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SHUT UP AT HOME ?

ISSUES IN THE DEVELOPMENT OF A RESIDENTIAL RESPITE POLICY FOR
PEOPLE WITH PHYSICAL DISABILITIES IN THE
EASTERN HEALTH BOARD AREA

A Report for
Disability Federation of Ireland



Judith Kiernan and Brian Harvey

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ACKNOWLEDGEMENTS

The authors acknowledge the assistance of all people contacted in the course of this study. The response was unfailingly informative and cordial. The commitment of all those people interviewed to the provision of worthwhile services was obvious.

Particular thanks must be given to the people who participated in often lengthy interviews and people who were contacted repeatedly.

The authors thank the staff of Disability Federation of Ireland for their valued comments on the early draft and for their assistance in the speedy completion of this report.

Disability Federation of Ireland acknowledges with thanks the Department of Social Welfare's contribution to the funding of this research.

SUMMARY AND RECOMMENDATIONS

There are 19 dedicated residential respite places for adults with physical disabilities located in the Eastern Health Board (EHB) area. The vast majority of these places are provided by non-governmental organisations (NGOs). It is apparent that this number of places is entirely inadequate to provide a meaningful service to those people who might wish to avail of it.

The present report demonstrates maximum utilisation of existing dedicated places. Waiting lists are excessively long in most of the dedicated facilities. This stands in contrast to the virtual non-use of the non-dedicated places within the EHB area. This report shows unequivocally that non-dedicated places, available to people with physical disabilities under the age of 65, are not being used for this group.

The underlying policies and existing services of most of the dedicated facilities have developed on an *ad hoc* basis. Despite this, the underlying rationale of the services is remarkably similar. They each focus on relief of the strains of on-going care and on the requirements of people with physical disabilities. All facilities provide planned repeated respite placement as their preferred strategy. In addition, many of the facilities attempt to provide crisis placement, but this is seen as distinct from the planned respite service.

Service providers do not publicise their respite services because they know they cannot meet demands. Access to information and to places is often through informal channels. This is inequitable. There are inequities too, in the access to residential respite facilities by particular disability groups. There are trends of service use in terms of older and younger age groups. This patchy and inadequate service outcome is inevitable in the absence of State/Health Board planning.

Some groups who ostensibly require extensive assistance are not being catered for by the existing services. The present report identifies a number of groups not being addressed by existing services;

- i) young people with chronic disabilities;
- ii) people with terminal illness;
- iii) people with severe physical disabilities; and
- iv) families with more than one member with a physical disability.

In addition, the report indicates that people living outside the EHB area have almost no residential respite services available to them. People with physical disabilities living in rural areas need appropriate services currently denied them. This needs to be documented in a separate report.

The cost of some residential respite services is remarkably low. Realistic comparison of the costs of the different facilities was not possible. Relative costs in comparison to provision of other non-residential services are unknown. Further investigation of both matters is required.

Residential respite care is a service sought by people whose daily lives are made difficult by physical disabilities. Demands for respite services and use of existing services are, therefore, symptoms of a deeper problem. If service provision is to have any cogency the wider problems need to be acknowledged and addressed. The present demand for respite care will continue and increase as long as the lives of people affected by physical disabilities remain as they are.

SPECIFIC RECOMMENDATIONS

1. Definitions

A comprehensive definition of respite services is required. This must give effect to the perspectives of people with disabilities and of carers and set standards for service provision. This could be a task for the *Commission on the Status of People with Disabilities*. The *Review Group on Physical and Sensory Disability* should also clarify its perspective on the purpose of residential respite services. The Department of Health must insist on clarity of definition within all the Health Boards. The current linguistic and service obfuscation of the importance of dedicated services for this group must be clarified.

2. Structures

The relevant Government departments (Department of Health and Social Welfare) must develop a coherent structure which focuses on the social gain to be obtained *through effective targeting of respite care*.

3. Residential respite services

The Eastern Health Board needs to re-evaluate its position regarding its purported respite service provision. The EHB should advertise its non-dedicated respite places, not only in the locality but also further afield. The EHB should address the particular needs of specific groups in this report. This is probably best done by non-residential services in the first instance.

Each Health Board should immediately identify a number of places, within suitable accommodation and with appropriate services, as dedicated residential respite places for people with physical disabilities under the age of 65.

4. Finance

Funding issues need to be clarified by the statutory bodies as part of a comprehensive policy review in the area of residential respite services.

