

NEEDS AND ABILITIES A POLICY FOR THE INTELLECTUALLY DISABLED

REPORT OF THE REVIEW GROUP ON MENTAL HANDICAP SERVICES

July 1990

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Pupils from the Holy Family School, Cootehill, Co. Cavan

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Dr. Rory O'Hanlon T.D. Minister for Health

Dear Minister,

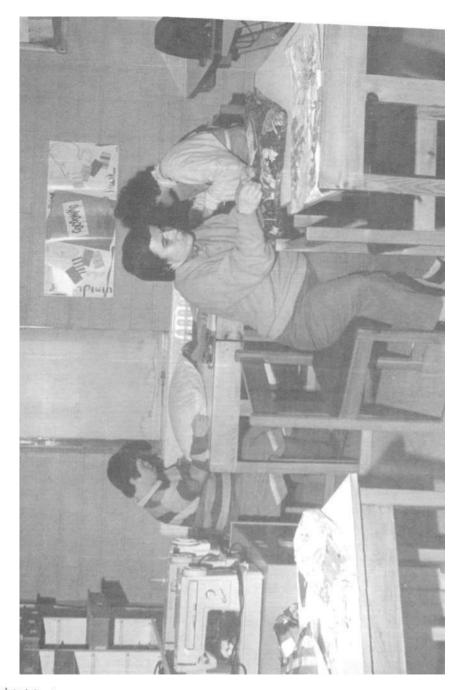
It is my pleasant task to submit to you the Report of the Review Group on Mental Handicap Services. Our task was to review existing services and to recommend guidelines for their development. We approached our task from the individual's point *of* view, focusing *on* the nature *of* the services required at different stages of life.

The philosophy underlying our approach was the right of every person with an intellectual disability to as fulfilling and normal a life as possible. Our report is a practical attempt to outline the best approach to meet the needs and realise the abilities of people with intellectual disability. We believe that with the right kind of services, the overwhelming majority of people can live in the community.

We hope our recommendations will be accepted and that they will enhance the lives of the present generation of people with intellectual disability. As regards the future generation, we hope that as new thinking emerges and as new approaches are perfected, our recommendations will be revised to take them on board.

Yours sincerely,

G. GUIDON Chairman



Work training in progress, Daughters of Charity Services, Dublin.

NEEDS AND ABILITIES - A POLICY FOR THE INTELLECTUALLY DISABLED

Contents

CHAPTER		PAGE
1.	INTRODUCTION	1
2.	SUMMARY OF RECOMMENDATIONS	4
3.	TERMINOLOGY	13
4.	PERSONS WITH GENERAL LEARNING DIFFICULTIES	15
5.	PREVENTION	17
6.	IDENTIFICATION AND EARLY SERVICES	20
7.	CHILDREN OF SCHOOL AGE	26
8.	DAYCARE AND EMPLOYMENT FOR ADULTS	32
9.	LIVING ARRANGEMENTS FOR ADULTS	37
10.	ELDERLY PERSONS	41
11.	SOME ADDITIONAL AREAS OF NEED	43
12.	INTELLECTUALLY DISABLED POPULATION	46
13.	PERSONNEL	49
14.	ORGANISATION AND CO-ORDINATION OF SERVICES	51
15.	FINANCIAL IMPLICATIONS OF UNMET NEEDS	57
	APPENDIX - TYPE OF PROVISION AND CATEGORY OF DISABILITY.	64

Introduction

1.1. The Review Group on Mental Handicap Services was established in 1986 following discussions between the Department of Health and representatives of some of the major organisations providing services for people with intellectual disability. (For the reasons discussed in chapter 3, the term "mental handicap" is not used throughout this report). The establishment of the Review Group may be seen against the background of rapid and radical changes in the approach to services for intellectually disabled persons. In 1965, the Report of the Commission of Inquiry on Mental Handicap marked a watershed in the development of these services in Ireland. The Commission accepted, as a general principle, that community care (i.e. care provided outside residential centres) was therapeutically better, permitted a fuller development of personality and avoided the problems of adjustment to normal life which were frequently experienced after prolonged care in an institution. The Commission did stress, however, that community services would not be feasible for all individuals and recommended that an appropriate mix of facilities should be provided.

1.2. In 1980, fifteen years after the publication of the Commission's report, the *Report of the Working Party on Services for the Mentally Handicapped* made estimates of the prevalence of the different categories *of* intellectually disabled persons in Ireland and *oi* the numbers in each category requiring residential care as against those who could be maintained with suitable and adequate support services within the community. In the years since the publication *oi* that report, new approaches to care in a community setting have tended to show that even greater numbers of children and adults for whom hitherto admission to a residential centre would have been envisaged can, in fact, live to their full potential within the community.

1

1.3. In the early consideration of how the Review might be undertaken, some thought was given to the establishment of a working party which would be representative of the various interested parties. In the decision not to adopt this "working party" approach, account was taken of the other reports which had already been prepared in this area. For example, considerable work had been done for the 1980 report. In the same year the National Economic and Social Council issued a report¹ on services for handicapped persons. In addition, the mental handicap census report of 1981 was available, together with the Report on the Education and Training of Severely and Profoundly Mentally Handicapped Children in Ireland (1983). the report entitled Training and Employing the Handicapped (1974) and the Green Paper entitled Towards a Full Life (1983).

1.4. As part of the consultative process, a large number of interested parties and organisations was invited to submit views and over seventy written submissions were received. In addition, discussions were held with representatives of many of the organisations concerned.

1.5. In parallel with the Review Group's deliberations, Comhairle na n-Ospideal produced a report² on the medical aspects of the services for intellectually disabled persons, in the course of which it indicated the criteria it will use in assessing future applications for appointments of consultants in these services. That report has been circulated by An Comhairle to all agencies providing services to intellectually disabled persons.

1.6. The submissions from and discussions with the various interests consulted have confirmed that there is substantial agreement on the fundamental principles which should underlie the provision of services. report outlines what these principles This are and draws some conclusions implications about their for the organisation and development of the services.

Acknowledgements

1.7. We would like to express our appreciation of the ready and wide response to our invitation for views. The range and the quality of the submissions we received from the different groups involved in the care of the disabled was impressive. We also wish to acknowledge especially the contribution to our report made by **Mr. Brendan Ingoldsby** and

Ms. Dora Hennessy of the Handicapped Services Division of the Department of Health who displayed an exceptional commitment to and understanding of this area of work of the Department.

Membership

1.8. The following were appointed members of the Review Group:

Mr. Shaun Trant	(to March 1988) Assistant Secretary, Department <i>oi</i> Health, Chairman.
Mr. Gerard Guidon	(from March 1988) Principal, Department <i>oi</i> Health, Chairman.
Mr. Frank Foley	(to March 1987) Principal, Department <i>oi</i> Health.
Mr. Dermot Smyth	(from March to July 1987) Principal, Department of Health.
Bro. Alfred Hassett	Provincial, Brothers <i>oi</i> Charity and part-time adviser to the Department <i>oi</i> Health on mental handicap.
Mr. Brendan Ingoldsby	Assistant Principal, Department of Health.
Dr. Roy McConkey	Psychologist, Director of Training and Research, Brothers of Charity, St. Aidan's, Melrose, Scotland. Formerly with St. Michael's House, Dublin.
Mr. Michael McLoone	(To 1988) Programme Manager, Community Care, North Western Health Board.
Dr. Michael Mulcahy	Medical Superintendent, Stewart's Hospital, Dublin.
Dr. Dermot Walsh	Inspector of Mental Hospitals, Department of Health.
Mr. Michael Walsh	A/Programme Manager, Special Hospitals, Eastern Health Board.
Ms. Dora Hennessy	Higher Executive Officer, Department <i>oi</i> Health, Secretary.

National Economic and Social Council: Report No. 50, Major Issues in Planning Services for Mentally and Physically Handicapped Persons.

Comhairle na n-Ospideal: *Report of the Committee on the Medical Aspects of the Mental Handicap Services,* April 1988.

Summary of Recommendations

- Chapter 3 1. The term "mental handicap" should no longer be used. Formal debate should be initiated amongst the interests concerned with a view to arriving at a consensus on the most appropriate terminology to be used. (3.4.)
- Chapter 4 2. Children with general learning difficulties should not be referred for assessment to centres for intellectually disabled persons. (4.1.)
 - 3. Multi-disciplinary support services to pupils with general learning difficulties should not be the responsibility of services for intellectually disabled persons. (4.2.)
 - 4. Children and adolescents with general learning difficulties should not be referred for residential services if the only reason for doing so is to facilitate attendance for special education. (4.3.)
 - 5. The Departments of Health and Education should ensure that a higher level of multi-disciplinary support is available to the pupil with general learning difficulties leaving local educational services. (4.5.)
 - 6. The Departments of Education and Labour should take action to facilitate those with general learning difficulties in pursuing further education, vocational training and employment placement for school leavers. Second and third level educational establishments operated under

the Department *of* Education should be especially conscious of the need to facilitate the further education of these young people. (4.6.)

- Chapter 5 7. A single authority should be charged with the task of periodically reporting to the Minister for Health on the current situation in relation to preventive measures recommended. It would be appropriate *for* the Health Promotion Unit of the Department of Health to undertake this task. (5.1.)
 - 8. Consultancy services and laboratory facilities for a genetic counselling service should be made readily available as a matter of urgency. (5.4.)
 - 9. A number of pilot educational and support programmes for parents should be undertaken by health boards in conjunction with the Department of Education to complement services for disadvantaged children. (5.7.)
- Chapter 6 10. The health board pre-school developmental service should be particularly directed to those children in districts where cultural, social, emotional and material deprivation are evident. General practitioners and other community care personnel should receive special training in the screening and detection *of* abnormalities. (6.2.)
 - 11. Relevant skills should be emphasised in training programmes for professionals who are likely to have to inform parents that their child has or is likely to have a disability. Personnel providing support to families should have available for supply to parents a dossier of informational material. (6.3.)
 - 12. Close liaison is required between the maternity and general community health services for children and the services for intellectually disabled persons. (6.4.)

