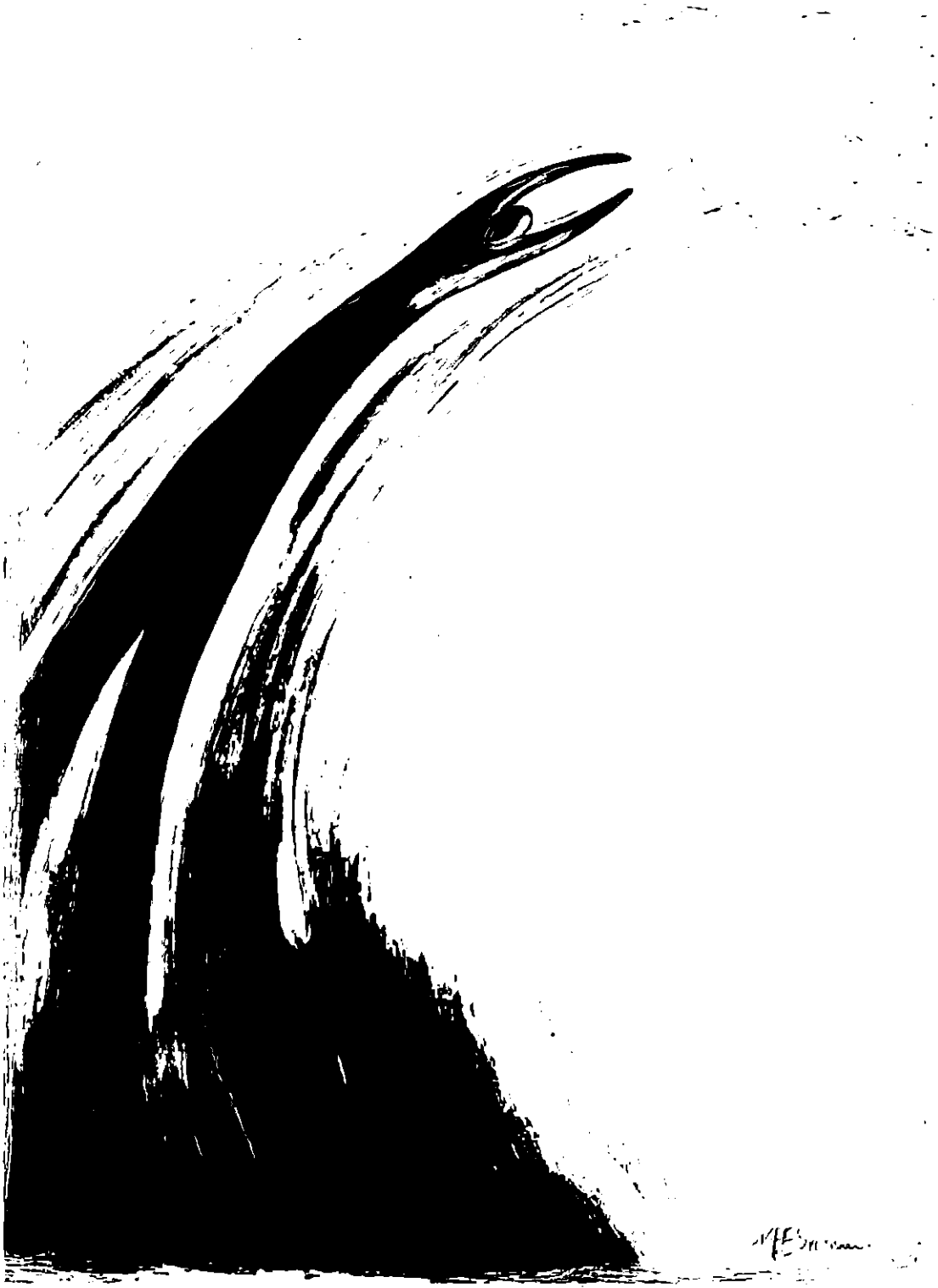
TOWARDS AN INDEPENDENT FUTURE



SUMMARY OF THE REVIEW GROUP REPORT

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

TOWARDS AN INDEPENDENT FUTURE

SUMMARY

OF THE REVIEW GROUP REPORT

ON HEALTH AND PERSONAL SOCIAL SERVICES

FOR PEOPLE WITH PHYSICAL AND SENSORY DISABILITIES

December 1996

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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

Establishment and Terms of Reference

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.*

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."*

The members of the Review Group are listed in the appendix.