The Department of Social Welfare should seek to develop a niche for itself with respect to funding of projects designed to alleviate the burden specifically on carers in the first instance.

5. Non-residential respite services

The Eastern Health Board should target non-residential respite assistance, specifically home care attendance and home-helps to the needy groups identified.

6. Research

Further research should be carried out on the service requirements and preferences of people with physical disabilities and people providing on-going care for them. Research on the requirements of people with disabilities in rural areas is an urgent necessity.

Chapter 1: General Introduction

1.1 Introduction

The present report, commissioned by the Disability Federation of Ireland (DFI), examines the issues surrounding provision of residential respite services, specifically for people with chronic physical disabilities. This group of people has particular requirements in terms of accommodation, mobility and personal assistance not observed with other groups. In Ireland and other countries, provision of respite services for people with physical disabilities, particularly adults, has lagged behind similar provision for other groups, such as the elderly or people with mental handicap.

The report presents a study of dedicated residential respite facilities located in the Eastern Health Board (EHB) region for people with physical disabilities. This study describes the existing facilities along a series of parameters. It identifies patterns and policies of service provision. It seeks to identify the main reasons why residential respite services are used, and the particular groups using them. It also considers the respite care policies, concerns and requirements of organisations representing the views of people affected by physical disabilities.

The report considers reasons why residential respite services remain poorly developed. It asks how current respite services may be maximised and improved for people with physical disabilities. The report also examines a variety of alternative approaches to some of the stated needs.

It is the first report of its kind in this country and one of a remarkably small number of published studies on the topic in any country. It therefore seeks to place the discussion in a coherent structure for future reference. The report sets out to:

- provide an overview of the relevant literature,
- describe the respite services available currently to people with physical disabilities,
- compare these with respite services available for other groups,
- consider the issues surrounding perceived and potential need for residential respite services for people with physical disabilities,
- and recommend specific courses of action to a wide range of bodies including the Department of Health, the Department of Social Welfare and Health Board Community Care Programme Managers.

The research was carried out from January to May 1994.

1.2 Disability Federation of Ireland

Disability Federation of Ireland (DFI) is the umbrella organisation for those non-statutory groups in Ireland providing services to people with disabilities. There are over 50 constituent organisations providing a range of services to people with physical, sensory, learning and psychiatric disabilities. DFI was originally founded in 1960 and was called the Union of Voluntary Organisations for the Handicapped (UVOH). DFI is grant-aided by the Department of Health.

For some years now the issue of respite services has been of concern to certain members of DFI. Several member organisations of DFI have met on a number of occasions to exchange information on their existing and future plans for the development of respite services for people with physical disabilities. In 1990-1991 a *Working Group on Respite Care* was set up within UVOH to examine the issue. This group presented a first report in May 1991. This report was enlarged and modified at the UVOH Annual Conference in 1991.

DFI views respite provision as a vital part of a comprehensive community care service which may be required by a wide range of people including people with mental handicap, diseases of old age, psychiatric difficulties and people with significant physical disabilities. DFI considers that a wide range of options in respite services should be countenanced. DFI accepts that *residential* respite placement is an expensive aspect of community care service and for that reason must be planned carefully and systematically. One of the concerns of DFI is that organisations may pursue their own

policies for respite services in isolation, without regard to other groups or services. In order to ensure proper and effective planning and co-ordination of future services, we must be informed about the existing level of provision and anticipate the future level of demand for services.

1.3 Residential respite services and physical disability

Groups within DFI representing people with significant physical disabilities perceive their respite requirements as different from other groups. This perception has focused on residential respite services. It stems in part from the unique accommodation and aids/appliances needs of people with significant physical disabilities. As a result, DFI has commissioned this report on dedicated residential respite services for people with physical disabilities. Because of considerations of time, scale and cost, the report deals only with facilities in the Eastern Health Board (EHB) area. As there are few other dedicated facilities in the country, the present report examines almost all of the residential respite places available for people with physical disabilities.

Other groups, represented within DFI, such as organisations providing services to people with mental handicap, the elderly and people with psychiatric illness are not the primary concern of this report. The structure of health service provision in this country means that all people over the age of 65 are dealt with by geriatric services. This report does not address the matter of residential or other respite services for the elderly. The present report focuses on adults with physical disabilities under the age of 65.