- Specialist early intervention teams should be available in each region. (6.5.)
- 14. Services for children up to age three should be delivered mainly in the home. The early intervention team should direct its attention initially to assisting the family to adjust to its new situation. (6.6.)
- 15. One person should have primary responsibility within the early intervention team for co-ordinating the support services as required. (6.7.)
- 16. Support groups should be encouraged by the health boards and contact between parents and these groups should be facilitated at the earliest possible opportunity. (6.8.)
- 17. Children of approximately three years whose development is delayed should be facilitated to attend local pre-schools or playgroups for other children. (6.9.)
- 18. Where pre-schools are unsuitable, unavailable or unable to cope with the child because of the severity of the developmental delay, a special child development centre will be necessary. (6.10.)
- 19. Arrangements for substitute families for temporary or long-term care must be facilitated where the child's home is not able to meet his or her needs adequately. There is also a need for a limited number of crisis and planned relief facilities. (6.11.)
- Chapter 7 20. Close liaison will be required between the frontline and multi-disciplinary support personnel of the pre-school programmes and their counterparts in the school programme. (7.2.)
 - 21. Existing inputs to special education programmes by multi-disciplinary support teams funded by the

Department of Health should be formally recognised by the Department of Education. (7.3.)

- 22. No child should be placed in residential accommodation away from home solely on the basis of the need to avail of special education. (7.4.)
- Close links are desirable between child education and development centres (CEDCs) and special and/or ordinary schools. (7.5.)
- 24. The location of the CEDC should be convenient to the population served and in facilities separate from residential facilities. (7.6.)
- 25. The Departments of Health and Education and the Federation of Voluntary Bodies Providing Services to People with Mental Handicap should discuss the future role of teachers within CEDCs. (7.9.)
- 26. Children in CEDCs should progress to a senior cycle *at* about the age of twelve. (7.10.)
- 27. A small number of alternative homes staffed to meet intensive medical needs or to provide intensive behaviour management programmes should be provided within each region. (7.12.)
- 28. There is a need for short-term breaks for some of those families which have members with a moderate degree of intellectual disability living at home. (7.13.)
- Chapter 8 29. All pupils who avail of special educational programmes should have access to pre-vocational and vocational training as appropriate. Vocational training should be of at least three years' duration and centres should be locally based and close to ordinary schools and colleges. (8.4.)

- 30. Work training in the vocational training centre must relate to the employment opportunities in the area. (8.5.)
- 31. Sheltered employment provision need not necessarily take the form of workshops as we have known them but could be resource centres based in local neighbourhoods. (8.6.)
- 32. Local committees should be established to promote employment opportunities. (8.7.)
- 33. The Department of Labour should in future play a greater role in the training and employment of intellectually disabled persons capable of and suitable for open employment. (8.8.)
- 34. Day care programmes for severely and profoundly disabled persons should be provided in small local units. (8.10.)
- 35. Individual programmes for each client are essential. (8.11.)
- 36. The educational curricula of students of all relevant professions should be reviewed to ensure that they are aware of and trained to deal with disabled persons in the community. (8.12.)
- Chapter 9 37. Large numbers of highly dependent intellectually disabled persons should not be placed in one location. New residential provision should be in small clusters of 3 or 4 houses at a number of locations. (9.6.)
- Chapter 10 38. It is desirable that all intellectually disabled persons over the age of forty have an annual multi-disciplinary assessment. (10.2.)
 - 39. Where any intellectually disabled person seeks the option of returning to a residential centre for retirement, this wish should be respected. (10.4.)

- 40. On retirement, intellectually disabled persons in supervised accommodation should continue to live in their place of residence. (10.5.)
- Chapter 11 41. Assessment teams from the services for intellectually disabled persons should carry out a detailed assessment of the condition and total circumstances of such persons who are in psychiatric hospitals. (11.2.)
 - 42. Where disturbed behaviour is a problem, consideration must first be given to effecting a change for the better in the person's daily environment. Of paramount importance in the prevention and management of disturbed behaviour is the provision of adequate staff. A ratio of 1.5 frontline staff per disturbed person is required overall. The emphasis should be on personnel rather than on special buildings. (11.6.)
- Chapter 12 43. Health boards should be responsible for ensuring that a comprehensive regional data base is established and maintained, including recording of other persons requiring services in addition to those already served. (12.6.)
- Chapter 13 44. A multi-disciplinary approach should be maintained in the employment of personnel. (13.1.)
 - 45. Guidelines on staffing structures should be drawn up by a group of experts. (13.2.)
 - 46. A range of certificate courses should be established offering in-service post-graduate training in residential programmes to personnel. (13.3.)
 - Personnel with specialist training in behaviour management should be assigned to programmes for intellectually disabled persons with challenging behaviour. (13.4.)

9

- 48. Training courses for personnel in residences should place greater emphasis on the training of these personnel in the skills of home making and personal support services. (13.5.)
- 49. Immediate attention should be given to the serious shortage of physiotherapists and speech therapists. There should be a more equitable distribution of available time of multi-disciplinary personnel between intellectually disabled persons in psychiatric hospitals and their counterparts in other agencies. (1 3.6.)
- 50. Greater emphasis should be placed on the recruitment, induction, training and management of voluntary personnel. (13.7.)
- Chapter 14 51. The existing arrangements for the organisation of services should continue, strengthened by the reconstituted co-ordinating committees. (14.6.)
 - 52. The re-constituted health board co-ordinating committees should each produce a report at regular intervals on progress in relation to the health board plans. (14.7.)
 - 53. (a) There should be time-limited secondments of experts to the Department of Health from senior posts in the services for intellectually disabled persons.(b) The Review Group should continue in existence and meet periodically. (14.8.)
 - 54. Service providers should ensure that their structures encourage intellectually disabled persons to use the services availed of by the rest of the community. Also, those responsible for providing health services to the general population should ensure that these services are made readily accessible to intellectually disabled persons. (14.10.)

- 55. The Department of Health should initiate discussions with appropriate public agencies to investigate the scope for service-providing agencies to provide selfsupporting employment for people with a learning difficulty or intellectual disability. (14.11.)
- 56. An assessment of the housing requirements of intellectually disabled persons should be undertaken when more accurate data is available from the health board registers. (14.12.)
- Chapter 15 57. Provision should be made to meet accumulated needs over the four years commencing in 1990, estimated at 150 residential and 250 day places per annum. (1 5.2.)
 - 58. In each of the five years commencing in 1990, a further 40 residential places and 200 day places should be provided to meet emerging needs. (15.4.)
 - 59. A planned programme for the transfer of intellectually disabled persons from inappropriate institutional care should be established at the rate of 250 per annum for the five years commencing in 1 990. (1 5.6.)
 - 60. A sum of £500,000 should be made available in each of the five years commencing in 1990 to strengthen the level of multi-disciplinary support staff in the community. (1 5.8.)
 - 61. The detailed analysis of cost-effectiveness of alternative levels of care carried out by an analyst of the Department of Finance should be examined further by the Health Policy Research Unit of the Economic and Social Research Institute. (15.11.)

(A summary of capital and revenue costs involved in these recommendations is contained in paragraphs 15.9 and 15.10.)



Participating in the Open Road project, St. Michael's House, in association with Aer Rianta.

Terminology

3.1. The term "mental handicap" was comprehensively defined in 1965 by the *Report of the Commission of Inquiry on Mental Handicap*. The term as used since then covers a wide spectrum of persons with differing conditions and circumstances. The intellectual abilities of those at the upper end of the range covered by the term "mental handicap" are markedly different from those at the lower end of the range.

Further, it has long been recognised that the association with brain damage is less prevalent among the upper ability group. For example, a WHO report* noted that "in most surveys less than one-third of mildly mentally retarded individuals show evidence of organic impairment, most are found to be suffering exclusively from the impoverishment of their social environment". The report concluded that "not only do these groups differ in incidence and prevalence, but also in degree of handicap and ultimate prognosis. Although it is not appropriate to think in terms of a sharp dividing line, persons with an IQ below 50 ... are generally characterised by some form of biological impairment involving the central nervous system while the mildly mentally retarded are much less affected in this way".

3.2. Experience in Ireland and elsewhere has shown that once the demands of formal education are passed, the majority of people labelled "mildly mentally handicapped" merge successfully with the non-handicapped adult population. Moreover, if they require special services, they do not look to mental handicap agencies to provide them. People described as "mildly mentally handicapped" also have a keen awareness of the stigma attached to the label. They even avoid mentioning the name of the special school they attended.

3.3. There is no widely accepted alternative to the term "mental handicap" at present. Descriptions which might be adopted include "intellectual disability" and "developmental disability". It must be admitted that any new term can be debased over time and a simple change of label in itself will not have a long-lasting positive effect unless a concurrent attempt is made to change professional and public attitudes. Nonetheless, terminology has significance both for the morale of the individual described and for community perceptions.

3.4. It is recommended that the term "mental handicap" should no longer be used and that two entirely distinct terms should be used in future to denote persons previously referred to respectively as "mildly handicapped" and "moderately, severely or mentallv profoundly mentally handicapped". It is further recommended that formal debate be initiated amongst the interests concerned with a view to arriving at a consensus on the most appropriate terminology to be used. This approach is recommended as it is felt that any term handed down by a body such as this Review Group might not achieve the universal acceptance which is necessary if an effective change in terminology and perception is to be achieved. Meanwhile, because of the disfavour into which the term "mental handicap" has fallen at the international level, it is felt that it is no longer appropriate to use this term. For the purposes of this report and until an agreed terminology is in place, the term "mild mental handicap" is replaced by the term "general learning difficulties" and the designation "moderate, severe or profound mental handicap" by the designation "moderate, severe or profound degree of intellectual disability".

World Health Organisation Mental Retardation: Meeting the Challenge 1985

Persons with General Learning Difficulties

4.1. It is recommended that children with general learning difficulties should not be referred to centres for intellectually disabled persons for assessment as has been the practice. We are of the opinion that there is a case for the full-time employment of specialist staff such as psychologists, social workers and speech therapists in the educational service. However, where these disciplines are not employed by the Department of Education, assessments could be carried out by the multidisciplinary teams of the intellectually disabled service as an integral part of the school system. We recommend that discussions should take place between the Departments of Health and Education to give formal recognition to these arrangements.

