities and outlets and close to accessible public transport.

6.2.6 It has been represented to us that the existing respite facilities which cater almost exclusively for adults are unsuitable for children. **Accordingly, we recommend that health boards, in consultation with the co-ordinating committees, should provide appropriate respite facilities for children with disabilities.** It was suggested to the Group that this might be achieved by having specific periods during which children would be accommodated in a facility proposed in the previous paragraph rather than having a specific facility for children. As in the case of respite care for adults, consideration should be given to providing attractive accommodation and appropriate daytime recreation.

6.2.7 The precise mix of the different types of service required will have to be established by the co-ordinating committees. We consider that respite facilities should not accommodate more than fifteen people at any one time, preferably in individual rooms. Staff should receive specific training concerning the physical, emotional and social needs of people in their care.

Admission/discharge policy for respite places

6.2.8 It is important to ensure, especially in cases where dedicated respite places are part of long-term respite facilities, that respite places do not become long-term residential places. **While a certain degree of flexibility is required, we recommend that each centre put in place a proper admission/discharge policy for respite services.**

6.3 Residential services

Residential care for adults

6.3.1 There are approximately 390 adults with a physical disability in Ireland living in residential homes, the majority of which are Cheshire Homes. Homes for adults with a sensory disability provide a further 156 places.

6.3.2 A number of homes have been refurbished and extended recently and now provide single units of accommodation to residents. However, we consider that many residential buildings are unsuited to the purpose they are now serving and require planned upgrading to meet current building standards. Many would benefit from considerable refurbishment and provision of appropriate aids and appliances. **We recommend that each health board undertake a planned programme of refurbishment of residential homes over the next five years in consultation with the co-ordinating committee, and the agencies responsible for the homes.**

6.3.3 The living units recently provided by the Cheshire Foundation in Sligo, Letterkenny and Galway, and funded under the Department of the Environment Capital Assistance Scheme, are designed to provide a mixture of independent living facilities together with individual units of accommodation for more dependent people. Other developments, such as that provided by the Irish Wheelchair Association in Galway, also funded under the Department of the Environment Capital Assistance Scheme, provide a temporary step down facility prior to living independently. **We welcome these developments and recommend them as models for future provision of residential care for people with disabilities. In addition, we consider that residents of new and existing developments should be involved in the management of the home.**

6.3.4 New residential developments should be accessible to wheelchair users. The residents of existing homes which are located in rural areas should be provided with appropriate transport to retail and leisure outlets to ensure that they are not isolated. **The Group recommends that new residential homes and independent living units should be located where they are easily accessible to retail and leisure facilities.**

Independent living arrangements

6.3.5 In the context of residential care, an independent living arrangement offers a person with a disability an opportunity to live in a domestic dwelling, supported with the necessary health and social services. Increasingly, this option is being sought as an alternative to a place in a residential home. The Group welcomes this development and considers that it must be encouraged because it promotes independence and respects the service user's right to choose the form of care most appropriate to him or her.

6.3.6 Voluntary organisations have developed their role in the provision of housing using the Department of the Environment's Capital Assistance Scheme. Of particular merit is the Irish Wheelchair Association development described in paragraph 6.3.3. The IWA development, by providing appropriate accessible independent living units and the necessary supports and training for people with disabilities in all aspects of independent living, facilitates the move to fully independent living. **We recommend that each health board, in consultation with the co-ordinating committee, should examine the viability of establishing such schemes in its area. In addition, health boards and voluntary bodies providing services to people with disabilities should liaise closely with social housing organisations and local authorities to ensure that an adequate number of accessible houses is available to people with disabilities who wish to pursue this option.**

6.3.7 The merits of the independent living option on a personal and social basis are substantial. It accords with the principle of the **Health Strategy** aimed at ensuring that health care is provided in the most appropriate setting. As more semi-independent living accommodation is provided as part of residential care facilities, the independent living option is likely to grow in popularity.

Future requirements

6.3.8 The implementation of our recommendations in Chapter 5 in relation to the provision of community-support services and the availability of appropriate respite care services should reduce the demand for long-term residential places considerably. **Accordingly we recommend that the assessment of the likely requirement for residential care over the next five years should be made by health boards, in consultation with the co-ordinating committees, on the basis that the necessary community-based supports and respite care services will be put in place.**

6.3.9 Nevertheless, we are satisfied from the information available to the Group that there is an immediate need for an additional 100 residential places for people with disabilities. **We recommend that health boards, in consultation with the co-ordinating committees, arrange for the provision of these 100 residential places in dedicated facilities for people with disabilities as soon as possible.**

Residential accommodation for young hearing impaired persons

6.3.10 The Review of Needs of Young Hearing Impaired Persons undertaken jointly by NRB, the National Association for the Deaf, the Department of Education and the Eastern Health Board in 1987 identified the problem of inappropriate placement of young persons with a hearing disability. An update of this study highlighted the social consequences of inappropriate placement for young persons with a hearing loss. The availability of staff who can communicate with deaf people in a residential home would reduce the level of isolation that these people currently feel and would facilitate the transfer from psychiatric homes of those deaf people who are inappropriately placed there. **Accordingly, we recommend that the health boards, in consultation with the co-ordinating committees, examine the need for suitable residential services for young persons with a hearing impairment.**

Units for persons with long term disabilities requiring constant nursing care

6.3.11 The Group identified a need to establish special facilities for young persons who have a permanent disability such as severe multiple sclerosis or severe head injury requiring continuing professional care, primarily nursing. Such facilities should also provide a range of therapy services and rehabilitative assessment. At present, such persons are maintained in a variety of hospital settings including geriatric hospitals and district hospitals, not all of which are appropriate locations for their care. The Dublin Hospital Initiative Group also pointed to the fact that a number of people with severe disabilities were inappropriately placed in acute hospitals.

6.3.12 Our assessment of existing services highlighted a significant shortfall of appropriate places for persons with long term disabilities requiring constant nursing care. The collection of accurate data on persons with a long term disability who require continuous professional care should be made as a priority by the health boards, in consultation with the co-ordinating committees. It would seem that there is a need for at least one unit for the young chronic sick per health board area. A particularly urgent requirement exists now for the expansion of such services in the Eastern Health Board area. Despite the recent provision of twenty-five new places in Cherry Orchard for people requiring constant nursing care, the Board estimates that, in the Board's hospitals alone, eighty persons under the age of sixty-five years are currently inappropriately placed.

6.3.13 We recommend that health boards arrange for the provision of an additional 200 places for persons with long term disabilities requiring constant nursing care.

Facilities for children attending schools for the deaf and blind

6.3.14 There are five residential centres in Dublin providing five-day care for children attending the special national schools for the deaf and blind. There are 350 children in these residences which are funded by the Eastern Health Board.

6.3.15 The Report of the Special Education Review Committee recommended that "only in the most exceptional circumstances should it be necessary for a child to live away from home in order to avail of an appropriate education". The report was also satisfied that specific educational facilities were required for profoundly or severely deaf children. The Group is aware that, because of the greater integration of deaf and blind children in mainstream education, the need for residential accommodation associated with special schools is decreasing. Accordingly, **we recommend that the Departments of Health and Education, as part of the consultation recommended by the Special Education Review Committee, as a matter of urgency and in consultation with the schools, should examine the likely future demand for residential care for children attending schools for the deaf and blind and take appropriate steps to reduce the need for residential places as far as possible.**

6.3.16 In the interim, we recommend that no child should attend a residential school for the deaf unless the local school inspector and a senior health professional certify that it is in the child's best interests that he or she so attend.

6.3.17 There are no national standards applying to school residential centres and they are not regarded as coming within the terms of the Child Care Act, 1991. **We recommend that statutory residential care standards, similar to those applying to children's residential homes under the Child Care Act, 1991 should apply to the residences attached to schools.**

6.4 Investigation of complaints

6.4.1 The issue of procedures to deal with complaints of abuse by staff of service users in day or residential centres was raised at the consultative seminar. **The Group recommends that each organisation providing services for children have a set of guidelines for investigating complaints of abuse in conformity with the 1987 Department of Health published Child Abuse Guidelines and all statutory requirements.** It should be noted that the provisions of the Child Care Act, 1991, which enable health boards to investigate cases of abuse, apply to all children, including children with disabilities, regardless of their location. The Group commends the proposed establishment of the Inspectorate of Social Services whose principal function will be the quality assurance and audit of child care practice. **The Group recommends that its remit should be extended as soon as possible to include children with disabilities.**

6.4.2 **The Group also recommends that agencies which do not yet have them should put in place, following discussion with health boards, procedures for the investigation of complaints of abuse in relation to vulnerable adults.**

6.4.3 Residential homes for people with disabilities are not registerable under the Child Care Act, 1991 or Nursing Homes Act, 1993. **We recommend that the Department of Health give consideration to introducing registration of residential homes for people with disabilities.**