1.4 Structure of the report

A general overview of the notion of respite care is first presented. This provides a framework for discussion of the topic. The experience in the Irish situation is next summarised. The focus of the present research, namely residential respite services for adults with physical disabilities, is approached from three standpoints:

- i) the current dedicated facilities in the EHB are surveyed. Detailed information on the number of placements, the procedures for admission and use, the types of services, the policy and other ramifications are explored by means of a uniform questionnaire;
- ii) organisations representing people who use or might wish to use residential respite facilities are interviewed. A uniform questionnaire is used to provide comparable information. The principle focus is on residential respite services, the organisations' use of and evaluation of existing services, their views on the diverse issues surrounding the matter and their perception of how to proceed at this stage; and
- iii) finally, a series of interviews with a wide variety of individuals interested in or affected by residential respite provision, or working with or for people with physical disabilities, provides a wide-ranging overview of the present situation in this country. In addition to seeking views from relevant organisations within DFI, organisations which represent people affected by disability, but not affiliated to DFI, were also contacted in the preparation of this report. A full list of all organisations contacted is provided in Appendix I.

These results are analysed and conclusions drawn. Recommendations are given regarding use of present facilities and on possible avenues forward at this time.

Throughout the present report a balance is struck between the demands, needs, perceptions and rights of people requiring regular personal assistance as a result of physical disability and the people who provide it. These groups are sometimes designated as people requiring care and "carers", terms which will be used in the present text. These terms hold implications which are not necessarily accepted by the present authors. Other terms are either equally linguistically problematic or are descriptively inappropriate.

1.5 Definition of respite care

Numerous definitions of respite care have been put forward. The differing definitions arise from distinct views of who the service is for and under what circumstances. These differences have had real effects on the nature of the services provided.

"Respite" per se is defined as the "temporary relief of an intolerable situation" (Random House dictionary). Warren et al (1985) accepted a definition of respite care as a "temporary relief service for families or primary caregivers" (p66). This type of definition focuses on the needs of people who provide on-going care. Temporary cessation of that care is the aim of the policy. It fails to address the role and standard of care to be provided for the person with disability. More satisfactory definitions involve consideration of both parties, those who do the caring and those who are cared for. An example of such a definition is that currently used by DFI:

"Respite care is temporary care, either community or centre based, which provides relief and personal development opportunities for the carer and the person requiring care, within a variety of facilities. The need for care ranges from crisis intervention to planned regular breaks." (UVOH Annual Conference 1991).

The implications of how respite care is defined in terms of its primary goals, and in terms of the nature, extent, and variety of services are central to the topic of the present report.

1.6 Overview of "respite care"

A brief overview of the evolution of respite services is presented. The functions of respite care, factors influencing calls for its provision, the nature and quality of services provided and the disparate perspectives of those involved are summarised.

1.6.1 Historical background

In the 1960s the conceptual basis for the management of long-term problems such as mental handicap, mental illness and physical disabilities was altered. The then existing policy of segregation of these groups by institutionalisation was observed to be an expensive option and a denial of human integrity (Warren et al 1985, Schädler 1991, O'Sullivan 1991). As a result, a policy of de-institutionalisation, for financial and social motives, became the norm. The new focus of health policy for people with chronic disabilities stressed that integration and maintenance in the community were paramount. The perceived need and the growing demand for respite care derive directly from the policy that people with significant disabilities be cared for, whenever possible, at home.

1.6.2. Who requires respite: being cared for by carers

Since the introduction of "care in the community", services have been provided to individuals and families directly affected by chronic disability. Various agencies have provided on-going care assistance, therapy, education, training, work experience, day-time activities, social outings, assistance with mobility and a range of support payments for people with chronic disabilities. Standards of service provision have differed widely from country to country, within individual regions of countries and between groups of people affected by different disabilities. Recognition of ethical concerns of self-determination has been partial. Desire to limit the cost of providing services has often overshadowed the policy commitment to integration and acceptable quality of life. The conflicting demands of budgetary rectitude and service provision particularly affect people with chronic physical disabilities, who may need aids, special access and personal assistance in addition to the services all other groups require. For many people with significant chronic disabilities their lives are spent in the confines of their homes and they are seen to be the responsibility of their "carers".

Typically, the task of "care" has been taken on by family members. Most carers are women relatives; wives, mothers and daughters. As "caring" is traditionally viewed as an adjunct of women's unpaid work in the home, the financial implications of caring have been ignored or addressed in a pejorative manner (Finch, 1991). The independent lives and aspirations of carers have been overlooked.