4.2. The Review Group welcomes the fact that increasing numbers of pupils with general learning difficulties are now being provided with educational opportunities in their local environment. *It recommends that the multi-disciplinary support services to such pupils should not be the responsibility of services for intellectually disabled persons.* The Departments of Education and Health should co-ordinate their efforts to ensure that appropriate support services are available to such pupils.

4.3. The Review Group recommends that children and adolescents with general learning difficulties should not be referred for residential services if the only reason for so doing is to facilitate attendance for special education. Where family circumstances make it necessary to provide an alternative residential arrangement for a child or adolescent with general learning difficulties, this should be arranged in association with the multi-disciplinary support team. Preference should be given to seeking a place for the child with a substitute family and placement should continue only for as long as is deemed necessary.

4.4. Where a child or adolescent with general learning difficulties has significant additional handicapping factors necessitating residential placement, this service should continue to be provided under the Department of Health in accommodation which is as ordinary as possible, bearing in mind the welfare of the child or adolescent and his or her special requirements.

4.5. Although the growth of local educational services for children with general learning difficulties within the primary educational sector has not yet been matched by a similar growth within the post-primary sector, the Review Group presumes that the greater part of the provision for pupils of all ages will in future be localised. *The Review Group recommends that the Departments of Health and Education should co-ordinate their efforts to ensure that a higher level of multi-disciplinary services is available to the pupil with general learning difficulties leaving local educational services than that which has been available up to now to pupils leaving special schools. The multi-disciplinary team is a vital link in assisting the school leaver to obtain further education and training and appropriate employment.*

4.6. The Departments of Education and Labour should take action to facilitate those with general learning difficulties in pursuing further education, vocational training and employment placement for school leavers with general learning difficulties. They should recognise that these school leavers need special additional help to prepare themselves adequately to enter the workforce.

Second and third level educational establishments operated under the Department of Education should be especially conscious of the need to facilitate the further education of these young people. In addition, the training agencies such as FAS, which operate under the Department of Labour should make special efforts to incorporate these young people into their mainstream programmes of training and preparation for employment. We recommend that the Youthreach Programme for the early school leaver, provided jointly by FAS and the Department of Education, take particular account of the requirements of these young people.

16

Prevention

5.1. The Report of the Commission of Inquiry on Mental Handicap in 1965 comprehensively treated the subject of prevention. The consultations which the Review Croup has had with the various interests in the field confirm the view that the recommendations of the 1965 report continue to be valid. The principal preventive measures discussed in that report related to health education, obstetrical services, control of epilepsy, early identification, routine testing of infants, aenetic counselling and alleviation of cultural or environmental deficiencies. The challenge we face is one of ensuring that the implementation of these recommendations is given the highest priority. Since the responsibility for implementing these recommendations is spread across a number of service sectors, it is desirable that a single authority should be charged with the task of periodically reporting to the Minister for Health on the current situation in relation to each of these measures. As the subject of prevention is relevant to the state of health generally we consider that it would be appropriate for the Health Promotion Unit of the Department of Health to undertake this task.

5.2. To be effective, health education programmes aimed at prevention must be promoted at both national and local levels. Associations of parents and friends and personnel in the services for intellectually disabled persons have for long been active at local level in stimulating interest in intellectual disability and in issues related to prevention. It is desirable that the Health Promotion Unit of the Department of Health would maintain liaison with and support these local groups in addition to providing a complementary national programme of education and awareness.

The Review Group would also wish to draw particular attention to the important work being done in the schools through the CARA and other similar programmes. It is desirable that a programme of this nature should become an integral part of the post-primary school curriculum.

5.3. Early intervention (discussed in detail in chapter 6) is vitally important in preventing developmental delay, in lessening the impact of intellectual disability on the family and in preventing the growth of secondary disabilities.

5.4. In our consultations with the various interests in the field, the need for adequate genetic counselling services was strongly emphasised. It is recommended that the appropriate consultancy services and laboratorv facilities be made readily available as a matter of urgency. Ideally genetic counselling services should be available in a number of regional centres, e.g. Dublin, Cork, Galway, from which services would be provided locally on a visiting basis. The need for this service is, of course, shared with other branches of the health services. It has been suggested that a significant number of serious congenital abnormalities may be prevented by counselling alone. The significance of a national service in terms of savings to the health service is obvious. There should be full access to the services for families for whom it is indicated. General practitioners and other community care professionals have an important role to play in establishing links between genetic counselling services and individuals and families who could benefit from such counselling. The importance of genetic counselling services should also feature in general health education programmes.

5.5. The progress made in reducing infant and perinatal mortality during the past twenty years has been remarked upon in recent reports on perinatal statistics*. The provision of more specialised services on a regional basis has helped significantly to reduce the incidence of intellectual disability associated with avoidable birth trauma. However, the reduction in perinatal mortality is likely to bring about an increase in the survival rate of children with serious disabilities and this must be taken into account in future planning. The Review Group also recognises the contribution made to the prevention of intellectual disability by the national screening programme for a number of conditions which could, if undetected, contribute to the development of a disability.

5.6. People involved in the provision of services to intellectually disabled persons have increasingly drawn attention to the damaging effects of cultural, social, emotional and material deprivation, the victims of which so often come to be catered for in services for intellectually disabled people. Earlier reports, such as the 1965 Commission of Inquiry

18

and that of the NESC on services for handicapped persons have already discussed the significance of socio-economic factors such as family size, housing conditions, level of educational achievement of parents and siblings in cases *oi* sub-cultural *or* familial learning difficulty and intellectual disability.

5.7. More concerted efforts should be made to break the cycle of deprivation. For example, services for disadvantaged children in special schools and pre-schools or through special measures in ordinary schools, if they are to be successful, need to be complemented by educational and support programmes for the parents. A number of pilot projects targeting these groups should be undertaken by health boards in conjunction with the Department of Education.

5.8. The growing trend towards the provision of integrated communitybased services raises the question of the adequacy of support for the persons concerned in these developments. As a practical example we may cite the need to have sex education and family planning advice made available for people with general learning and intellectual disabilities.

5.9. There is also need for a greater awareness by community planners of the implications of uprooting settled communities and dispersing them to new and unfamiliar surroundings, with concomitant serious problems of adjustment, damage to family and community support structures and contribution to developmental delay in children. For this reason, consultation with the health and education authorities should be an integral part of the planning process.

Department of Health Perinatal Statistics 1984 and 1985 and 1986.

Identification and Early Services

6.1. The early identification of infants with delayed development is a crucial element in the delivery of an effective, efficient and comprehensive service to families.

Examination of Infants and Young Children

6.2. Almost all births now take place in hospital, which facilitates the detection of seriously disabling conditions at an early stage. Every infant born in a maternity hospital is examined by medical staff and screened for inborn errors of metabolism. In addition to the neo-nata! service, the health board pre-school developmental service has an important role to play in the detection and assessment of abnormalities which were not or could not have been detected at birth. The resources of this service should be particularly directed to reach those children in districts where cultural, social, emotional and material deprivation are evident.

In the absence of a developmental paediatric examination at regular intervals during infancy and early childhood, the identification of a child with delayed development is dependent upon the family doctor and community care services personnel. It is, therefore, important that general practitioners and other community care personnel should receive special training in the screening and detection of abnormalities. The adequacy of existing arrangements in this regard should be considered by the Postgraduate Medical and Dental Board, An Bord Altranais, and other professional training bodies.

Identification of Disability

6.3. The identification of children with severe disabilities will normally occur at birth and during the pre-school period. For other children identification will come in early childhood, while for those with general learning difficulties, discovery may not occur until the early years at school.

There is no easy way of informing parents that their child has or is likely to have a disability. *Relevant skills should be emphasised in training programmes for professionals such as obstetricians, paediatricians, midwives and social workers, who are likely to have to inform parents* since the manner in which the information is conveyed can have an important bearing on the attitude of parents throughout their child's life.

The needs of parents will be many and varied at this time. All are likely to require information, support and practical advice. *Personnel providing support to families should have available from their health board, for supply to parents, a dossier of printed material* containing information on the disability, the name, address and telephone number of appropriate community care staff and of the local service for intellectually disabled persons together with details of entitlements.

6.4. Close liaison is required between the maternity and general community health services for children and the services for intellectually disabled persons to facilitate referral and ensure that appropriate staff are available to the child and family as necessary. It was represented to the Group that such links had yet to be established in many areas. This is an example of the possible inadequacy of local arrangements for co-operation which it would be appropriate for the health board co-ordinating committees (paragraph 14.7) to consider.

Early Intervention Teams

6.5. Specialist early intervention teams should be available in each region to develop the appropriate levels of expertise and experience in meeting the specialist needs of infants and young children with developmental delay. The early intervention team should be multidisciplinary in character. The disciplines involved should include (as appropriate) paediatrician, psychologist, social worker, speech therapist, physiotherapist, teacher and community nurse. The teams should be maintained by the health boards or by voluntary bodies as agents of the health board.

The purpose of early intervention is

- (a) to assist the parents to cope with the trauma of having a child who is developmentally delayed;
- (b) to facilitate the acceptance of the child by parents and siblings as a full member of the family;



Children preparing for Christmas at Stewart's Hospital, Dublin.

- (c) to prevent the subsequent development of secondary disabilities (physical/emotional);
- (d) to offset the delay in the development of these children by systematic teaching and training programmes and by guiding the parents in how best to nurture the child's progress.

6.6. Services for children up to age three should be delivered mainly in the home and should include

- (a) initial assessment and an ongoing programme to meet the needs of the child;
- (b) support services to the family.

The early intervention team should direct its attention initially to assisting the family to adjust to its new situation, helping it to acquire realistic expectations for the child's future and increasing the confidence of the family to meet the needs of the new family member. Experience has shown that the provision of ongoing support to the family facilitates the integration of the child into the community and is of considerable assistance in maximising the child's development.

Key Worker

6.7. The early intervention team should choose one of its members to be the link between the team, the family, the community and other service providers. *This person should have primary responsibility within the early intervention team for co-ordinating the support services as required.* The choice of the key worker will be influenced by the particular needs of the family. Where other service providers are also involved with the family, care must be taken by the key worker and the early intervention team to avoid duplication of inputs, undue upset to the family or inconsistency in management of the family's situation.