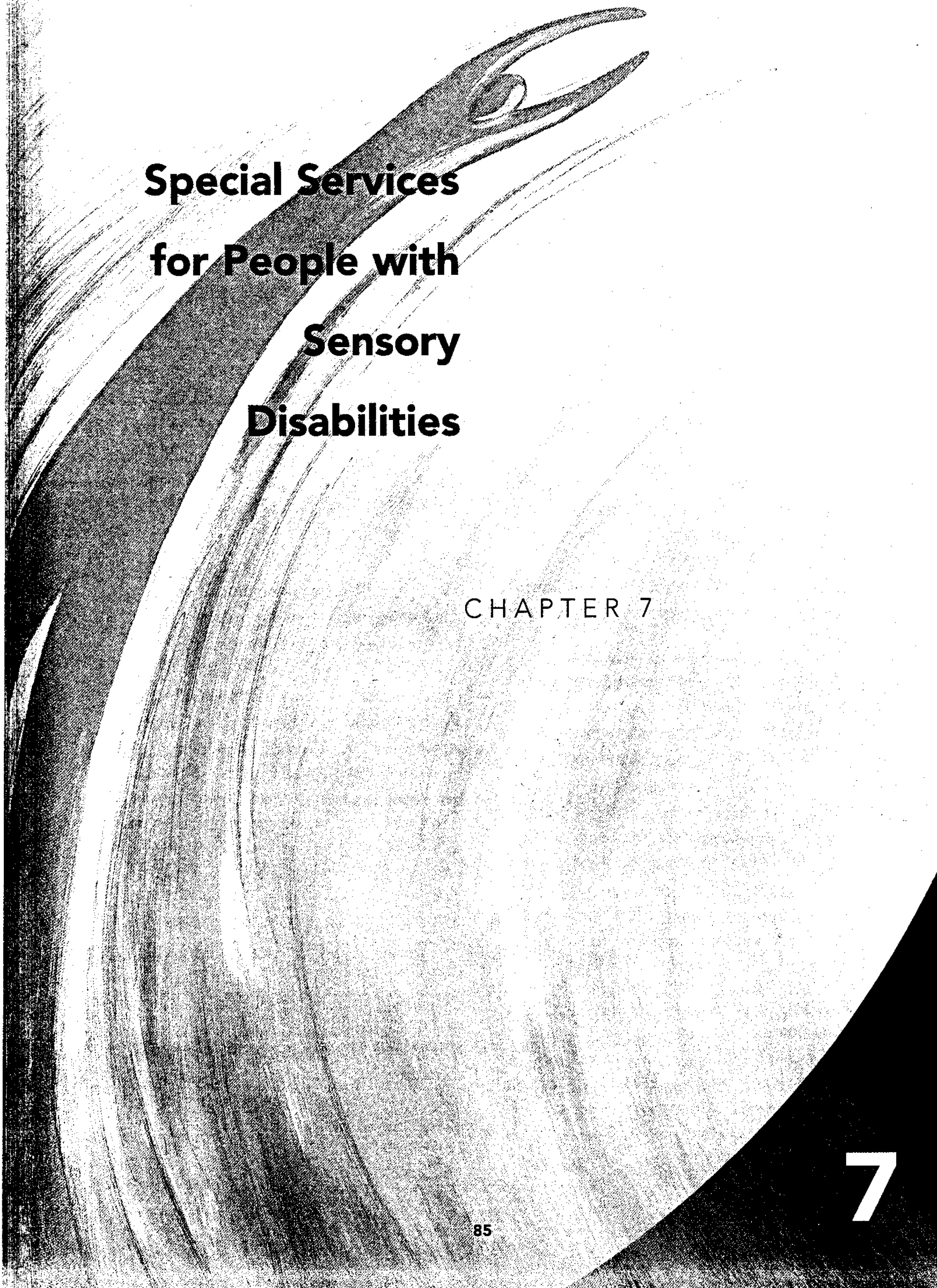
6.5 Conclusions

6.5.1 There will be a continuing need for residential places for people with disabilities. Residential care should offer a range of options, from independent living, to respite care to constant nursing care. Many persons with a significant disability are living in inappropriate residential accommodation. Some could live in more independent arrangements. Others should be cared for in dedicated units for the physically disabled. The provision of more dedicated facilities will also enable those services currently inappropriately providing residential care, such as hospitals, to revert to their primary purpose.

6.5.2 Providing the range of services we propose will require considerable additional investment over a period of time. The most immediate priority should be the development of respite facilities for adults and children. Providing these facilities will have a direct beneficial effect on the person with the disability and on the personal needs of carers who have their own social and recreational needs.

6.5.3 Each health board should provide the range of residential care options for adults and children outlined in this Report. Planning the provision of residential facilities will require a balance between the benefits of accessibility to local communities and those of specialised care. The re-organisation of residential care facilities will take some time to achieve but, when implemented, will have considerable health and social gain for the users of the services.

6.5.4 The development of independent living arrangements will involve designing new standards of care for those professionals providing support to clients by way of health or social services. We suggest that the professions involved, the providers of independent living arrangements and service users should work together to produce a code of practice for such care.



Special Services for People with Sensory Disabilities

CHAPTER 7

7.1 Introduction

7.1.1 The term *person with sensory impairment* is used to describe a person who is deaf or hard of hearing (hearing impaired); blind or partially sighted (visually impaired); or who is both deaf and blind (deaf-blind).

7.1.2 Sight and hearing are key components in learning, in communicating and in living independently. People with sensory disabilities require a range of specialised support services which often fall under the heading of social gain rather than health gain.

7.1.3 It is important to note that, although for the purposes of this Report "*sensory disability*" is used as a cover term for all of the above disability categories, it does not imply that people with these disabilities are a homogenous group with the same service needs. Deaf people do not have the same service needs as blind people. In the same way, deaf people do not have the same needs as those who are hard of hearing.

7.1.4 The Group considers that the services for people with sensory disabilities are underdeveloped and believes that an injection of resources is needed to improve them.

7.2 Visual impairment

7.2.1 Health service developments proposed already in Chapters 4 and 5 will benefit children with visual impairments and their parents. The improvements in referral procedures, the development of child assessment teams and increased numbers provided for by the community nursing service, as well as the general availability of speech and language specialists, should all contribute to better availability of support and services for families with a visually-impaired child or children.

7.2.2 The Group recommends that the child assessment teams provided for in paragraph 4.2.16 should include a specialist in motor movement development of visually-impaired children and a specialist family support worker for families with visually-impaired members when visually-impaired children are being assessed.

7.2.3 Where possible, children with a visual impairment should be educated in their own locality. Integration in normal schooling will require an investment in technical supports which should be supplied promptly. **The Group recommends that the Departments of Health and Education identify clear lines of responsibility for the supply of low vision devices and technical aids required in and out of the classroom setting.**

7.2.4 An arrangement with the National Council for the Blind of Ireland (NCBI) for developing a pool of aids which would be made available on loan to people as they need them could be a useful approach. Use of this pool should also extend to students at third level colleges who will also require assistance with the provision of technical devices. **The Group recommends that a once-off sum of £250,000 be set aside to develop a pool of suitable aids and to help defray the routine costs of maintenance, the funding to be reviewed after three years.**

Rehabilitation

7.2.5 People with a visual impairment require a specific rehabilitation service designed to maximise their independence. Rehabilitation of visually-impaired persons usually takes the form of counselling the individual on the social and economic consequences of sight loss and supporting the person through the various stages of learning to cope with such loss. This involves teaching them to use any residual vision to its optimum, to move safely with the use of a long cane or guide dog, to use alternative forms and different media for writing and reading and teaching the techniques of daily living to enable them to manage at home. Rehabilitation services may be delivered through short training courses in specialised centres or through a regime of domiciliary visits or a combination of both.

7.2.6 The Group recommends that rehabilitation services for visually-impaired persons be improved and towards this end, each community care area should have available to it the services of a rehabilitation worker with an expertise in visual impairment. Ideally, this person should form part of the technical/paramedical staffing of the health board or be provided by arrangement with the NCBI. In time, services of this nature being supplied by the NCBI may be provided by health boards in all community care areas. The NCBI may then provide a supporting service and assist the health boards with the initial and ongoing training of rehabilitation workers for the blind.

7.2.7 Health boards should contribute to the rehabilitation costs of visually-impaired persons in specialised centres at a rate and on a scale of fees for approved agencies agreed by the Department of Health. Funding should also extend to centres providing persons with their first and replacement guide dogs. Health boards may also pay a fee, at an agreed hourly rate, for the provision of domiciliary rehabilitation services as an alternative to, or in support of, centre-based rehabilitation programmes.

7.2.8 The Group recommends that the Department of Health ensure that publications of its Health Promotion Unit are accessible to people with visual impairments.

Social work, counselling and family support

7.2.9 Social work services to visually-impaired persons have traditionally included a wide range of services, including a rehabilitation programme to encourage the person to lead an independent life. This composite service of social work and rehabilitation is currently provided through the NCBI, part funded by the health boards.

7.2.10 The Group sees this work continuing through the NCBI but gradually reducing as health boards employ the rehabilitation workers for the blind recommended in paragraph 7.2.6. Visually-impaired persons will also have increasing access to the health board social workers recommended in Chapter 5. The health boards should continue to fund, through the NCBI, support services for the visually impaired which would include social work, family support work and counselling through professionals and through a peer counselling programme. The Group supports the development of family and support counselling programmes for the visually-impaired delivered as part of the recommendation at paragraph 5.4.27. Such services for the visually-impaired should be developed on a regional basis, rather than on the current community care area basis.

Specialised reading and library services

7.2.11 For most of the population, reading and writing are skills learned in the early years of school without much difficulty. The difficulties encountered by people with significant physical disabilities are usually of a mechanical nature, such as requiring books to be held and pages turned mechanically. Persons who are totally blind or whose sight will not allow them to read normal print require reading material on tape, disc or in Braille. Materials have to be specially prepared and then housed in collections or libraries for lending. The preparation of materials usually entails the use of recording studios and Braille printing machines. Tapes can be played only on specially modified tape recorders that overcome the problems related to copyright. There must be discussions between the Department of the Environment and NCBI about the funding and development of this essential service.

Low vision aids

7.2.12 It is important that people are assisted to use their residual vision to the full. Through the provision of low vision aids, children can be retained in normal schools, employment prospects are enhanced and the pursuit of leisure and recreational activities by the elderly is made possible. **Health boards, in**

consultation with the NCBI, should develop a comprehensive low vision service providing equipment prescribed in respect of visual impairments.

Technical aids

7.2.13 An increasing number of persons with reduced sight are availing of technical aids and appliances to communicate with the visual world. Generally, the cost of such items in Ireland is higher than in most EU countries where items such as talking kitchen scales and large-print calculators are subsidised or provided free of charge because they are deemed to be essential in an educational, work or recreational setting. **The Group recommends that the Department of Health, in consultation with the NCBI, draw up a list of technical non-medical equipment needed for independent living which would be approved for health board funding.** The provision of equipment for use in educational settings is a matter for the Department of Education.

7.3 Hearing impairment

7.3.1 In designing services for people with hearing impairment, care must be taken to deliver specific types or levels of service appropriate to the person's communication needs, through sign language, lip-reading or use of residual hearing with assistance from technical aids.

Early assessment and rehabilitation

7.3.2 A number of recommendations in relation to early assessment and rehabilitation already contained in this Report, if implemented, will have tangible benefits for both hearing-impaired children and their parents. Other recommendations, more specific to the needs of people with hearing impairments, are set out below.