Terminology

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.

Summary of Main Recommendations

The Review Group was aware of the need to develop a continuum of service which is supportive of people with disabilities and their families, especially in the early stages following diagnosis, and which helps to develop early the potential of people to achieve the maximum benefit and independence.

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

Information Requirements – Database

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 as a matter of priority.

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

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.

Early Assessment and Rehabilitation

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

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

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.

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

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.

11. The Department of Health should develop a detailed policy on physical and sensory rehabilitation within the framework set out in this Report and in the Health Strategy *"Shaping a Healthier Future"*.

Community Services

12. The Department of Health should publish national guidelines on eligibility for community services as soon as possible.

Community Support Services

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

14. 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.

15. 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.

16. 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.

17. The twilight nursing service should be extended to be uniformly available throughout the country to persons with disability.

18. 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.

19. An additional 1,600 places in day service facilities for people with disabilities should be provided. Day centres should 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 to each person attending,

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

20. The regional co-ordinating committees should give urgent consideration to the rationalisation of transport to day services.

21. 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.

22. All health boards should examine and review the services available in their area for people with head injuries.

23. 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.

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

25. In the interim, an additional 200 sheltered employment places should be provided for people with disabilities.

26. 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.

Personal Assistance Services
(three levels)

The Advisory Group on Personal Assistance Services for People with Physical Disabilities (Department of Health, 1995), 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 (hereinafter referred to as a PAS (personal assistance service));

(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.

27. 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.

28. 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.

29. Assessment procedures should be established for the provision of personal assistance services.

30. An appeals procedure should be developed to deal with cases where the client disagrees with the assessment result.

31. Preparatory training/peer counselling should be provided for prospective PAS users and, where necessary, their families.

32. 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.

33. We support implementation of the recommendation of the Advisory Group on Personal Assistance 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.

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

Community Therapy Services

35. Health boards should plan an annual increase in speech and language therapists of fifteen over the next decade.

36. Provision should be made for a further eighty occupational therapists to develop services for people with disabilities.

37. An additional eighty-five physiotherapists should be recruited to meet the identified needs of people with disabilities.

38. The health boards should increase the number of social workers providing support services to people with disabilities and their families in the community by forty.

39. 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.

40. 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.

41. Health boards should increase psychologist posts by ten over the next three years to develop effective psychology services for adults and to further develop services for children.

Technical Aids and Appliances

42. 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. The funding available for aids and appliances should be increased by £5 million.

43. 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.

Respite and Residential Care Services

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

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

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

47. Each health board should undertake a planned programme of refurbishment of residential homes in consultation with the co-ordinating committee and the agencies responsible for the homes.

48. 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.

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

50. 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.

51. An additional 100 residential places in dedicated facilities for people with disabilities should be provided as soon as possible.

52. 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.

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

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

55. 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.

56. 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.

57. 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.

58. 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.

59. 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.

60. The Department of Health should give consideration to introducing registration of residential homes for people with disabilities.

Special Services for People with Sensory Disabilities

Visual impairment

61. The recommended child assessment teams 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.

62. 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.

63. 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.

64. 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.

65. The Department of Health should ensure that publications of its Health Promotion Unit are accessible to people with visual impairments.

66. 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.

67. 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.

Hearing Impairment

68. The Department of Health should 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.

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

70. Radio aids or appropriate technical equipment should be provided for hearing-impaired children attending local schools without any time delay.

71. Audiological rehabilitation should incorporate lip-reading classes in addition to provision of hearing aids.

72. The National Rehabilitation Board (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.

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

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

75. 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 ten posts are required.

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

77. 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.

78. 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.

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

Organisation and Co-ordination of Services

80. 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.

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

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

83. Each health board should appoint a Director of Services for people with a physical or sensory disability.

84. Appropriate base levels of funding must be developed to counter the funding uncertainties facing individual agencies.

85. 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.

86. Health boards should take a lead role in developing a coherent information service in their region for people with disabilities.

Health Promotion and Disability Prevention

87. 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.

88. 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.

APPENDIX

1.2 Membership

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.

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DEPARTMENT OF HEALTH
AN ROINN SLÁINTE

Designed and produced by BFK Design Group