In addition to helping the family through the initial stages of adjustment to the child's developmental delay, the early intervention team through the key worker, will provide practical advice and information on the best methods of promoting the child's development, and assistance in identifying the resources that are available within the family and the wider community to help in this task.

Support Groups

6.8. Support groups such as the mother and baby groups, parents and

friends provide a valuable source of practical assistance for parents by sharing experiences. They also provide ongoing support. Support groups should be encouraged by the health boards and contact between parents and these groups should be facilitated at the earliest possible opportunity.

Pre-School

6.9. As far possible, developmentally delayed children as should be approximately three years attend local pre-schools facilitated at to or playgroups for other children subject to the pre-school teachers and playgroup leaders following a programme recommended by the early intervention team. Additional help by way of specialist support services, transportation, or improved staffing ratio may also be required. The benefits to be derived from providing such a service include

- (a) stimulation for the child with developmental delay by contact with other children and by different surroundings;
- (b) the opportunity to increase parent and family skills in meeting the needs of the child;
- (c) facilitation of the integration of the child into the community;
- (d) providing the parents with some relief from the strains of continuous care.

Child Development Centres

6.10. Where pre-schools are unsuitable, unavailable or unable to cope with the child because of the severity of the developmental delay, a special child development centre will be necessary. This service should be provided locally for small groups and in facilities that are not over specialised. The Review Group has observed such developmental centres operating effectively from ordinary bungalows with minor adaptations. Such facilities are much less threatening to families and make it much easier to establish links with communities and with other facilities such as playgroups.

In small urban areas with a rural catchment area, the most effective provision seems to be for not more than about twelve children.

6.11. The number of children under the age of 5-6 years who will require to be accommodated outside of the home will be very small. Where the home is not adequately able to meet the needs of the child whose development is delayed, substitute families are being sought with increasing success either for temporary or more long-term care and these arrangements must be facilitated in the allocation of resources. There is also a need for a limited number of staffed crisis and planned relief facilities if we are to respond adequately to the needs of all children with developmental delay (see also paragraph 7.13).

Children of School Age

Children with a Moderate Degree of Intellectual Disability

7.1. At the age of 5-6 years the child with a moderate degree of intellectual disability usually moves from an early childhood development programme, pre-school or playgroup to a special school, special class or integrated education within the ordinary classroom. The Review Group welcomes the increasing localisation of educational opportunities for children with a moderate degree of intellectual disability.

7.2. The stage of transfer from pre-school programmes to special school, special class or ordinary class is a time of concern for the child and the family. Close liaison will be required between the frontline and multidisciplinary support personnel of the pre-school programme and their counterparts in the school programme if this transfer is to be successfully achieved.

7.3. The Review Group recommends that the existing inputs to special education programmes by multi-disciplinary support teams funded by the Department of Health be formally recognised by the Department of Education and that formal discussions be held between the Departments of Education and Health, the voluntary agencies involved and the health boards regarding the development and future structure of these supports.

7.4. The localisation of special educational opportunities for children with a moderate degree of intellectual disability has greatly reduced the need for residential accommodation for these children. The Review Group welcomes this development and recommends that *no child* should be placed in residential accommodation away from home solely on the basis of the need to avail of special education.

26

Children with a Severe to Profound Degree of Intellectual Disability

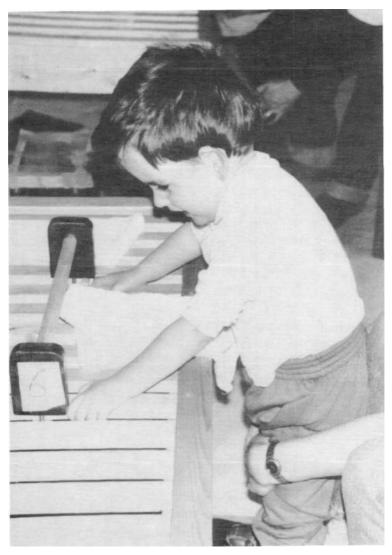
7.5. The needs of these children have been discussed at length in the *Report on the Education and Training of Severely and Profoundly Mentally Handicapped Children in Ireland*.* In common with that report, the Review Group acknowledges that the child education and development centre (CEDC) model, which has been developed by a number of voluntary sector service providers since the early 1970s, has served the needs of this group well.

However, we would like to see close links between CEDCs and special and/or ordinary schools. This type of centre caters for children with a severe or profound degree of intellectual disability as well as for children with a moderate degree of intellectual disability who would not benefit from placement in a special class or school. These placements should be for limited periods prior to transfer to special classes or schools. Such children are entitled like any other child to education and development appropriate to their needs and capacity.

7.6. The CEDC should be convenient to the population served and should always be in facilities which are separate from residential facilities and preferably on a different site. While location of CEDCs in association with special schools can sometimes be advantageous, many of the successfully established centres are free standing. Consideration should also be given to associating the CEDCs with ordinary schools to facilitate the practical integration of CEDC pupils with their peer group.

7.7. Where accommodation in ordinary schools is used, special physical adaptations of buildings may be necessary. Many of the children will have additional handicapping conditions. Particular attention will, therefore, need to be given to access, circulation and storage space, provision of adequate rooms for group and one-to-one work, play and recreational space indoors and outdoors, toileting and washing facilities, activity materials and equipment.

7.8. The most effective CEDCs seem to be reasonably small with not more than ten to fifteen pupils and with a frontline team of staff drawn from a number of disciplines - teaching, nursing, care assistants and household personnel. Each member of the team is expected to share in all aspects of the care, training and education of the children and in the planning of the individual programme which is implemented for each child within the CEDC. Regular support from a multi-disciplinary team in



Participating in a conductive education programme in the Brothers of Charity services in the West.

planning, implementing and monitoring programmes and in linking parents and other family members to the care and training of the pupil are also seen as essential features of a good CEDC.

7.9. In establishing CEDCs in the 1970s, service-providing agencies wishing to employ professionally trained teachers in these facilities as

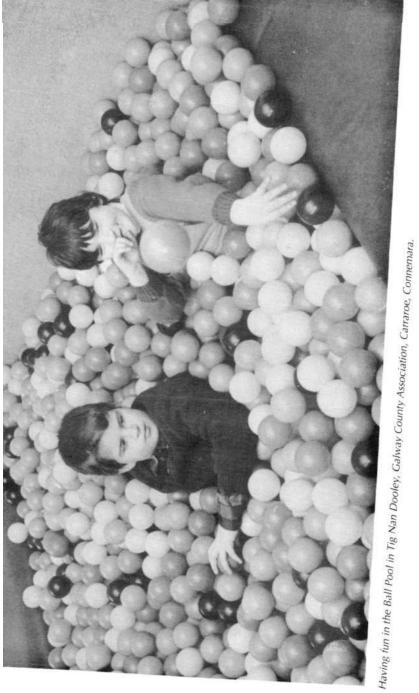
members of the inter-disciplinary frontline team found it necessary to exercise the only option available by recruiting these teachers as trainer/educators under the Department of Health. The more recent recommendation of the Report on the Education and Training of Severely and Profoundly Mentally Handicapped Children proposed that teachers be allocated by the Department of Education to CEDCs and that they be supervised by the principal of the most proximate special school for pupils with a moderate degree of intellectual disability. The role within the CEDCs for the teachers proposed by the report referred to remains to be clarified by the Department of Education particularly insofar as it relates to the nurse/educator and other disciplines in these centres. It is recommended that the Departments of Health and Education and the Federation of Voluntary Bodies Providing Services to People with Mental Handicap should discuss the future role of teachers within CEDCs and the most appropriate methods of training, supervising and financing them, bearing in mind the existing structure of CEDCs and of the agencies operating them.

7.10. In keeping with the practice in mainstream education, *it is recommended that children in CEDCs should progress to a senior cycle at about the age of twelve years and* should remain within that cycle to the age of approximately eighteen years. While the senior cycle will also be a programme of care, education and training aimed at increasing the basic social competence of the pupils, care should be taken to engage the pupils in activities appropriate to their age.

7.11. The Review Group recognises that a small number of children and adolescents with intellectual disability will require to be accommodated outside the family home. These will include

- (a) children whose families are unable, for a variety of reasons, to respond adequately to their needs;
- (b) children whose medical needs are so intensive as to require specialised attention;
- (c) children whose behavioural maladjustment is so significant as to require intensive specialist intervention.

7.12. While a significant number of these children may be successfully placed with substitute families, *the Review Group recommends that a*



small number of alternative homes staffed to meet intensive medical needs or provide intensive behaviour management programmes be provided within each region.

7A3. The Review Group also wishes to draw attention to the *need for short-term breaks for those families who have family members with intellectual disability living at home.* The Review Group recognises that many agencies have developed a range of options including breakaway schemes, shared care schemes and planned and crisis intervention services to assist these families. They wish to stress the value of all these services in helping families to maintain these children within the home. For children in the senior cycle, particularly those with higher dependency levels, it will be necessary to provide a greater level of family support, more frequent short-term planned and crisis services and a greater number *oi* places in full-time accommodation outside the family home.

Report of a Working Party to the Minister for Education and the Minister for Health and Social Welfare - *The Education and Training of Severely and Profoundly Handicapped Children in Ireland* 1983.

Day Care and Employment for Adults

8.1. It is essential that the stimulus and effort provided in early intervention and school programmes should be continued and complemented by appropriate programmes during adulthood. For many families, their child's attendance at a school or care unit for some hours during the day will have been a major factor in helping them to keep their child at home. Many parents of disabled children look forward with considerable foreboding to the time when their child will reach school-leaving age.

8.2. Once school-leaving age is reached, many families may feel unable to continue to provide for their son or daughter in the family home. In circumstances where families find themselves having to provide continuous care, their ability to continue managing this situation will greatly depend on the availability of support services.

Moderately and Severely Intellectually Disabled Persons

8.3. The primary concern of the services should be the provision of training and employment for people with a moderate or severe degree of intellectual disability and for those people with a general learning difficulty who, because of significant additional disabling conditions, would be unable to avail of or benefit from mainstream training programmes.