7.3.3 The Group recommends that the Department of Health ensure that publications of its Health Promotion Unit are accessible to deaf and hearing-impaired persons, through subtitling of videotapes and through sign language where feasible.

7.3.4 Where necessary, professional health care staff should have access to sign language interpreters/lipspeakers when dealing with deaf or hard of hearing parents. Staff working primarily with deaf people should be proficient in sign language communication.

7.3.5 The Group recommends that, when children with hearing loss are being assessed, the proposed regional child assessment teams should include a psychologist and speech therapist with specialist knowledge and expertise with deaf children and a specialist family support worker for deaf families.

7.3.6 The Group recommends that radio aids or appropriate technical equipment be provided for hearing-impaired children attending local schools without any time delay and that this matter should be monitored by the Inter-departmental Committee of the Departments of Health and Education.

7.3.7 The Group recognises that, while the Department of Education provides radio aids for children who attend mainstream schools, no formal arrangement exists for students in third level education and at post-leaving certificate education. The Group considers that the feasibility of developing a pool of appropriate aids such as radio aids and amplifying devices for use in these cases should be considered by the Inter-departmental Committee. **We recommend that a once-off sum of £50,000 be set aside by the Department for Education to develop this pool and to help defray the routine costs of maintenance over the next three years.**

Rehabilitation policy

7.3.8 A person whose hearing has deteriorated may receive only partial benefit from using a hearing aid. Instruction in lip-reading is usually essential to improve communication and benefit from the appliance. **The Group recommends that audiological rehabilitation should incorporate lip-reading classes in addition to the provision of hearing aids.**

7.3.9 The Group welcomes the recent secondment of a lip-reading teacher by the Department of Education to the National Association for the Deaf (NAD) to train lip-reading teachers. **The Group recommends that the provision of lip-reading classes and the training of further lip-reading teachers be examined by NRB in consultation with the NAD. A once-off grant of £20,000 should be provided by the Department of Health during the pilot phase of three years towards the development of course materials and the provision of a training course for up to 24 lip-reading teachers.**

7.3.10 The Group recommends that vocational training centres, where appropriate, should make specific provision for the communication needs of deaf trainees in the delivery of training.

Community services

7.3.11 The major obstacle to deaf and hearing-impaired persons accessing many existing community services is the communication barrier arising from hearing loss. This obstacle is best overcome through the availability of a communication support service such as sign interpreters, lipspeakers and deaf-blind communicators. **The Group recommends that each health board should arrange for such a service to be available to it.** It is estimated that an average allowance of 15 hours' communication support per annum for 3,500 people should cater for this demand.

Speech and language therapy

7.3.12 The Group is aware that hearing-impaired children are not generally in receipt of speech and language therapy services and should benefit from improvements arising from the implementation of recommendations for the development of speech and language therapy services in Chapter 5.

7.3.13 The Group recognises that specialised speech and language therapy services are required for some people with hearing impairments such as people with cochlear implants. **Accordingly, the Group recommends that at least one of the speech and language therapy posts recommended in Chapter 5 be assigned to the NAD.**

Social work

7.3.14 The Family Support Service recently established by the NAD is recognised as a core service for deaf people and their families and is the primary support mechanism available to them. The current service, staffed by four social workers/counsellors, is not adequate for the demands placed on it and needs to be extended. **The Group recommends that health boards, in consultation with the NAD, should arrange for the provision of adequate social work and counselling services for people with hearing impairments and their families. The Group considers that an additional 10 posts are required.**

Psychology and mental health services

7.3.15 The Group considers that at least one of the 10 psychologist posts recommended in Chapter 5 be assigned to provide services to the deaf and could be attached to the NAD Family Support Service.

7.3.16 The Group was made aware of the serious problems experienced by profoundly-deaf persons in accessing mental health services. **The Group recommends that each health board take steps to develop a specialist mental health service to cater for the needs of profoundly-deaf service users.**

Technical aids and appliances

7.3.17 Hearing-impaired persons rely heavily on a small number of vital technical appliances in order to live independently. These devices include safety equipment, such as special smoke alarms, in addition to door-bells, baby alarms and communication equipment. **The Group welcomes the initiative between the NAD and the Eastern Health Board in relation to baby alarms for hearing-impaired parents and recommends that this be extended to all health boards. In addition, we recommend that the**

Department of Health, in consultation with the NAD, draw up a list of non-medical technical equipment necessary for independent living which would be approved for health board funding.

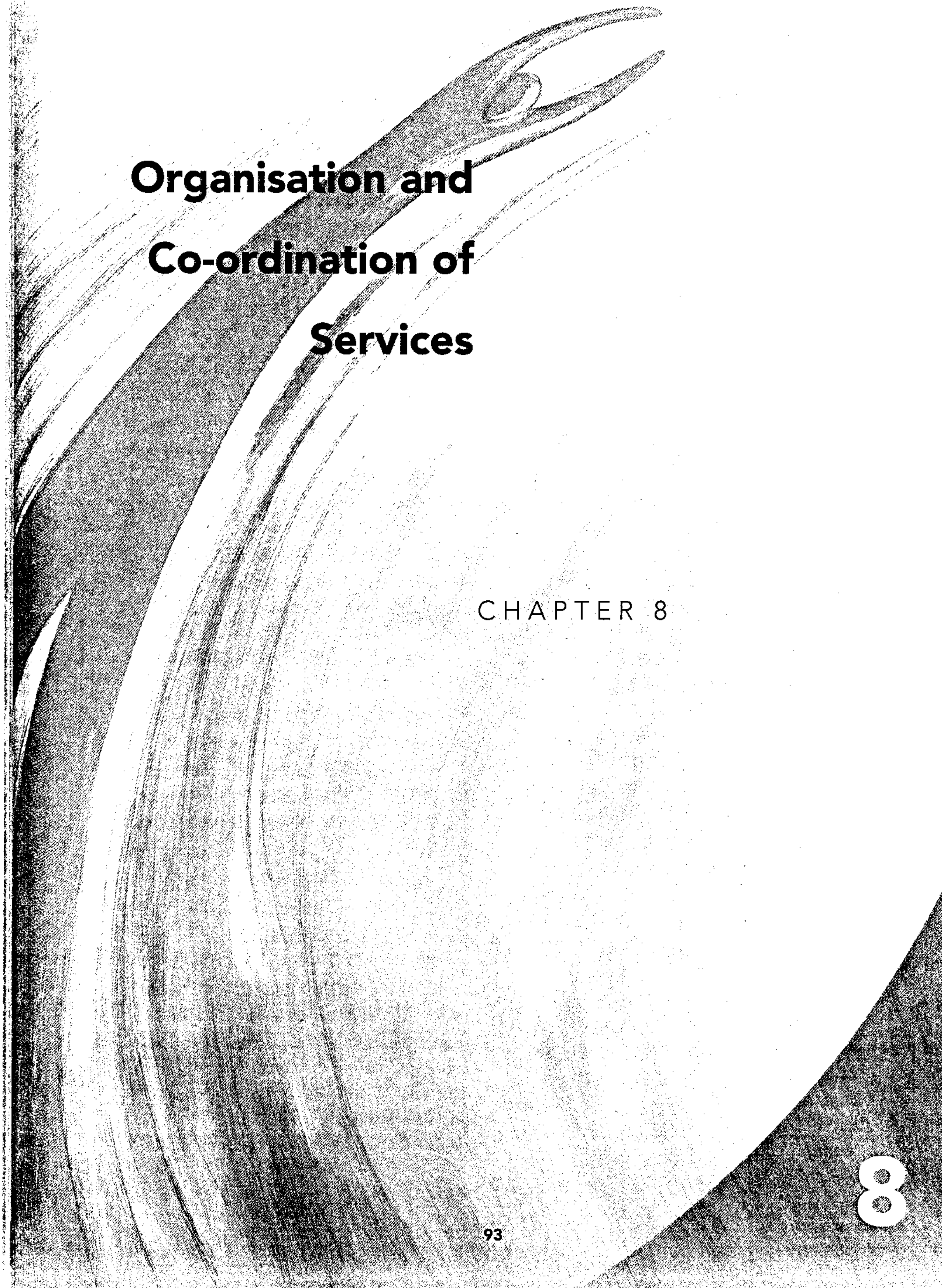
7.3.18 The Group recognises the need for a locally-accessible technical aids service for the deaf, on the lines of the "Deaftech" service provided by the NAD. The provision of this service should be examined in tandem with the recommendation at paragraph 5.5.9.

Peer counselling

7.3.19 The Group recommends that each health board support the provision of trained peer counsellors for the deaf to work with the NAD Family Support Team in each region, with a particular role in mental health services. As part of the recommendation at paragraph 5.4.27, a once-off sum of £20,000 should be allocated by the Department of Health towards the training of additional peer counsellors and £40,000 per annum towards developing and supporting a peer counselling network for deaf people.

Residential accommodation

7.3.20 The need for a residential service for young deaf persons with additional difficulties has been highlighted since 1987. **The Group recommends that health boards, in consultation with the co-ordinating committees, examine the need for suitable residential services, staffed by both deaf and hearing staff fluent in sign language, for these service users as a matter of urgency.**



Organisation and Co-ordination of Services

CHAPTER 8

8

8.1 Introduction

8.1.1 The Group was concerned at shortcomings in the current arrangements for the delivery and co-ordination of services for people with disabilities. This concern arose from the experiences of the members themselves and from the many submissions to the Group which complained of lack of co-ordination and fragmentation of existing services.

8.1.2 It was also evident to the Group that, while there has been progress in recent years and some notable initiatives in creating a service which was user/family centred, much still needs to be done. For example, to receive information and advice regarding a particular impairment or disability, a person may have to contact a number of organisations such as the health board, voluntary hospital or voluntary organisation and deal with a number of people within each of these organisations. The services which an individual receives can be related more to his/her eligibility, that is whether he/she has a medical card, VHI cover or is insured under the Department of Social Welfare, or by the range of services available from the local agencies, than to his/her identified needs. A person's disability may mean that he/she requires a number of different types of support such as day care, occupational therapy, respite and home support. The submissions we received suggested that individuals have great difficulties in obtaining the "package" of services necessary to enable them to live as independently as possible. While this may be due in the first instance to the unavailability of a service in a particular area, the problem is exacerbated by inadequate planning and co-ordination at regional and community care levels as well as by under-resourcing.