8.4. All pupils who avail of special educational programmes should have access to pre-vocational and vocational training as appropriate. Pre-vocational training is especially necessary for pupils who leave school at the end of the compulsory school period. Vocational training programmes should be of at least three years' duration. Programmes should be designed to enable students to develop further the wider skills



Concentrating on the operation of a precision instrument, Galway County Association.

required for life in the community, to equip as many as possible to enter open employment and to prepare others for work in a sheltered environment. *Centres for this purpose should be locally based and close to ordinary schools and colleges* to facilitate the inclusion of students in those aspects of the ordinary education programme from which they would derive benefit. The model for this kind of centre already exists in the schemes introduced by the Department of Education some years ago. It is now appropriate that a comprehensive network of such centres be established. To facilitate localisation of these services, the capacity of each centre should, in general, not exceed 50 places.

8.5. To maximise the individual's potential for employment in an integrated environment the work training programme in the vocational training centre must relate to the employment opportunities in the area. Work experience placements in local businesses should also be encouraged.

8.6. On completion of their training and further education and where open employment is not possible, the majority will require employment in a sheltered environment. Existing facilities in this respect need to be expanded. These need not necessarily take the form of workshops as we have known them but could be resource centres based in local neighbourhoods. Such centres would have a wide-ranging programme, including educational and social skills development, outdoor and indocj leisure pursuits and the more usual vocational training opportunities. This would have implications for the type of staff recruited and choice of premises used.

8.7. A concerted effort is required to improve the availability of work opportunities for this group of people. *This effort should take the form of local schemes aimed at promoting employment opportunities.* It could be achieved through setting up special committees along the lines suggested in the 1986 Report of the National Association for the Mentally Handicapped of Ireland *Crisis of Unemployment.* Although this report was concerned essentially with the problems of persons with general learning difficulties, the recommendations are valid also for those with an intellectual disability. The report recommended that local committees be established representative of parents, pupils, teachers, workshops, training centres, job placement personnel and local trade union and employer interests. The committees would identify local job

opportunities, investigate possibilities for job creation, advise on the content of school and vocational training curricula and act as a resource in the creation of awareness among employers, unions and the population at large. We would expect the health board co-ordinating committees (see chapter 14) to take a particular interest in the establishment and operation of these local committees.

8.8. The Departments of Health and Education play a central role in the provision of services to persons with intellectual disability. While the Department of Labour has been involved, particularly in the training of some persons with general learning difficulties to prepare them to enter the workforce, there is a general view that it should in future play a greater role in the training and employment of intellectually disabled persons likely to be capable of following the training provided and being considered suitable for open employment. Support by other mainstream public agencies for the employment initiatives of the service-providing agencies is also recommended (see paragraph 14.11).

Day Care iov Severely and Profoundly Intellectually Disabled Persons

8.9. The results of a number of intensive programmes over the past decade have shown that there is scope for considerable improvement in the quality of life of persons with a severe or profound intellectual disability. Such programmes require a major input of personnel resources. Provision for this group of people simply by way of passive institutional care is no longer acceptable and a more optimistic view of their potential would be of substantial benefit.

8.10. Programmes should be provided in small local units and if at all possible at a separate location from the place of residence. There is a particular need for an increasing number of such units to facilitate adolescents transferring from children's units and to make way for younger children. A range of existing facilities within the community could be considered as suitable locations in which to provide such units, including vacant accommodation now arising within the education services. Alternative uses for redundant public properties, such as use for services for intellectually disabled persons, should be considered before any decision is made to dispose of them on the open market.

8.11. An individual programme for each person is essential. Intensive personalised approaches to the needs of such people will also reduce problem behaviour.

8.12. It is desirable that all intellectually disabled persons living within the community should have ready access to general and specialist medical services. Such access should be facilitated by the multidisciplinary support team working jointly with the general practitioner and other community care professionals. The educational curricula of students of all relevant professions should be reviewed to ensure that they are aware of and trained to deal with intellectually disabled persons within the community.



Cutting material used in the manufacture of headboards at Snipe Industries Ltd, Galway County Association.

Chapter 9

Living Arrangements for Adults

9.1. Adult persons with intellectual disability should continue to live at home if this can be achieved without placing undue strain on parents and relatives or on the intellectually disabled persons themselves. Experience in Ireland and elsewhere has shown that when adequate family support services are provided, many families happily continue to care for their son or daughter well into their adult years.

9.2. The primary objective of family support services should be to help families, including substitute families, to care for their intellectually disabled members and to resolve or alleviate the difficulties which may inhibit them from doing so. If this objective is to be achieved, such support services will be required to operate at weekends and unsocial hours, as it is at these times that families are most likely to encounter problems. If this goal is to be achieved, there will be a need for an increase in the level of support services. In paragraph 13.2, the Review Group recommends that guidelines in this respect should be drawn up.

9.3. The domiciliary care allowance, the disabled persons maintenance allowance (DPMA) and the mobility allowance, together with the local authority grants for the adaptation of housing and the provision of aids and equipment, are designed to assist families to cope with the physical care of disabled persons, including persons who are intellectually disabled. We welcome the proposal under consideration in the Department of Health for the substitution of a standard training allowance for the range of payments, such as DPMA, rehabilitation maintenance allowance and social welfare payments, which are at present made to disabled persons undergoing training. However, there is the problem of an appropriate income source for persons who have completed training. For the majority of intellectually disabled persons, open employment is an unlikely prospect and a reasonable wage in a

37

special work setting would be appropriate. It would enhance the selfesteem of many intellectually disabled persons if they were in a position to make a significant contribution to the cost of their residential accommodation from the wages they receive.

9.4. Other factors which would be of great assistance in helping families who provide for their intellectually disabled family member at home would include

- (a) a day service that is appropriate and challenging and that is within easy reach of the family home;
- (b) access to a multi-disciplinary support service team which can give practical advice and counselling;
- (c) short-term breaks on a planned basis, at a time of crisis or when other events or circumstances warrant it;
- (d) well-planned leisure activities with other intellectually disabled persons and with non-disabled peers;
- (e) ready access to health and welfare services including home helps;
- (f) a local community which is sensitive to the needs of intellectually disabled persons and their families and which is involved in friendship schemes and other schemes helpful to families;
- (g) a clear and certain knowledge on the part of the family that alternative and appropriate accommodation is available to their intellectually disabled family member immediately it is required.

9.5. If an intellectually disabled person has to leave the family home either permanently or for a period of time, the substitute home should have all the characteristics of a good family home. A range of options to meet this requirement might include

- (a) care by other relatives who take over the care of the intellectually disabled person and who should be given full right of access to the range of services mentioned above;
- (b) "other family care" schemes which are well established in many developed countries and which provide a form of adult foster care;
- (c) minimally supervised group homes in which a small number of more competent intellectually disabled persons share a home with assistance from a support worker who visits regularly;

- (d) staffed group homes where a small number of intellectually disabled persons are facilitated in sharing a home together by having continuous assistance. The number of residents and staff may vary according to the degree of disability of the residents, though the numbers would never be so large as to undermine the homely character of the dwelling. While the majority of group homes established for adults to date have been for adults with a moderate degree of intellectual disability, recent experience has shown that group homes appropriately located and intensively staffed can also provide a high quality service for persons with a severe or profound degree of intellectual disability;
- (e) placement in a residential centre. This is the least favoured option and is seldom recommended except for persons with a severe to profound degree of intellectual disability or for persons with intellectual disability who have significant additional handicapping conditions.

The Future of Residential Centres

9.6. We have been fortunate in Ireland that our residential centres have generally been small by international standards and many have never had the institutional characteristics which have been a feature of such centres in a number of developed countries. Amongst the agencies providing services to persons with intellectual disabilities there is a wide measure of agreement on the following

- (a) that existing residential facilities which are older and which are not domestic in scale should be discontinued as soon as possible and appropriate provision made for the present residents;
- (b) that children and adults with general learning difficulties and persons of all ages with a moderate degree of intellectual disability would in future be more appropriately placed in communitybased accommodation should it be found necessary for them to leave the family home;
- (c) that new accommodation for persons with a severe to profound degree of intellectual disability or for intellectually disabled persons with significant additional handicaps should be domestic in scale and as homelike as possible.

It is considered that large numbers of highly dependent Intellectually disabled people should not be placed in one location. While accepting

that established village complexes will have a role to play in meeting the needs of these people for some time to come, *new residential provision for this category of persons should be in small clusters of 3 or 4 houses at a number of locations.* These should be associated with intensive day programmes on separate locations which should not provide for more than twenty persons, some of whom would be day attenders.



Typical residence in the community, Daughters of Charity Services, Dublin.



Typical bedroom in a group home for adults, Brothers of Charity Services, Galway.

Elderly Persons

10.1. Elderly persons constitute a growing proportion of the intellectually disabled population because *of* improved life expectancy and because many such people age prematurely. In general, their needs mirror those of other elderly people in the community but their higher level of dependency necessitates additional attention.

10.2. The ageing process in the intellectually disabled is a subject of increasing study. The known association between down's syndrome and alzheimer's disease has stimulated much recent research. *It is desirable that all intellectually disabled persons over the age of forty have an annual multi-disciplinary assessment.* Otherwise, the social and medical needs of this population may remain unmet.

10.3. Elderly intellectually disabled persons have at least as many needs as their non-disabled peers. Consequently they should have ready access to a comprehensively organised service for the elderly. The requirements for such a service have been set out in detail in the Report of the Working Party on Services for the Elderly, *The Years Ahead - A Policy for the Elderly* (1988).

10.4. Where intellectually disabled people have lived for a significant period of their lives in a residential centre before moving to independence, they sometimes seek the option of returning to that centre for their retirement. Where this option can be offered, the wishes of the intellectually disabled person concerned should be respected.

10.5. On retirement, intellectually disabled persons in supervised accommodation should continue to live in their place of residence and have the option oi attending an appropriate facility for elderly persons on

a daily basis. Transfer from supervised accommodation should only occur when the safety and welfare of the individual determines it to be necessary.

10.6. Where intellectually disabled people have already grown old in residential centres and hospitals, special attention is necessary to adapt the facilities to cater for their changed needs. In particular it is important that they are cared for by staff who have a particular commitment to old people.

Some Additional Areas of Need

Intellectually Disabled People in Psychiatric Hospitals

11.1. At the time of the 1981 census of mental handicap there were approximately 1,900 people with a mental handicap in the care of the psychiatric service. The annual returns from this service indicate that the corresponding figure for 1988 is 1,060. The official policy in relation to accommodation of people with an intellectual disability the in psychiatric hospitals has been outlined in paragraphs 7.35 to 7.38 of the Report of the Study Group on the Psychiatric Services - Planning for the Future, (1984). That report notes that it has been the policy of the Department of Health for some years not to admit any more persons with an intellectual disability to psychiatric hospitals. It recommends for a start that those people with an intellectual disability who are at present in psychiatric hospitals should be segregated from the mentally ill. It should then be possible to consider placing some of them in specialised community services with adequate back-up facilities.

11.2. To implement the recommendations of that report and to ensure that programmes of care and activity are developed to suit individual needs, we recommend that as a first step assessment teams from the services for intellectually disabled persons should carry out a detailed assessment of each person's condition and total circumstances, identify that person's future needs, outline an individual programme and determine the resource requirements in terms of facilities and personnel to implement the plan.

11.3. Unless this assessment indicates that it is necessary for such persons to continue to be maintained within the psychiatric service, arrangements should be made for their relocation to existing programmes for intellectually disabled people and for an appropriate transfer of resources to the agency to which the transfer is being made. Where a

service does not exist or is not available for receiving such transferred persons, it will be necessary for the health board to provide a service to cater for them.

Disturbed Behaviour

11.4. We have recommended above that children with a general learning difficulty who require specialist intervention should obtain this from the generic services. Our consideration of the problem of provision for disturbed persons does not, therefore, embrace this group who will be dealt with mainly under the general psychiatric and psychological services.

11.5. It is generally accepted that settings which do not provide a person with meaningful activities and opportunities to develop positive relationships with other people are conducive to a higher incidence of disturbed behaviour. Consequently, as the quality and scope of services develop, the level of disturbance among people with intellectual disability should decrease.

11.6. In seeking solutions, therefore, for disturbed behaviour the first option to be examined is the possibility of prevention. In chapters 8 and 9 we discussed the day services and living arrangements which we consider to be appropriate for people with intellectual disability. Personalised day programmes, combined with family supports or a supportive living environment, will do much to prevent behavioural problems arising. Where disturbed behaviour is a problem, consideration must first be given to effecting a change for the better in the person's daily environment. In practical terms this will involve examining the extent to which the individual's personal needs are being met. Of paramount importance in the prevention and management of disturbed behaviour is the provision of adequate staff A ratio of 1.5 frontline staff per disturbed person is required overall. The staff concerned should be specially trained and should not be subject to frequent change. Unstable and fluctuating staff routines are particularly inappropriate. The support of a special multi-disciplinary team is a further requirement. This should include as a minimum a psychiatrist with special expertise in this area, a clinical psychologist with experience in behavioural management and a social worker familiar with the family background.

In general the emphasis should be on personnel rather than on special buildings. However, since overcrowding is especially conducive to

disturbance, it should be prevented through the provision of ample living space and the availability of quiet rooms.

11.7. There is a small number of individuals whose behaviour may be classified as dangerous to themselves, to other intellectually disabled persons or to the staff. While there is some risk that over reliance on special units to cope with this group may make the general body of staff in the services less tolerant of and less able to cope with disturbed behaviour, nevertheless a small number of such units is required. It will be necessary to prevent these units becoming blocked with long-term placements by having an effective admission and discharge policy.

While we do not recommend purpose-built units, we believe that the general movement of clients to community settings should free up some space at a small number of locations throughout the country which would make room for agencies to accommodate, on a short-term basis, persons whose current behaviour requires the type of unit mentioned above. Such protected settings should each accommodate only a small number of persons, be adequately staffed and have the regular support of a multi-disciplinary team.

Intellectually Disabled Population

Prevalence of Intellectual Disability in Ireland

12.1. The 1981 Census revealed a prevalence for "all levels of mental handicap" *oi* 6.68 per 1,000 total population. *Oi* this figure, 3.6 per 1,000 represented persons with a "moderate, severe or profound degree *oi* mental handicap". Altogether, 12,304 such persons were enumerated. From work at present being carried out in a number of areas, there are indications of an increase in the prevalence of intellectual disability since 1981.

The prevalence *oi* down's syndrome is unusually high in Ireland in relation to other countries. This trend still persists as is shown in the Eurocat report on the *Surveillance of Congenital Anomalies* for the years 1980-1983 which revealed that the incidence of down's syndrome in Ireland in 1985 was higher than in any other European country.

The prevalence of general learning difficulty is unknown in Ireland for the same reason as in other countries, namely that many persons with general learning difficulty are not formally identified. The indicated prevalence of 2.7 per 1,000 total population reported in 1981 should be interpreted with caution in the light of this fact. In recent years, there have been suggestions from Scandinavia that the incidence of general learning difficulty may be declining in those countries. This finding could reflect either a reluctance to categorise persons at this level of functioning or a true reduction.

Current Statistics

12.2. Details of the provision for different categories of disability in residential day and workshop centres in 1988 in respect of each health board area are set out in the Appendix to this report.

12.3. The availability of comprehensive and up to date details of persons requiring services is essential for proper planning. It is the intention that

the development of local registers as recommended in this chapter and the formulation of service plans under the co-ordinating committees will produce an exact picture of unmet need. In a number of areas, the preparation of such estimates is already well advanced.

Community Care Registers

12.4. The compilation of the 1981 Census of Mental Handicap facilitated the establishment of a mental handicap record system in the office of each director of community care. The record system was confined to those persons receiving a service and those identified as in need of a service because of an intellectual disability.

However, in many areas the manual mental handicap record system has not been kept up to date. The purpose of the record system is still as valid today as it was in 1979 when it was set up under the direction of the Medico-Social Research Board.

The cumbersome nature of a manual system presents difficulties in relation to extracting and keeping the information up to date. When only minimal information is being recorded, there is a severe restriction on the value of the system for research purposes. The planning and coordination of services is also hampered. The necessity for computerised systems is, therefore, clear.

Agency Registers

12.5. Until recently the method of collection of client information by service-providing agencies ranged from comprehensive computerised systems to minimal information maintained manually. This information was collected only in respect of those people for whom services were being provided or who were wait-listed for service. The limitations of local agency-based information systems are obvious. They do not embrace the total population. For example, persons attending special education or Jiving in psychiatric institutions are excluded. Further, where clients are wait-listed by two or more services, duplication results. Most agencies cannot provide an overall view of the population and their needs within a region. In addition there is considerable variation in the content and the manner in which information is being recorded.

Agencies dealing with intellectually disabled persons should continue to maintain records on people who are in receipt of their day, residential or support services. However, for overall planning and research reasons, it will be necessary for all agencies to contribute to the establishment and maintenance of a core data base on clients using accurate and detailed information based on standard terminology, clear classifications and a specific coding system. A valuable report in this regard was prepared in 1987 by a sub-committee of the Federation of Voluntary Bodies Providing Services to People with Mental Handicap.

Health Board Registers

12.6. The maintenance of uniform data by all agencies will facilitate the establishment of regional information systems based on health board areas or community care areas, whichever is more appropriate. *It will be the responsibility of the health board to ensure that other persons requiring services in addition to those already served are duly recorded.*

Since health boards are statutorily responsible for the provision of health services, it is logical that they should be responsible for ensuring that a comprehensive regional data base is established and maintained. They may, however, wish to have this function discharged by a service for the intellectually disabled which has the capacity and experience to do so. It is essential that whatever agency assumes the lead role should be firmly committed to that undertaking. A network of micro computers using compatible programmes would facilitate the maintenance of local data bases and the establishment of the regional record systems. They would also be capable of individual stand-alone functions such as storing the local data base and additional information required to be maintained by an agency.

Ethical and Legal Considerations

12.7. The establishment of a computerised mental handicap system should not pose insurmountable ethical problems, since such problems are associated with all medical data whether it is computerised *or* manually maintained. In operating the new system all professional workers in the field of intellectual disability will have regard to the ethical code under which they work.

The Data Protection Act, 1988 is designed to protect the privacy of individuals with regard to automated personal data and to give effect to the Council of Europe Data Protection Convention, 1981. In setting up and regulating the proposed record systems it will be necessary to have regard to the provisions of that legislation. Formal statements for each data base concerning its purpose, maintenance, regulation and access will be required to ensure compliance with ethical and legal requirements.

Personnel

13.1. Agencies providing services to intellectually disabled persons in Ireland have traditionally employed personnel from a wide range of professional backgrounds. The diversity of professional outlooks and backgrounds has proved to be a creative force in the development and operation of services. *It is recommended that this multi-disciplinary approach be maintained in the employment of personnel* both at the frontline and in the support services to clients and families. This approach would involve the expenditure of a greater proportion of the available resources on induction, in-service, post-graduate and refresher courses on the various aspects of intellectual disability.

13.2. It is important that there should be a consensus about the staffing structures which are appropriate for different areas of service provision. There are currently considerable variations between agencies in this respect. To a large degree these variations are due to the funding arrangements which were inherited by different agencies. However, there are also opposing views on the kind of staffing which is needed for an acceptable quality of service, for example, in the supervision and support of disabled persons in community settings. *It is recommended that the drawing up of guidelines in this respect should be one of the tasks of the group of experts seconded to the Department which is suggested in paragraph 14.8.*

13.3. In day services throughout the country, a variety *oi* disciplines is employed including nurses, teachers, occupational therapists and instructors/supervisors with qualifications and skills in a wide range of trades, crafts, technologies and sporting and leisure pursuits.

To promote similar diversity in residential services it is recommended that a range of certificate courses be established offering in-service postgraduate training in residential programmes to personnel from various professional backgrounds and residential settings, especially within the community. It is particularly important that these courses should offer opportunities for personnel to train to function in residences providing for severely and profoundly intellectually disabled persons.