8.1.3 The Group endorses the emphasis in the **Health Strategy** on developing a service-user centred health service. This approach is particularly important in the area of disability services because many service users will have a life-long involvement with the services. The delivery and impact of those services will have a major bearing on the quality of life and the ability of individuals to integrate into society to the greatest degree possible for them. A holistic approach designed around the needs of individual service users rather than around the organisational structures of the services is required.

8.1.4 Another aspect particular to people with disabilities availing of health services is the need for non-health support services which are an essential part of the package of support necessary to meet the requirements of service users, for example access to transport, suitable housing and education. These services come under the aegis of different government departments, public agencies or voluntary organisations. A co-ordinated approach by all those with responsibilities towards people with disabilities is essential if a "seamless" service is to be delivered.

8.1.5 Many dedicated persons are working within the statutory and voluntary services at present. The Group believes their commitment is not achieving its full potential due to inadequacies in existing structures and under-resourcing.

8.2 Background to organisational structures

Government departments

8.2.1 There is a need for better co-ordination between government departments, particularly between the Departments of Health and Education. Recent Court cases have challenged the adequacy of educational provisions for children with a handicap and sought appropriate educational services on a par with those of other children. Effective developmental policies for children which take into account both educational and health needs must now be formulated by these departments. The Group welcomes the establishment of the Department of Education and Health Inter-departmental Committee as an important first step. We suggest that this Committee make the establishment of a personal education/health development curriculum a priority. All the relevant sectors should be provided with an opportunity to contribute to the development of this curriculum which should be a flexible model.

8.2.2 There is a second important aspect to co-ordination between government departments which the Group wishes to address. At present the Department of Health is responsible for some services which are not related to health issues, for example training/employment for people with disabilities. This has resulted from the tradition of providing all services to people with disabilities through the structure of the health services. People with disabilities now expect particular services to be provided as part of the services generally available to the public and through the same agencies/ departments, whether this be employment, income support or transport. The transfer of the administration of the Disabled Persons Maintenance Allowance to the Department of Social Welfare is welcome in this regard. In general, there is a requirement for the needs of people with a disability to be taken into account by all government departments in formulating policies, referred to as "disability proofing". **The Group recommends that an appropriate and clear reallocation of non-health related responsibility among government departments be made in line with mainstreaming services for people with disabilities.**

Health boards

8.2.3 The health boards have the statutory responsibility for providing health services under the Health Acts. Health board services are organised in three programmes - community care, general hospital care and special hospital care. Two of the smaller health boards, the Midland and North-Western, have no special hospitals programmes. The community care programme provides primary health care, personal social services, child care, physical disability and mental handicap services. General hospital care provides acute hospital services. Special hospital care provides acute and continuing care services for the elderly and people with mental illness. The range of responsibility of each programme may vary between health boards.

8.2.4 In general, services for people with disabilities are provided under the community care programme. However, in the Eastern Health Board area there is a division of responsibilities with residential care provided under the hospitals programme and community services under the community care programme. Voluntary organisations which have to deal with both programmes have complained about the inefficiencies this division of responsibilities causes. Training services are usually provided in an integrated manner for people with all types of disability and are generally overseen by the special hospitals programme.

8.2.5 Services for persons with disabilities have had a lower public profile than the acute hospital services and some other disability areas such as mental handicap. They have lacked sustained investment and it is only in recent years, particularly since the advent of the Programme for Economic and Social Progress, that real planning of services has been undertaken and that additional funding has been provided on a consistent basis. Notwithstanding the benefits derived from this recent investment, it is clear that there is a need for significant additional resources to be made available.

8.2.6 In addition to "specialised" services, people with disabilities avail of other general community care services, general practitioner services and acute hospital services. The **Health Strategy** points out that hospitals, general practitioners and other community services should operate as elements of an integrated system within which patients can move freely as their needs dictate and acknowledges that, at present, the system is too compartmentalised to permit this flexibility. A key objective of the **Strategy** is to ensure that better linkages are forged between the various services and a number of measures are adopted in the Four-Year Action Plan of the **Strategy** to achieve this. We welcome this commitment which should result in improved delivery of services to the general public including people with disabilities.

Voluntary agencies

8.2.7 While health boards have the statutory responsibility for the provision of services, in practice much of the service has been provided by voluntary organisations either with or without assistance from health boards. Voluntary organisations have been defined by Dr Pauline Faughnan as "*formal organisations which are non-statutory, self-governing, non-profit distributing, of public benefit and utilising volunteers to a greater or lesser extent. There are national voluntary organisations and those which are exclusively local, organisations which rely predominantly on volunteers and those which employ large numbers of professional staff; those which provide material services and those which are also engaged in development work, advocacy or campaigning.*" [1]

8.2.8 The Group recognises the major role played by voluntary organisations in representing people with disabilities and in addressing their needs, in pioneering the development of services to meet these needs, in piloting innovative approaches and methods of service delivery and in generating considerable finance for the delivery of services. Estimated at over 100, these organisations meet their running costs from a combination of fund-raising, grants from health boards under Section 65 of the Health Act, 1953 and grants from other sources such as the National Lottery.

8.2.9 Volunteers play an essential role in the provision of many services for people with disabilities. These include the provision of transport, telephone help lines, organising social activities and fundraising. Preparation of individuals for their role as a volunteer is an important task which should be actively planned for in service provision. Adequate formal training for volunteers is vital to ensure that their role is fully understood and in harmony with the objectives of the organisation which involves them.

8.2.10 While the existence of many organisations, some of which are very small, can help foster the development of new ideas, it presents a challenge to agreeing priorities regarding which services to fund. Further difficulties in identifying priorities with regard to funding arise when different branches of the same organisation are vying with each other for assistance. In addition, the multiplicity of agencies creates a difficulty in providing these agencies with a united voice in the process of policy formulation at national level.

8.2.11 Many voluntary groups were established in order to provide information and support to people with a particular impairment and then became service providers because the services required by their members were either not available or inadequate. Voluntary groups which establish services with the use of once-off funding may then seek ongoing statutory funding to enable the services to continue and this, rather than actual service needs, then drives priorities in relation to resource allocation. Developed initially to provide support, it has been argued that there are now too many organisations seeking statutory funding from the boards' finite resources. In addition, it is clear that the sometimes unco-ordinated development of voluntary services has led to the provision of similar services in an area by a number of organisations, for example duplication of transport services to day facilities. Newly-emerging organisations tend to encounter particular difficulties in obtaining funding, due in part to the health boards' already-stretched resources and the fact that the organisations may not have a proven track record. The Group considers that a proper mechanism to enable co-ordination between voluntary organisations and health boards in planning and providing services should facilitate more efficient and effective service provision for people with disabilities.

8.2.12 Nearly 60 organisations in the disability field, the majority of which are concerned with physical and sensory disability, are affiliated to a national umbrella body for disability organisations, the Disability Federation of Ireland (DFI). The mission of DFI is to help its member organisations deliver the best possible range of services to people with disabling conditions. DFI has recently reorganised itself to provide greater support for its members on the broad range of issues that face them and has drawn up a strategic plan for the period 1995-1998. The work of DFI can be categorised under the main headings of networking; support on specific issues such as management development, finance, Europe; policy development and representation; and promoting good practice and support services to voluntary organisations and the community.

8.2.13 The Group recognises that organisational structures for the voluntary sector are a matter for the agencies themselves. However, the Group wishes to point out that this issue will impact increasingly on the effectiveness of the service as a whole because of the importance of the voluntary sector in providing services and it welcomes the commitment of DFI to developing the type of support services referred to above. In doing so, it would advise DFI to have regard, in determining its own structures, to the emphasis of the **Health Strategy** to devolving decision making to health board level. The Group considers that national organisations should continue to have an input into policy at national level through working groups and at official meetings with government departments.

National Rehabilitation Board (NRB)

8.2.14 Established in 1967, NRB is an advisory body to the Minister for Health and provides a number of services directly to people with disabilities including a technical aids information service, a national audiology service, psychological services, occupational guidance and training services. It also administers and monitors European funding for training of persons with disability. NRB is organised on a regional basis with fifteen offices outside Dublin. In recent years, NRB has become increasingly active in promoting awareness of disability issues and in the general area of advocacy and empowering people with disabilities. NRB's Strategic Plan for the period 1995-1997 acknowledges the fact that its Establishment Order has become outdated and states that the Board of NRB considers that the statutory instrument should be amended to reflect its current role and to enable it to meet new demands arising from current and future developments. **The Group recommends that the future role of NRB and its statutory relationship with government departments be reviewed in the light of decisions about the role of different departments in the provision of services on foot of the report of the Commission on the Status of People with Disabilities.**

8.3 Proposed arrangements for service delivery

8.3.1 The Group is strongly of the view that the effective delivery of the services described in Chapters 4, 5 and 6 and the achievement of the maximum benefit to service users and families/carers can be obtained only if improved organisational structures are put in place. The new structures must be underpinned by the development of measures to evaluate the effectiveness and efficiency of services. In this regard, the recently established Office of Health Gain has an important role to play in helping to establish consistent measures of quality across health boards. The Office of Health Gain was set up by the Chief Executive Officers of the health boards to facilitate conjoint action on issues, in particular in relation to the provision of information on entitlements and other services.

8.3.2 If new structures are to improve the delivery of services to people with disabilities, they must have the confidence of all parties. Five problems must be tackled in any new organisational structures:

(i) they must ensure that State and voluntary service providers work together effectively and adhere to agreed common priorities and service plans;

(ii) they should facilitate consultation with service users and their families/carers about their views and priorities in decisions about services;

(iii) they should address the current problem of under-funding, especially in the voluntary sector, in a systematic manner;

(iv) they should facilitate arrangements to support and develop management of the services;

(v) they should encourage more comprehensive and easily accessible information on services.