13.4./? is recommended that personnel with specialist training in behaviour management be assigned to programmes which propose to meet the training needs of intellectually disabled persons with challenging behaviour in either a segregated or an integrated setting.

13.5. /f is recommended that all training courses for personnel who propose to work in residences with intellectually disabled people place greater emphasis on the training of these personnel in home making, home sharing, housekeeping and home management, counselling and personal support to enable them to transmit these skills adequately to intellectually disabled residents.

1 3.6. While the Review Group recognises that there is a shortage of interdisciplinary support personnel in services for intellectually disabled persons, we also feel that there is a significant imbalance of disciplines amongst existing personnel, *it is recommended that immediate attention be given to the serious shortage of physiotherapists and speech therapists* and to the lack of adequate paediatric services in many areas. *Pending the transfer of intellectually disabled persons from the psychiatric hospitals, it is recommended that the available time of multi-disciplinary personnel should be more equitably distributed between persons with intellectual disability in psychiatric hospitals and their counterparts in other agencies.*

13.7. There is considerable voluntary potential within the community which should be drawn upon for practical assistance in services for disabled persons. The Group recommends that greater emphasis be placed on the recruitment, induction, training and management of voluntary personnel to assist intellectually disabled persons, especially in developing sport and leisure activities.

50

Chapter 14

Organisation and Co-ordination of Services

Existing Arrangements

14.1. Health boards by virtue of their general obligation to provide services under the Health Acts have responsibility for the health, welfare and rehabilitation needs *oi* intellectually disabled persons resident in their areas. However, these needs are catered for substantially by voluntary organisations. Most of the larger organisations relate directly to the Department *oi* Health for approval and resources to develop their services. The Department takes account of the views of health boards in relation to these proposals. Some of the organisations provide services in more than one health board area. In addition to the general health and welfare schemes provided by the boards to which intellectually disabled persons have access, the boards also make available a range of specialist services, either directly or through the agency *oi* local voluntary organisations, which they grant-aid to varying degrees.

Many of these bodies are largely dependent on voluntary fund-raising, **not only for** capital funds, but also for revenue funding. This dependence severely restricts their ability to respond to new needs and to engage in forms of voluntary support to services other than fund-raising. From the health boards' point of view, however, many local voluntary organisations embark upon new developments and are seen to expect funding from the boards for projects which the boards have not approved and for which they have not been allocated funds.

14.2. These arrangements have contributed to an uneven spread *oi* facilities. The need for co-operation in the planning and development of services has been recognised for some time in the existence of co-ordinating committees in most health board areas, representative of the statutory and non-statutory service agencies concerned. Agreement to establish co-ordinating committees in all health board areas was reached

51

in 1974, as a result ol discussions involving the Department of Health, the health boards and the voluntary organisations. Each committee was to be composed of representatives of the health board and voluntary organisations operating within the health board area.

While the co-ordinating committee offered a valuable forum in which all service providers could meet to discuss the co-ordination of existing services and the development of plans and policies for the future, it was largely ineffective principally because of the informal nature of the arrangements. The direct funded voluntary organisations were in some areas reluctant to accept the controls which such committees might impose, while some health boards were equally unwilling to accept these controls and were also sceptical about the effectiveness of committees to which some of the participants, namely the direct funded voluntary organisations. were not directly accountable. The restructuring of these committees as described in paragraph 14.7 is designed to correct these deficiencies.

Health Board View

14.3. The general view of the health boards is that since they have statutory responsibility for the provision of the services, they should also have control of the total resources for these services in their respective areas. The need for full consultation with the non-statutory sector in the development of policy is acknowledged but they consider that the ultimate decision about the allocation of the resources within their areas should rest with them.

As regards the concern that these particular services might suffer by competition with other services for which the health board is responsible, they believe that this could be satisfied by specifying the provision for them in the annual letter *oi* allocation to each health board.

The Non-Statutory View

14.4. The non-statutory organisations would be concerned at any suggestion that all funding should be arranged through health boards. Their first concern is that with the general pressure on funds available for health services, the services for the disabled would suffer in competition with stronger interests. Secondly, they do not believe that the health boards in general have the experience or specific commitment that the specialist organisations have, nor the freedom to resist political and economic pressures which would lead to a diminution in the quality of the services which would be unacceptable to the voluntary organisa-

tions. They also say that a health board is constrained by its statutorily defined responsibilities from responding in a comprehensive manner to the wide and complex range of needs of the disabled.

14.5. One suggestion has been that all services should be funded and directed from the Department of Health. However, such a system would run counter to policy in relation to the organisation of health services generally. It would also require considerable additional staffing resources at Departmental level and would create difficulties for liaison with generic services provided at community care level which are needed by the disabled population.

Organisation - The Future

14.6. It is recommended that the existing system continue, strengthened by the re-constituted co-ordinating committees (see paragraph 14.7). The basic need is for goodwill and good communication between the various agencies concerned. The co-ordinating committees, working against the background of a local plan and national guidelines in relation to various categories of service, are the most optimistic and realistic prospect at this time. It must be stressed, however, that if the committees are to fulfil their roles effectively, it will be essential that members are fully committed to the aims and that the level of representation reflects that commitment.

Co-ordinating Committees

14.7. Following discussions with health boards and the Federation of Voluntary Bodies Providing Services to People with Mental Handicap, it was agreed in 1988 to constitute new co-ordinating committees of the main service-providing agencies in each area, together with representatives of the health board and Department of Health to plan for the development of services in each area. Their function is to develop a co-ordinated service plan for each health board region in conformity with national policy. Their work will include the determination of needs, agreement on priorities and on catchment areas and content of service to be provided by each agency. They will also be concerned to ensure that the record system is established and satisfactorily maintained. In addition these committees will facilitate the identification of aspects of the service which could be rationalised. It is considered that there may be scope for greater co-operation and co-ordination between agencies, for example in administration and multi-disciplinary support services.

It is desirable that each committee should produce a report at regular intervals, say each two years, on progress in relation to the health board plan. Because of the extent of direct funding by the Department to the larger non-statutory organisations, it has been arranged that the Department will be represented on each of the regional committees. The statutory funding bodies will thus be fully represented in local discussions which will enable decisions regarding the financing and provision of services to be better informed. It is expected that these committees will meet at least once a quarter.

National Co-Ordination Body

14.8. During the course of our consultations it was suggested that a national co-ordinating body should be set up to co-ordinate and set priorities for the overall development of services. It would be difficult to reconcile the functions of such a body with those of the Department of Health and of the co-ordinating committees in each health board. We do believe, however, that there is an important need for ongoing advice on models of service and personnel matters. This need might be met by time-limited secondments of experts to the Department from senior posts in the services for the intellectually disabled to ensure a fresh flow of advice. It is recommended that there should be up to four persons on three-year (part-time) secondments to the Department, from the statutory and non-statutory sectors and covering a range of expertise, to advise on service developments, support the above committees, help to arbitrate among conflicting demands both within and between committees. monitor standards, promote quality assurance and help develop personnel policies and training opportunities. The functions they could fulfil are many and would involve little cost to the Department. In addition, we recommend that it would be of value if the Review Group were to remain in existence and to meet periodically, perhaps twiceyearly, to review progress on the implementation of the policies set out in this report.

The Commission on Health Funding

14.9. It is appreciated that there may be changes in the organisational structure of the health services in the light of the recommendations of the *Report 01 the Commission on Health Funding* (1989). However, such changes should not invalidate the thrust of the considerations in this chapter, at least in the short-term.

Access to Mainstream Services

14.10. Persons with intellectual disability have the same right of access as all other citizens to the services under the aegis of the various government departments. This right of access is becomina increasingly important issue as more and more persons with intellectual disability continue to reside in the community throughout their lives. We recommend that service providers, both statutory and voluntary, formally review their structures to ensure that these facilitate and encourage intellectually disabled persons to use the services availed of by the rest of the community. They should resist the tendency to provide directly facilities and services which can be readily provided through normal channels within the community. Moreover, those responsible for providing health services to the general population should also ensure that these services are made readily accessible to the intellectually disabled and, if necessary, positive measures should be used to facilitate such access.

14.11. The Review Group wishes to acknowledge the efforts made by agencies to provide self-supporting employment for people with a learning difficulty or intellectual disability. The capacity of agencies to maintain these efforts is severely restricted by the absence of adequate resources for working capital and wage subsidies. The Review Group recommends that the Department of Health initiates discussions with appropriate public agencies, in particular the Department of Industry and Commerce and the Industrial Development Authority to investigate these issues further.

14.12. The increased involvement of the Department of the Environment in the provision of housing for intellectually disabled persons is welcomed. It is to be expected that demand for housing will continue to grow, as larger numbers of intellectually disabled persons are relocated to residences in the community. It is recommended that an assessment of the housing requirement over a projected five year period be undertaken when more accurate data is available from the health board registers. This should also take account of the projected relocation of persons with intellectual disability from psychiatric hospitals to the community.

14.13. It is also recognised that a number of persons with learning difficulties or intellectual disabilities who fail to benefit from general educational and training programmes may ultimately find themselves in

serious conflict with the law. Although the existing liaison between the Department of Justice and the service providers is very close, there may be a need for a more formal and structured association. It is recommended that the health board co-ordinating committees should review the situation in this regard in their respective areas.



Pupils from the Holy Family School, Cootehill, Co. Cavan enjoying the great outdoors.

Financial Implications of Unmet Needs

15.1. This chapter estimates the quantity and financial implications of accumulated and emerging needs, transfers from inappropriate settings and further support services.

Accumulated Needs

15.2. A recent survey of unmet needs in the Eastern Health Board area has been carried out by the Mental Handicap Planning Committee of the Eastern Health Board. This survey identified a need for 325 residential places and 358 day places as a priority in the Eastern Health Board area alone.

The best estimates available for other areas suggest that the national total need currently stands at 600 residential and 1,000 day places. The Review Croup recommends that provision should be made to meet this need over the 4 years commencing in 1990, estimated at 150 residential and 250 day places per annum. It is satisfied that this is a minimum requirement.

Cost of Meeting Accumulated Needs

15.3. In estimating the cost of providing places in the Eastern Health Board area, the Mental Handicap Planning Committee expects to find a wide variation in the per capita costs, due to such factors as

- (a) existing facilities which can provide extra places at little additional cost;
- (b) new projects which must provide a total support package;
- (c) the views *oi* individual organisations as to what, in their opinion, would constitute the cost of an appropriate service.

Having regard to these considerations and also to costings provided in the report of a study on the cost-effectiveness of mental handicap services (referred to at 15.11), the Review Group estimates that the capital cost of the new residential and day places which are recommended at 15.2 above will be roughly £2 million in each of the 4 years. The additional revenue cost is estimated at £3.25 million in the first year, rising to £1 3 million at the end of the 4 year period.

Emerging Needs

15.4. In addition to the present unmet needs discussed above, the Review Group's research indicates that even when allowance is made for some reduction in the client population through natural causes, there will continue to be an annual growth in numbers requiring services for some years to come. In the medium-term, from the year 1990 to the year 2000, an annual emerging need for 40 residential places and 200 day places is expected. In the longer-term, the Review Group would not predict a "break-even" situation being reached until after 2010.

In accordance with these predictions, the Review Group recommends that in each year for the next five years at least, a further 40 residential places and 200 day places should be provided to meet the increasing needs described. Throughout this period the position should be regularly reviewed, in the light *oi* actual needs.

Cost of Meeting Emerging Needs

15.5. On the basis of the limited information on costings available to the Review Group, it is estimated that the capital cost of the new residential and day places which are recommended at 15.4 above will be roughly \pounds 1.4 million in each of the 5 years. The additional revenue cost is estimated at \pounds 1.4 million in the year 1990, rising to \pounds 7 million in 1994.

Transfer from Inappropriate Settings

15.6. A number of intellectually disabled persons are at present inappropriate institutional maintained in centres (predominantly psychiatric hospitals). In chapter 11, it was suggested that arrangements should be made for the relocation of such persons to more appropriate (see paragraph 11.3). lt is recommended that the programmes Department of Health (in consultation with the health boards and the regional co-ordinating committees) should establish a planned programme for the transfer of intellectually disabled persons from inappropriate institutional care. Such a programme should provide for a transfer rate of at least 250 persons each year for the next 5 years.

58

Cost of Transfer from Inappropriate Settings

15.7. The cost of effecting a transfer from institutional care was considered by a Department of Finance analyst in the course of an examination of relative costs in the mental handicap services (see paragraph 15.11). The report on that examination suggested that the capital costs of transferring people from institutional care to community-based services could be reduced dramatically by

- (a) using local authority housing instead of purchasing from the private sector;
- (b) renting accommodation for hostels and day centres;
- (c) using former psychiatric or residential premises as day centres.

Taking account of these various factors, it is estimated that the capital cost of effecting the transfers recommended above could be of the order of £1.5 million per year.

As regards revenue costs, experience has shown that the transfer of residents can be accompanied by a transfer of substantial revenue resources from the relevant institution. The amounts transferrable will vary from one centre to another. Where the more dependent residents are being transferred from institutions which are relatively poorly funded, the revenue funding associated with those residents may require to be augmented in some cases, if an appropriate service is to be provided. Accordingly, the Review Group estimates that the extra revenue cost associated with the transfers recommended at 15.6 will be about £1 million in each of the 5 years.

Additional Support Services

15.8. If people with an intellectual disability are to be supported in the community as envisaged throughout this report, it is crucial that they should be provided with adequate professional support. We have referred to the importance of the multi-disciplinary approach to providing services and we acknowledge that professional staffing in the relevant services at present is both inadequate in its provision and uneven in its distribution. While we have not made precise estimates of the numbers or categories of extra staff required, we are satisfied that the proper delivery of a service in the community for those with an intellectual disability will necessitate a significant increase in support staff from various disciplines including psychology, social work, physiotherapy, speech therapy and nursing. We therefore recommend

that, in addition to the financial provisions already recommended in this chapter, an additional sum of £500,000 revenue should be made available in each of the next 5 years to strengthen the level of support staff from the disciplines mentioned.

Summary of Capital Costs

15.9. The capital cost implications of the various recommendations in this chapter can be summarised as follows:-

Services						
Recommended	1990	1991	1992	1993	1994	Total
Accumulated needs (15.2)	2.0	2.0	2.0	2.0		8.0
Emerging Needs (15.4)	1.4	1.4	1.4	1.4	1.4	7.0
Transfers (15.6)	1.5	1.5	1.5	1.5	1.5	7.5
Totals	4.9	4.9	4.9	4.9	2.9	22.5

The additional average capital cost associated with our recommendations is £4.5 million per year. This compares with a capital provision of about £3 million (including £0.6 million from National Lottery Funds) in 1988 for services for intellectually disabled persons.

Summary of Revenue Costs

15.10. The revenue cost implications of the recommendations in this chapter may be summarised as follows:-

Services Recommended		Estima Re	Cumulative			
	1990	1991	1992	1993	1994	increase over 1989 (£m)
Accumulated needs (15.2)	3.25	3.25	3.25	3.25		13.00
Emerging Needs (15.4)	1.40	1.40	1.40	1.40	1.40	7.00
Transfers (15.6)	1.00	1.00	1.00	1.00	1.00	5.00
Support services (15.8)	0.50	0.50	0.50	0.50	0.50	2.50
Totals	6.15	6.15	6.15	6.15	2.90	27.50

Our recommendations, if implemented, will have the cumulative effect of increasing the level of revenue spending on services from about $\pounds131m$ in 1989 to $\pounds158m$ in 1994 (an increase of about 21% over 5 years). While this increase may be considered substantial, it represents the minimum estimated cost of achieving a level of service which would conform to what has already been accepted and enunciated as national policy.

Distribution of Existing Resources

15.11. A review of the allocation of existing resources for different levels of disability is also important, for the sake of equity and efficiency in the present services and to provide a scientific basis for the distribution of additional finance which may be made available. During the course of the Review an analyst with the Department of Finance was seconded to the Department of Health for the purpose of comparing the cost-effectiveness of alternative levels of care for intellectually disabled persons and to make recommendations based on this analysis. He

concluded that the services in Ireland require major re-structuring if they are to provide a more effective service. This re-structuring would require two major elements

- (a) the transfer of people with an intellectual disability from psychiatric hospitals to services for intellectually disabled persons;
- (b) the transfer of suitable clients in services for the intellectually disabled from an institutional to a community setting.

The Review Group fully concurs with this view, as will be apparent from the tenor and content of this report. The Analyst believed that these major changes could largely be achieved by making better use of existing resources. He also recommended that inequities in the level of resources to different agencies should be considerably reduced. The detailed analysis which led to these conclusions should be examined further by the Health Policy Research Centre which has been established by the Economic and Social Research Institute to build on existing expertise in the area of health economics and policy evaluation. The analysis should also be a subject for discussion in the consultations with the service-providing agencies about the development of the policy recommended in the Review Group's report. It is noted that the Report of the Commission on Health Funding has recommended that appropriate costs per place for particular levels of handicap and type of care setting should be established and agencies funded on this basis (paragraph 19.27). The consideration of these costings proposals should form part of the further examination recommended above.

Signed

G. Guidon, Chairman
Dr. A. Hassett
Brendan Ingoldsby
Roy McConkey
Michael Mulcahy
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M. Walsh
Dora Hennessy, Secretary

Appendix

Type of Provision and Category of Disability 1988

Health Board	No. of	Persons served					
	Units	Mild	Moderate	Severe	Profound	Total	
EASTERN							
Res. Centres	21	368	855	621	228	2,072	
Hostels	70	97	191	20	n/a	308	
Day Care Centres	22	72	404	359	89	924	
Workshop / Training Centres	27	523	596	81	8	1,208	
MIDLAND							
Res. Centres	2	11	62	91	24	188	
Hostels	n/a	n/a	n/a	n/a	n/a	n/a	
Day Care Centres	6	8	42	28	8	86	
Workshop / Training Centres	4	22	66	5	1	94	
MID-WESTERN							
Res. Centres	5	n/a	227	185	63	475	
Hostels	16	8	65	n/a	n/a	73	
Day Care Centres	5	8	31	12	5	56	
Workshop / Training Centres	5	95	148	2	n/a	245	
NORTH EAST							
Res. Centres	1	n/a	42	172	30	244	
Hostels	10	6	34	3	n/a	43	
Day Care Centres	6	15	35	55	21	126	
Workshop / Training Centres	7	62	123	n/a	n/a	185	
NORTH WEST							
Res. Centres	5	11	184	153	35	383	
Hostels	23	41	80	5	1	127	
Day Care Centres	8	18	93	26	3	140	
Workshop / Training Centres	7	90	120	1	n/a	211	

Health Board	No. of	Persons served						
	Units	Mild	Moderate	Severe	Profound	Total		
SOUTHERN								
Res. Centres	8	90	193	316	68	667		
Hostels	27	54	84	51	19	208		
Day Care Centres	11	75	56	101	6	238		
Workshop/Training Centres	9	339	221	47	1	608		
SOUTH EAST								
Res. Centres	8	33	134	120	122	409		
Hostels	11	43	33	4	n/a	80		
Day Care Centres	9	21	49	45	41	156		
Workshop / Training Centres	10	124	140	14	3	281		
WESTERN								
Res. Centres	3	13	35	135	12	195		
Hostels	55	116	144	79	6	345		
Day Care Centres	14	11	63	100	13	187		
Workshop /Training Centres	21	129	263	79	3	474		
ALL HEALTH								
BOARDS	50	500	1 722	1 702	593	4 (22		
Res. Centres	53	526	1,732	1,793	582	4,633		
Hostels	212 81	365 228	631 773	162 726	26 186	1,184 1,913		
Day Care Centres Workshop / Training	81 90	1,384	1,677	229	180	3,306		
Centres	90	1,304	1,077	227	10	5,500		
Overall Total		2,503	4,813	2,910	810	11,036		

Notes

1. To avoid a misleading impression of the total population served, persons who are living in hostels and who also attend day care and workshop/training centres are not included in the statistics for the latter.

2. n/a = not applicable or not available.