8.3.3 The submissions we received also reveal a degree of frustration and anxiety among service users because of the lack of clarity about the range of services to which they are entitled. It has long been recognised that there is not a uniform provision of community services across the health boards. It is noted that there is a commitment in the **Health Strategy** to introducing national guidelines on eligibility where existing provisions are absent. Such guidelines are an essential prerequisite to effective planning at health board level. **The Group recommends that the Department of Health should publish national guidelines on eligibility for community services as soon as possible.**

8.4 Recommendations for new organisational structures

8.4.1 We consider that future service provision would be best served by:

(a) strategic regional plans based on national policy guidelines drawn up by each health board in consultation with a regional co-ordinating committee;

(b) local co-ordination of services;

(c) co-ordinated care plans for individuals.

Regional co-ordinating committees

8.4.2 We recommend that the Chief Executive Officer of each health board establish a regional co-ordinating committee for services for people with physical and sensory disabilities. The co-ordinating committee should have the following membership:

- Programme Manager, Community Care (or equivalent)
- Director of Services (see paragraph 8.4.7)
- Appropriate health board personnel
- Major voluntary sector service providers and non-major voluntary sector service providers to be nominated by DFI
- Representatives of service users, ie people with disabilities
- NRB.

8.4.3 When necessary, the committee should consult with other bodies such as the Department of Education or the relevant local authority.

8.4.4 The co-ordinating committee should be chaired by the Programme Manager Community Care or at the level of Programme Manager and should meet at least on a quarterly basis.

8.4.5 The functions of the co-ordinating committee will be to advise the Chief Executive Officer on the following:

(i) the commissioning of an assessment of the needs of people with a disability;

(ii) the formulation and review of a multi-annual plan for the development of services for people with disabilities which is costed and prioritised;

(iii) opportunities for co-operation and flexibility among service providers to ensure best utilisation of resources;

(iv) issues relating to quality and effectiveness of service;

(v) the effective provision of information to service users;

(vi) opportunities for inter-sectoral co-operation and the drawing up of protocols in this regard;

(vii) the prioritising of programmes for the allocation of development funds;

(viii) supporting the development of a comprehensive database in co-operation with the database committee recommended in Chapter 3.

8.4.6 At the national level, policy guidelines on the development of services for people with disabilities should be established for the health boards to follow. In addition, there must be effective overview and evaluation of programmes to ensure that they are achieving their objectives and that they are using public resources efficiently. This involves both public and private bodies. **We therefore recommend that the Department of Health put in place a process for the ongoing evaluation of health services for people with disabilities.**

Regional management of services

8.4.7 The Review Group recommends that each health board appoint a Director of services for people with a physical or sensory disability. In the smaller health boards, such a Director might also have a responsibility for other care groups such as mental handicap or mental health. The Review Group's view is that in the larger health boards, one such post will be required for physical and sensory disability and in the Eastern Health Board it is likely that two such posts will be required. The Director should report to the Programme Manager Community Care and have responsibility for policy development, planning, evaluation, quality assurance, the development of protocol, procedure and practices, the co-ordination of services between the different programmes within the health boards and the co-ordination of services between the health boards and voluntary agencies. The Director should work closely with the co-ordinating committee and also have a responsibility in the allocation of resources to both health board service providers and to voluntary agency service providers. The Group emphasises the need to ensure effective care packages for individuals who need to access a range of services. It will be the Director's responsibility to ensure that processes are put in place to provide a seamless co-ordinated service for clients irrespective of who actually provides the service.

Service user and family/carer involvement

8.4.8 In Ireland, as in the rest of Europe, there is a growing rights movement among people with disabilities. Increasingly, people with disabilities are demanding to have a say in the type of support services they require and receive, rather than being passive recipients of care. Service users and their families/carers must be fully consulted as part of the decision-making process.

8.4.9 A truly family-centred service must be developed which supports the service user in the family environment through childhood and later supports them and their family during the move to independent living. For all service users, but especially for those who continue to live at home, parents must have the assurance that the future needs of their children are being planned for, with their involvement, so that these will be met when parents are not able to continue their supportive role. In particular, families must be involved at all stages in the planning and the provision of care for their children. This involvement must start from the very beginning when the impairment or disability is first diagnosed. We have made recommendations about the provision of effective family counselling and support at this critical time and subsequently elsewhere in the Report. The need for family involvement in the rehabilitation of a family member, for example prior to discharge back into the family home, is increasingly recognised by professionals and service providers and is now being encouraged. This process of involvement must be assisted by appropriate structures established through the regional planning and priority setting process.

8.4.10 Health and personal social services are only one of many concerns of people with disabilities. In making our recommendations, we considered that it was essential to take account of the wishes of people with disabilities themselves and to provide for their contribution to the planning of services. This approach reflects the emphasis in the **Health Strategy** on user satisfaction and participation. Among the proposals in the **Strategy** to improve the consumer orientation of services are:

- service user satisfaction surveys and quality initiatives;
- establishment of advisory groups in each health authority area to provide an input from the users of the various services;
- a requirement on all health authorities to put appropriate complaints procedures in place.

8.4.11 Service user involvement must happen at all levels and in all sectors. Voluntary agencies and health boards are major providers of services for people with disabilities for which they are in receipt of substantial sums of public funds. People with disabilities must also be given a right of consultation in the operation of the services provided by these organisations.

8.5 Funding of existing services

8.5.1 It is recognised that many individual voluntary organisations have developed services over the years in the absence of publicly-funded services. Often, they are the major service provider in a region. The growth of these services has been demand led and the original voluntary sources of funding over the period have been replaced in large part by Section 65 grants. However, public funding has historically been given as a contribution toward services rather than linked to activity levels. This has resulted in financial difficulties for a number of agencies as services have grown. Although the statutory contribution has grown over the years, the financial position of agencies has become more pressing due to reductions in fund-raising receipts. The Group accepts that many organisations are underfunded and have great difficulty in meeting the balance of costs from fund-raising and other sources.

8.5.2 The Group is aware that a number of voluntary organisations have built up considerable financial deficits as a result of these funding problems. Intermittent financial support from health boards at a time when fund-raising receipts are falling has meant the uncertain provision of services. In other cases, Section 65 grants to voluntary organisations have been delayed leading to an increase in costs for voluntary agencies as they incur interest charges on borrowings. It is acknowledged that new payment arrangements are now in place in health boards which have facilitated speedier payment of grants to voluntary agencies. Particular difficulties in obtaining funding are encountered by newly-emerging organisations.

8.5.3 Voluntary organisations now invest considerable time and effort in securing finance from fund-raising as well as from an increasingly-broad range of sources. Raising the funding necessary for their services requires a level of expertise and time not always available to voluntary organisations, in particular the smaller ones.

8.5.4 The Group considers that an appropriate base level of funding for individual agencies must be developed to counter the uncertainties referred to above. We also recognise that a balance will have to be achieved between funding new services and resolving problems in financing existing services. This may require a review of the mechanism used to fund voluntary agency services - Section 65 of the Health Act, 1953. The main issues to be addressed are:

- the financial problems of the agencies, including the funding of pensions;
- cash flow arrangements;
- procedures and practices for making grants;
- effects of the arrangements on long-term planning, especially in the larger agencies.

8.5.5 The **Health Strategy** recognises the integral role played by the voluntary sector in the provision of health and personal social services. It goes on to announce that the larger voluntary agencies will have service agreements with the health boards with more appropriate arrangements for the smaller agencies. It is recognised by the voluntary sector that more secure funding arrangements must go in tandem with improved accountability arrangements together with a structured review process in relation to the services which they provide from public funds. Accordingly, under the **Health Strategy**, they will retain their operational autonomy but will be fully accountable for the public funds they receive.

8.5.6 Recognising and tackling individual deficits are a matter for the Department of Health, the health boards and the agencies concerned. **The Group recommends that health boards, in consultation with the relevant organisations, make every effort to reduce the financial deficits so as not to hamper the development and operation of new services.** In this regard, new resources must be equitably distributed.

Management development

8.5.7 The implementation of many of the Group's recommendations will be carried out by line managers in the services. They will face many challenges:

- ensuring that services are put in place in a cost effective manner;
- responding to accountability requirements;
- relating to service users and families in new ways.

8.5.8 They will be responsible for ensuring that the maximum benefit is achieved for people with disabilities from public investment. They will be accountable to the health boards for their performance in relation to publicly-funded services. Managers will be expected to demonstrate that their organisations are not only financially efficient but also effective, that targets are set for service delivery and that success in meeting these targets is measured. This is in line with the management approach now being adopted in relation to public services.

8.5.9 The **Health Strategy** put a special emphasis on the need to re-orientate and improve training for professionals and managers. The health boards and larger voluntary agencies are already well advanced in developing the management skills of their staff. As the smaller agencies grow, the management task will become more complex and such organisations will have to develop an ever more professional approach. This can be supported in part by the health boards but if the separate identity of the voluntary sector is to be maintained in this pressured environment, these agencies will need to develop their own support structures as well.

8.5.10 The management development approach advocated by DFI should continue to be developed. DFI should be properly resourced for this purpose. Opportunities for confidence-building between the health boards and voluntary agencies should not be lost. The health boards and DFI should work together to develop joint training initiatives as part of the process of building a good relationship between the boards and voluntary sector.

8.6 Information

8.6.1 It is clear from submissions to the Group that people with disabilities are experiencing considerable difficulty in finding out about and accessing services. Good information is the first step to accessing services; its absence is a real barrier. It is essential that available information is comprehensive, accessible and understandable to people with sight or hearing impairments, covering the full range of health and personal social services available locally, and is kept up-to-date.

8.6.2 At present a wide range of statutory and voluntary bodies provide information to people with disabilities. These include:

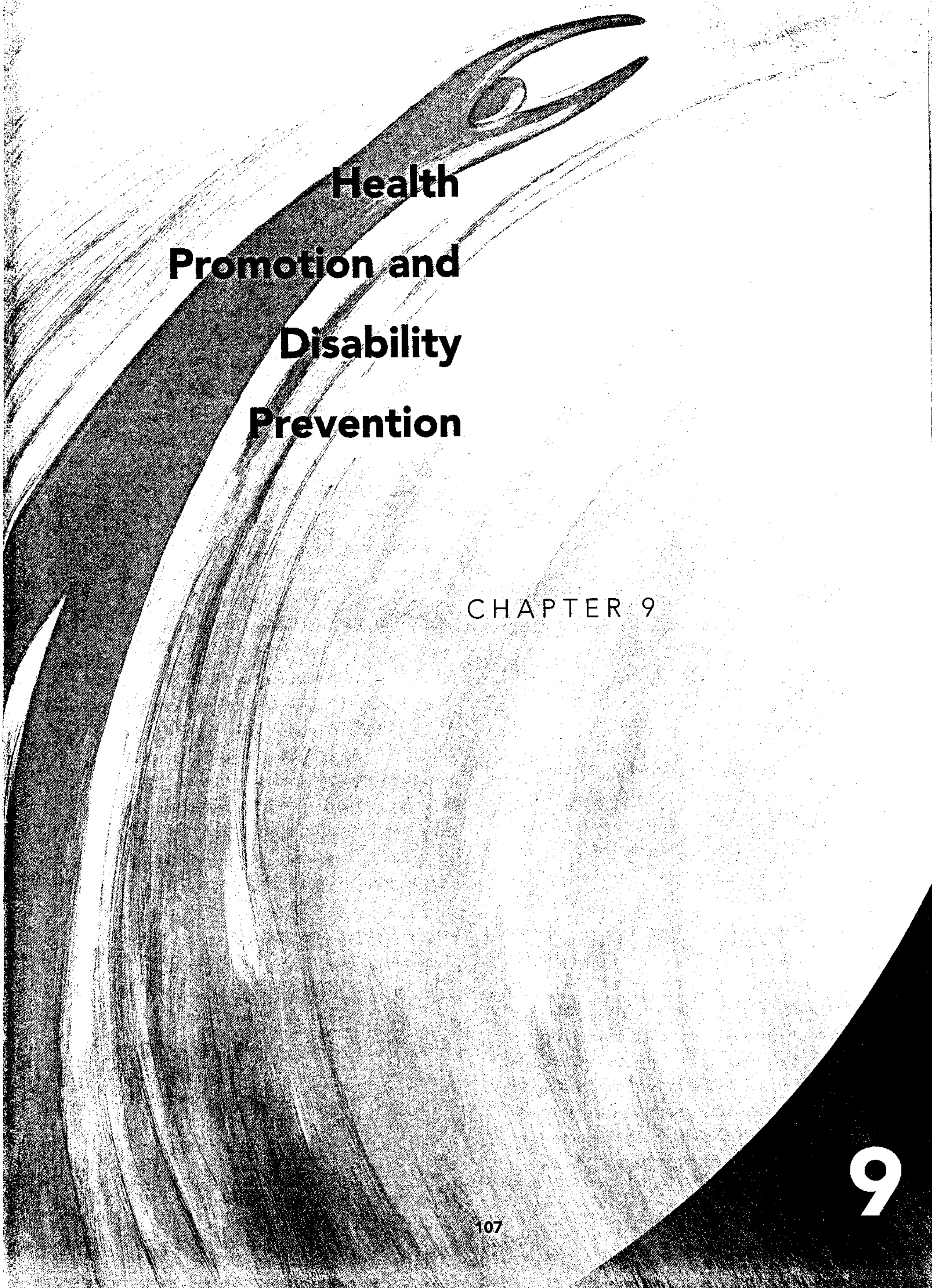
- Health boards
- NRB
- National Social Service Board
- Disability Federation of Ireland
- Individual voluntary agencies
- Community information services

8.6.3 It is evident that there are considerable overlaps in information provision between the various bodies. Despite the multiplicity of sources of information, consumers continue to experience difficulty in accessing information.

8.6.4 Many individuals considered that there should be a "one-stop shop" approach to the provision of information on entitlements and availability of services. All the agencies listed above will continue to be asked for information by their clients and should be in a position to supply it. The key issue is not who provides the information (the more outlets the easier the access) but rather ensuring that the information is comprehensive, current and in a format most accessible to the user. The greater the number of small local groups who give out information, the greater the chances of some of it being out of date. A proper information dissemination strategy is required. The health boards, as the major funders of services, are in a unique position to bring the information from the diverse sources together and to maintain its currency. **The Group recommends that the health boards should take a lead rôle in developing a coherent information service in their region for people with disabilities.**

8.6.5 The use of the Internet to supply a basic set of information would greatly increase access for home-bound people. This possibility should be further investigated and piloted in one region. The availability of "Handynet", which provides international information on aids and appliances, through the eight regional NRB offices, should be more widely publicised.

[1] Faughnan, Dr Pauline, "Charitable Associations within the EC" Seminar Report, April 1992



Health Promotion and Disability Prevention

CHAPTER 9

9

9.1 Introduction

9.1.1 The prevention of disability or limiting its effects through early intervention programmes is an important objective of health services for people with disabilities.

9.1.2 The **Health Strategy** identifies accidents, cancer and heart disease as the three most common causes of premature deaths. They are also the most common causes of preventable disability in adults. Disabilities acquired as a result of disease or accident create their own particular practical and emotional challenges both for those who, sometimes overnight, may find themselves with a disability which may change their life radically and for their families.

9.1.3 While it is not possible to quantify the cost of preventable disabilities from the data available at present, it is clear that they have significant human and financial implications.

9.2 Health promotion

9.2.1 The **Health Strategy** *"Shaping a Healthier Future"* promised a Health Promotion Strategy to set detailed goals and targets in health promotion and disease prevention and plans for their achievement. The Health Promotion Strategy *"Making the Healthier Choice the Easier Choice..."* was launched in July 1995 and presents a detailed strategy for the promotion of health in Ireland. It acknowledges that the primary causes of premature mortality and morbidity are linked to unhealthy behaviours and lifestyles. These would include smoking, alcohol misuse, drug misuse as well as accidents which are the single greatest cause of death in persons under 45 years and account for a third of deaths in this age group. Smoking and alcohol misuse may result in considerable disability.

Accident prevention

9.2.2 Accidents are also a common cause of acquired physical disability and a health promotion accident-prevention strategy has a particular relevance in the area of disability. The Group welcomes the initiative of the Office for Health Gain in preparing an accident prevention strategy. As a first step, it has published a study *"Accidental Injury in Ireland - Priorities for Prevention"* which found that injury is now the leading cause of morbidity and mortality in Ireland in people up to 45 years of age.

9.2.3 The study recommends the establishment of a representative multi-sectoral national committee to achieve a co-ordinated approach to injury prevention. The Group recognises that the development of prevention strategies is not currently within the remit of NRB.

However, it is empowered to furnish advice, information and assistance to any health authority. Given the potential reduction in avoidable disability of an effective accident reduction strategy, the Group recommends that NRB should make its expertise available to the Office for Health Gain. NRB should be represented on the national committee on injury prevention if it is established.

9.3 Antenatal health

9.3.1 The contribution a healthy lifestyle during pregnancy makes to the health of babies is increasingly being recognised. Good nutrition, moderate intake of alcohol and elimination of other addictive substances, the cessation of smoking and the careful prescription and consumption of therapeutic agents are important elements of any health promotion initiative in this area. For example, research has shown the effectiveness of folic acid supplements prior to conception in preventing the occurrence of neural tube defects (NTDs), such as spina bifida and anencephaly, which account for disability in approximately 50-60 new born babies in this country each year. The Department of Health has recommended folic acid supplements for prevention of NTDs. It is of particular importance in preventing the reccurrence of NTDs in women with a previous history. The provision of educational materials and advice in relation to these matters should be a major component of the ante-natal care provided to mothers in the hospital out-patients or in the combined mother and infant care scheme in which general practitioners participate. We welcome the Department of Health promotion of the importance of folic acid supplements for women planning pregnancy to help decrease the incidence of babies born with neural tube defects.

9.4 National Primary Childhood Immunisation Programme

9.4.1 The Department of Health has responsibility for the promotion of immunisation programmes. The National Primary Childhood Immunisation Programme's objective is to achieve and maintain an uptake level of not less than 95 per cent of the total childhood population to eliminate conditions such as diphtheria, tetanus, polio, Hib diseases, measles, mumps, rubella and pertussis. The Programme has contributed to an enormous reduction in the prevalence of many dangerous and potentially lethal conditions. Cases of diphtheria and polio have not been reported for many years, the incidence of measles has been significantly reduced and congenital rubella syndrome almost eliminated, as have been the disabling conditions associated with these diseases. The Hib vaccine is a recent addition to the immunisation schedule and it is anticipated that neurological sequelae to Hib meningitis can be eliminated from the list of causes of disabilities such as deafness.

9.4.2 There cannot be any complacency in the promotion and provision of immunisation programmes. With the childhood immunisations currently available, it is possible to eradicate the diseases in question if an uptake level of 95 per cent of the child population is achieved and maintained. We fully support adoption of the Review Group on Immunisation recommendation that a 95 per cent minimum uptake be set as the national standard.

9.4.3 The 1994 report of the Review Group on Primary Childhood Immunisation recognised that the general practitioner was ideally placed to deliver the primary childhood immunisation programme. Agreement was reached in early 1996 on the delivery of this programme by general practitioners.

9.4.4 We are concerned that some groups, such as children of travellers, may not be availing of the immunisation service. It is important that all health boards make arrangements to ensure their immunisation. Section 12 of the report of the Review Group on Primary Immunisation refers to measures to be taken by health boards where uptake of immunisation is unacceptably low.

9.5 Genetic counselling

9.5.1 Many conditions, such as cystic fibrosis, friedreich's ataxia, retinitis pigmentosa and congenital cataracts are genetically determined. Many families express a desire for guidance and assistance in understanding the implications of inherited disorders. The report of the Committee to examine Medical Genetic Services (1990) recommended the establishment of a consultant-led genetic counselling service to be based initially in Our Lady's Hospital Crumlin. **We welcome the establishment of the Genetic Counselling Service in 1994 and recommend that urgent attention be given to the need to expand and develop this service both in Dublin and other centres such as Cork and Galway.**

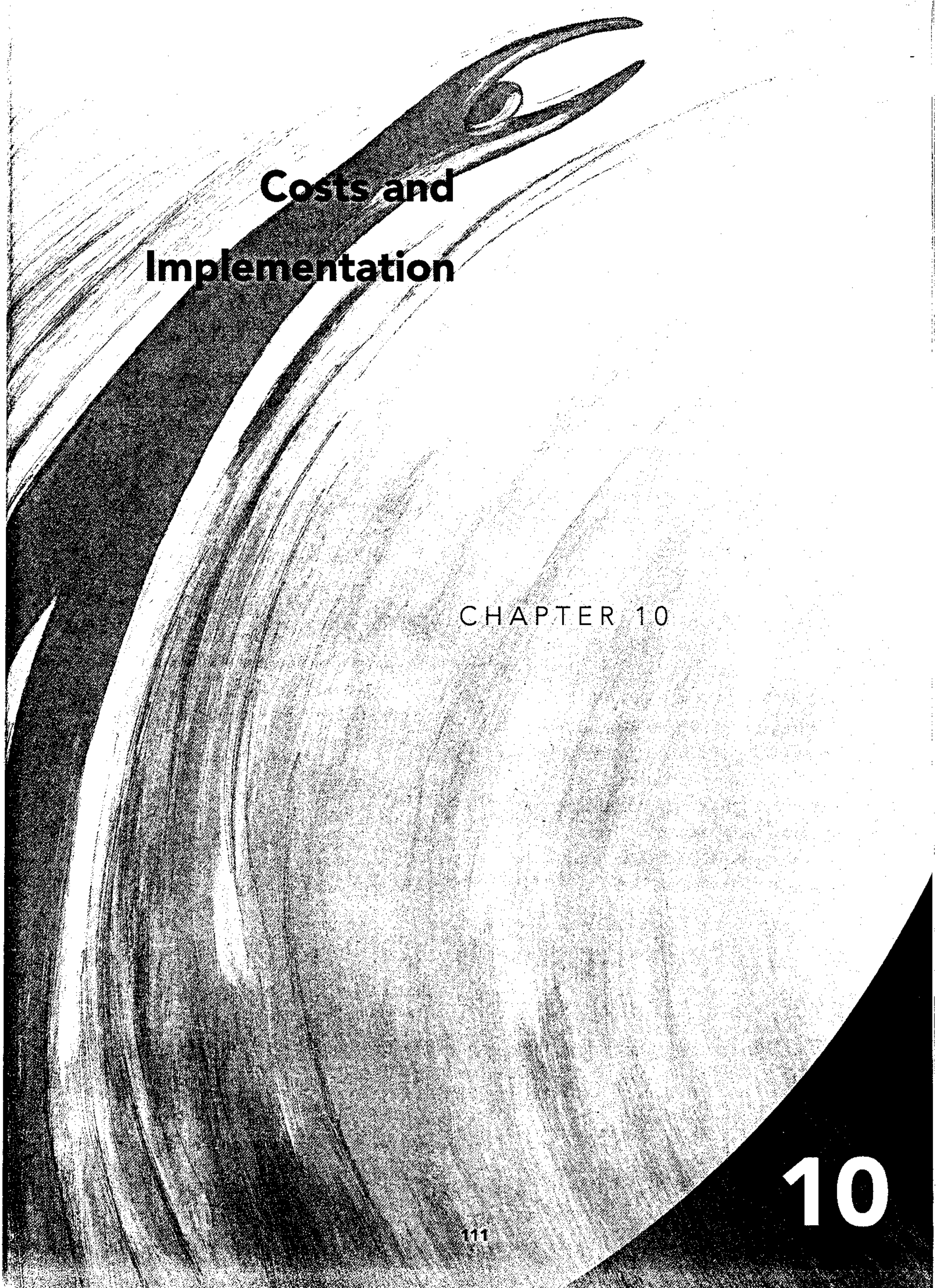
9.6 Research

9.6.1 The promotion of medical and scientific research is a key factor in the prevention of disability. It is recognised that the voluntary sector has an important role to play in the promotion of such research. **The Department of Health in consultation with the Health Research Board should develop a strategy for promoting medical/scientific research into conditions causing physical and sensory disabilities.**

Costs and Implementation

CHAPTER 10

10



10.1 Introduction

10.1.1 In this Report, we have made recommendations on the level of services required by people with disabilities based on our assessment of clear gaps in current provision. With the establishment of a comprehensive database, more detailed long-term planning at both national and regional levels should be undertaken.

10.1.2 In this Chapter, we set out the steps to be taken to ensure the effective implementation of the recommendations in this Report as well as estimating the financial implications of our recommendations. Some of our recommendations cannot be costed accurately on the basis of the information available to us, for example the development of regional assessment centres is dependent on staffing levels and facilities to be agreed at local level. Accordingly, the Group wishes to stress that funding, additional to that recommended in this Report, will be necessary to implement the recommendations emanating from the work of the regional co-ordinating committees which will be able to carry out more detailed examinations of the health and personal social services needs of people with disabilities. In addition, the Group recognises that there will be costs associated with the establishment and operation of the database.

10.2 Implementation

10.2.1 We believe that the specific steps which should be taken to ensure the effective implementation of the recommendations in this Report are as follows:

(i) The regional co-ordinating committees should be established immediately. Each health board, in consultation with the committee should produce a five-year service development plan which would, *inter alia*, take account of the urgency we attach to improving day and residential services, therapy services and personal assistance services. A national service development plan based on regional plans should also be produced.

(ii) We recommend the immediate establishment of a database development committee under the aegis of the Department of Health. This Committee should report to the Department within six months of its establishment (see Chapter 3).

(iii) Where further examinations of particular issues have been recommended, such examinations should be carried out without delay.

(iv) At present, there are no service-based costings available which relate costs to dependency levels. We recommend that such costings be developed by the Department of Health and that an initial pilot programme be undertaken. This should not impact on the need to commence without delay the implementation of specific recommendations.

10.3 Financial implications

10.3.1 The costs set out in this section are our best estimates based on the information currently available.

Chapter 4 - Early assessment and rehabilitation

10.3.2 The ability of people with sensory disabilities to access mainstream or specialist health services was of concern to the Group. Currently, provision of interpreter services to enable people with hearing impairments to access health services is funded in the main through the National Association for the Deaf. The Group considers that each health board should have a specific budget enabling it to fund interpreter services where needed and recommends that an annual allocation of **£40,000** be made for this purpose. Consideration must also be given to the provision of information in an accessible format for people with visual impairments by the Department of Health and health boards in conjunction with the National Council for the Blind.

10.3.3 Submissions to the Group identified financial problems encountered by parents, especially those living in rural areas, in accessing assessment and rehabilitation services for their children. We recommend that an initial annual sum of **£100,000** be provided to enable health boards, where necessary, to assist parents in meeting transport, accommodation and other costs in accessing services.

10.3.4 The Group recommends that an additional **£800,000** be phased in over the next five years to enable health boards to meet demands for funding artificial limbs/prostheses in respect of medical card holders.

Chapter 5 - Community services

Community support services

10.3.5 The Group recommends the expansion of the community nursing service by an additional 100 whole-time equivalent nurses to provide the requisite nursing care to people with a disability and expand the twilight nursing service. The Group recommends that these be phased in over a five-year period at a total estimated cost of **£2 million.**

10.3.6 Given the shortage of dedicated day service places for people with disabilities, the Group recommends that an additional 1,600 places be provided. The Group recommends that these be phased in over a five-year period at a total estimated cost of **£16 million.**

10.3.7 The Group recommends that a once-off investment of **£200,000** be provided for the adaptation of vehicles used to transport people to and from services.

10.3.8 The Group recommends the provision of funding for an additional 200 sheltered employment places at an estimated cost of **£1.6 million.**

10.3.9 The Group recommends a 25 per cent increase in the Employment Support Scheme allocation, that is an increase of **£250,000.**

Personal assistance services

10.3.10 The Group recommends that funding of **£5 million** should be phased in over a three-year period for the development of all personal assistance services for people with disabilities.

Community therapy services

10.3.11 The Group recommends the recruitment of an additional 150 speech and language therapists over the next decade and accordingly it is recommended that **£3.3 million** be phased in over 10 years to develop this service.

10.3.12 The Group recommends that funding of **£1.6 million** be phased in over a five-year period for the recruitment of 80 additional occupational therapists.

10.3.13 The Group recommends that funding of **£1.7 million** be phased in over a five-year period for the recruitment of 85 additional physiotherapists.

10.3.14 The Group recommends that funding of **£1 million** be phased in over a five-year period for the recruitment of 40 social workers to develop social work services for people with disabilities.

10.3.15 The Group recommends that **£600,000** be allocated in respect of training and development for peer counselling and other support services as an integral part of the community support services available to people with disabilities.

10.3.16 The Group recommends that funding of **£330,000** be provided for the recruitment of 10 additional psychologists.

Technical aids and appliances

10.3.17 The Group recommends a total increase in health board aids and appliances budgets of **£5 million** to be phased in over five years.

Chapter 6 - Respite and residential care services

10.3.18 The Group estimates the cost of providing an additional 200 dedicated respite places for adults and children with disabilities and 100 residential places for adults to be **£6.5 million** to be phased in over five years.

10.3.19 The Group recommends the provision of an additional 200 places for the young chronic sick and accordingly that **£5 million** be phased in over a five-year period to develop this service.

Chapter 7 - Special services for people with sensory disabilities

10.3.20 The Group recommends that a once-off sum of **£300,000** be provided to develop and maintain a pool of low vision and poor hearing devices and technical aids to be used by students in third level colleges.

Chapter 8 - Organisation and co-ordination of services

10.3.21 The Group recommends that funding arrangements for voluntary agencies be reviewed as a priority in consultation with the agencies and the health boards. In the interim, we recommend that a once-off sum of **£2 million** be provided to tackle the individual deficits and to continue to fund essential services.

SUMMARY OF COSTS OF RECOMMENDATIONS

Services	Year 1 £	Year 2 £	Year 3 £	Year 4 £	Year 5 £
Day places	3,200,000	3,200,000	3,200,000	3,200,000	3,200,000
Sheltered work	1,600,000	–	–	–	–
ESS places	250,000	–	–	–	–
Residential/ respite care	1,300,000	1,300,000	1,300,000	1,300,000	1,300,000
Young chronic sick units	1,000,000	1,000,000	1,000,000	1,000,000	1,000,000
Nurses	400,000	400,000	400,000	400,000	400,000
Speech and language therapy	330,000	330,000	330,000	330,000	330,000
Occupational therapy	320,000	320,000	320,000	320,000	320,000
Physiotherapy	340,000	340,000	340,000	340,000	340,000
Social work	200,000	200,000	200,000	200,000	200,000
Psychology	130,000	100,000	100,000	–	–
Personal assistance	1,650,000	1,650,000	1,700,000	–	–
Peer counselling and family support	120,000	120,000	120,000	120,000	120,000
Prostheses	160,000	160,000	160,000	160,000	160,000
Aids and appliances	1,000,000	1,000,000	1,000,000	1,000,000	1,000,000
Interpreting service	40,000	–	–	–	–
Total	12,040,000	10,120,000	10,170,000	8,370,000	8,370,000

APPENDICES

APPENDIX 1

List of organisations/individuals who made submissions to the Review Group

Action for Mobility
Advocates of the Visually Impaired
Association for the Promotion of Conductive Education
Association of Occupational Therapists of Ireland
Brainwave, Irish Epilepsy Association
Cheshire Foundation
Central Remedial Clinic
Cerebral Palsy Ireland
Cerebral Palsy Waterford
Crowe, Sr E., Sister in Charge, General Outpatients Department, Meath Hospital
Cystic Fibrosis Association of Ireland
Disabled Drivers Association
Disability Federation of Ireland
Eastern Health Board
Eastern Health Board Community Physiotherapists
Forum for People with Disabilities
Friedreich's Ataxia Association
Hallinan, Mr P. - Cheshire Home Resident
Headway Ireland (National Head Injuries Association)
Institute of Community Health Nursing
Irish Association of Social Workers
Irish Association of Speech and Language Therapists
Irish Council for Social Housing
Irish Deaf Society
Irish Guide Dogs Association
Irish Hard of Hearing Association
Irish Society of Chartered Physiotherapists
Irish Society of Medical Officers of Health
Irish Wheelchair Association
ISAAC Ireland (Irish Chapter of the International Society for Augmentative and Alternative Communication)
Limerick Handicapped Children's Committee
McDonnell, Mr P.
Midland Health Board
Mid-Western Health Board
Multiple Sclerosis Society of Ireland
Muscular Dystrophy Ireland
National Association for the Deaf
National Association for Home Care Organisers
National Council for the Blind of Ireland
National Rehabilitation Board
National Rehabilitation Hospital
North Eastern Health Board
North Western Health Board

Rehabilitation Institute
Richmond Cheshire Home
Royal College of Physicians of Ireland
Royal Hospital, Donnybrook
Ryan, Dr M.F., copy of Thesis submitted for MFPHMI
Social Workers in Specialist Services
South Eastern Health Board
Southern Health Board
St Joseph's House for Adult Deaf and Deaf Blind
St Joseph's School for Visually Impaired Boys
Superintendents and Senior Public Health Nurses Association
Syringomyelia Self Help Group
Western Health Board

APPENDIX 2

List of organisations represented at the Consultative Seminar

In addition to the organisations represented on the Review Group, the following organisations were represented at the Consultative Seminar on 21 February 1996:

Central Remedial Clinic
Cerebral Palsy Ireland
Cheshire Foundation of Ireland
Commission on the Status of People with Disabilities
Cystic Fibrosis Association
Disability Federation of Ireland
Friedreich's Ataxia Society of Ireland
Headway Ireland
Health boards
Muscular Dystrophy Ireland
National Rehabilitation Hospital
RP Ireland

APPENDIX 3

Summary of Interim Report Recommendations

1. The present home-help service should, as an initial step, be expanded to cater for an additional 500-600 people with physical and sensory disability.

2. Home care assistance schemes should be expanded to provide assistance to approximately 200 disabled people and their families.

3. A sum of £50,000 should be set aside to enable health boards and voluntary bodies to provide flexible home supports which can respond in a non-structured way to meet special needs.

4. As an interim measure, pending the report of the Special Education Review Committee, additional support services for children in full-time education should be provided through the health boards.

5. Additional capital resources of £500,000 should be provided in 1993 to enable building work to proceed on a number of day care/therapy centres.

6. Additional funding of £250,000 should be provided to enable existing day care centres to open for extended periods and to adapt other premises in the community for use as day care centres.

7. As an immediate step towards meeting the need for respite care places, health boards should arrange for the provision of respite care places in nursing homes or other suitable locations.

8. As an initial step, 50 community based therapists in the different disciplines (physiotherapy, occupational therapy and speech therapy) should be recruited immediately.

9. An additional sum of £250,000 should be made available on an ongoing basis to improve the availability of technical aids and appliances.

10. In order to meet the immediate need for residential facilities and pending the availability of purpose-built accommodation, health boards should examine the possibility of providing residential accommodation in specially dedicated units at existing hospitals. The question of placements in suitable nursing homes should also be examined.

11. Additional revenue funding of £150,000 should be provided in 1993 to facilitate the opening of new residential developments at Sligo and Letterkenny.

12. A sum of £1m should be made available to redress the current funding deficits, staffing shortages and disparity in pay rates in the voluntary sector.

13. Additional sign language interpreters should be trained.

14. Additional funding of £30,000 should be made available to expand driver training.

15. The Motorised Transport Grant should be increased to £2,500.

16. The recommendations of the Commission on Social Welfare, subsequently endorsed by the Commission on Health Funding, in regard to the transfer of income maintenance schemes for people with disabilities to the Department of Social Welfare should be implemented as a matter of urgency.

17. Planning of at least four 20-place residential care units should commence in 1993.

18. Planning should also commence immediately on four 10-place respite care centres.

19. The provision and funding of sheltered work/employment should be the subject of a separate examination as a matter of urgency.

APPENDIX 4

Healthy Strategy - Shaping a Healthier Future

The Strategy describes how the planning and delivery of health services should be reshaped to make them more effective. This reshaping has three dimensions:

(i) Prevention, treatment and care services will be more clearly focused on improvements in health status and the quality of life with increased emphasis on the provision of the most appropriate care.

(ii) The management and organisational structures will provide for more decision-making and accountability at local level, allied to better methods of performance measurement.

(iii) There will be a greater sensitivity to the right of the consumer to a service responsive to his or her needs in an equitable and quality driven manner. Greater recognition will be given to the key role of those who provide the services and the importance of enabling them to do so to their full potential.

Principles underpinning the Health Strategy

Three key principles underpin the Health Strategy:

(i) Equity

(ii) Quality of Service

(iii) Accountability

Equity

The achievement of an equitable health service has a number of dimensions. Access to health care must be determined by actual need for services rather than ability to pay or geographic location. Formal entitlement to services is not enough; those needing services must have them available within a reasonable period. Furthermore, the pursuit of equity must extend beyond the question of access to treatment and care, and must examine variations in the health status of different groups in society and how these might be addressed.

Achieving equity in the health care system will involve not only ensuring fairness, but also being seen to be fair. The Strategy contains important steps to ensure greater equity in:

- Implementing uniform rules for eligibility and charges for services across the country
- Measures to reduce waiting times for those availing of public services
- Giving special attention to certain disadvantaged groups.

Quality of Service

The services must meet the highest possible quality standards within the resources that are available. This requirement has two aspects:

- The technical quality of the treatment or care must be such that the best possible outcome is achieved in return for the resources which are committed to it. It is not sufficient to assess the services in terms of volume of activity; a crucial element of the reorientation is towards a more critical evaluation of the outcome of services through techniques such as clinical audit.

- The consumer's perception of the quality of the services he or she receives will be greatly influenced by factors such as the efficiency with which they are organised, the courtesy shown and the physical surroundings in which they are delivered. The maintenance of quality standards in these areas is also therefore of great importance.

Accountability

The principle of accountability has a number of strands. It includes formal legal and financial accountability arrangements which are in place and which are subject to ongoing development. It also includes the requirement on those providing services to take explicit responsibility for the achievement of agreed objectives. This has been lacking in the health services, and its development is a key element in the Strategy's organisational and management reforms. Finally, there must also be mechanisms to ensure that those with decision-making powers are adequately accountable to the consumers of the services.

Four-Year Action Plan

The Strategy sets out a Four-Year Action Plan which maps out what will be achieved between 1994 and 1997. National objectives for service development must be translated into more detailed targets and objectives at national and regional level and, where appropriate, beyond, and this process should take account of the views of all interested parties.

In the case of people with physical or sensory disabilities, services will be further developed on the basis of locally-assessed need. In our interim report, we identified a number of areas which required urgent attention. The Strategy envisaged the main focus of service developments over the next four years, subject to the Review Group's detailed recommendations, to be as follows:

- To provide extra facilities for day care, respite care, home care, and 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 people 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 of 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, steps will also 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.

The wider dimension

The Health Strategy sets out targets for achieving measurable improvements in selected priority areas. Many of these may be achieved by action within the health sector, but others are reliant on the involvement of agencies outside the health sphere. To this end a key function of the Minister and Department of Health will be to ensure that all other sectors take the health implications of their own policies and practices fully into account.

While responsibility for ensuring that the public health dimension in the activities of other agencies rests with these agencies, the task of the health sector is twofold:

- To act as the guardian of the public health interest.
- To encourage those outside the health sector to appreciate the health significance of their actions. This will be done by the Department of Health which will arrange regular interdepartmental meetings in order to ensure that the health implications of policies formulated by other bodies are fully assessed.

TOWARDS AN INDEPENDENT FUTURE

REPORT OF THE REVIEW GROUP
ON HEALTH AND PERSONAL SOCIAL SERVICES FOR PEOPLE WITH PHYSICAL AND SENSORY DISABILITIES

**DEPARTMENT
OF HEALTH**
AN ROINN
SLÁINTE

ISBN 0-7076-3793-7

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Designed and produced by BFK Design Group