"It is important to emphasise the appalling degree to which it is taken for granted that relatives are expected to limit drastically their autonomy and their self-determined life plans" (Schädler 1991, p52).

The physical and emotional health of people providing unpaid care has not been prioritised. Many unpaid carers are aged and infirm. In this regard, unique physical demands are made on those providing daily care for people with physical disabilities.

Carers as a group have become more articulate, presenting financial and service demands on the system. Their main requirement is the provision of effective direct assistance to them, which addresses their needs as ordinary people in extraordinary situations. Responses to this have varied and have included financial assistance, counselling services, home assistance, "sitting" and respite services. People with disabilities have stated their requirement for relief from the often challenging and frustrating situations which they live in, both at home and in other placements. These calls from both carers and people with disabilities have led to the development of ranges of respite services.

1.6.3 Categories of respite provision

Respite care provision may be considered in three distinct categories: crisis, planned and planned repeated. Each attempts to address specific problems which may arise. In crisis provision, the carer becomes temporarily and unexpectedly unavailable to continue to provide care. This can occur for many reasons, for example, personal ill-health or other family commitments. Some temporary arrangement is required immediately. Respite care of this type is the most readily funded. Health service financiers reason that this expenditure supports on-going care in the community and prevents long-term residential placement, with its substantial costs. Implicit in certain views of crisis respite care is that any minimal service which attends to the basic needs and provides a safe environment for the person with disability is all that is required. As a result, the standard of alternative care provided in a crisis, particularly when residential, can be entirely unsuitable and place strains on the person with disability and an additional burden of concern on the absent carer.

Alternatively, temporary care for the person being cared for may be sought to permit a short "break" or holiday for the carer. Service financiers may consider this to be value for money because, following the break, on-going care will be resumed. All research has shown that carers avoid forms of respite care which place strains on the person with a disability, even if this means that their own health and independence is affected. Thus, the standard of the respite services available has become an issue.

In the past number of years, the consensus of informed opinion suggests that people with disabilities have needs at certain times to be apart from those who routinely care for them. In the context of severe physical disability the possibility of a break or holiday in the conventional sense is typically impossible due to lack of access, absence of assistance for personal needs and financial constraints. In particular, for people with progressive physical disabilities there is a recognised need to come to terms, at certain times, with their changing situation and to recharge emotionally. Additionally, there has been a growing awareness of the rights of people with disabilities to be consulted and taken into account in matters which affect them. As a result, the expectations on respite services in terms of number of placements and quality of service have increased substantially.

Planned repeated respite placement is a response to on-going need. This involves multiple breaks from the routine caring arrangements during the year. It may involve days, weeks or even months of regular cessation and resumption of the usual caring arrangements. This level of provision is usually confined to people with substantial needs who are under on-going strain. From a financial perspective it is clearly the most expensive option.

1.6.4 Types of respite care

Respite care may be provided at home. It may be obtained through day placement. Respite may be provided by placement in another family home, a system widely used for people with mental handicap and for some elderly people. Some of these schemes are labelled "holidays" or "breaks".

Residential respite care provides an out-of-home placement for the person with disability. It may be located in a purpose-built respite facility, as part of a long-term residential unit, in nursing homes or hospitals. At its best it can provide both the carer and the person cared for with a productive and

rewarding experience. At its most unpalatable residential respite care has involved the temporary removal of people with disabilities from their families to long-stay institutions, notably psychiatric hospitals.

The respite may last for mere hours at a time or extend for weeks or in some cases for months. The caring may be performed by volunteers, by paid staff, some of whom may have specific or generally applicable training. Frequently the carers are women. As a result, payment is low, sometimes derisory. The provision of funding has typically come from State agencies through local and charitable organisations.

1.7 Special needs of people with physical disabilities

Unique problems are faced by people with physical disabilities. Their lives are restricted by access and assistance needs. In cases of significant need of assistance, many people may live trapped in their own homes, which are only partially modified to suit them. Wheelchair users may be denied general access to public transport; the problem of accessible toilets is well documented. Together with social attitudes and lack of other services, these problems constitute a major barrier to providing realistic positive alternatives to residential respite care (Robinson 1991, Sandeman et al 1991). To address these issues requires a concerted strategy and a substantial financial commitment.

1.7.1 Respite requirements of people with physical disabilities

The Social Services Inspectorate of Northern Ireland Report (1990) noted the diversity of physically disabling conditions and recommended that provision of services take account of individual needs. In 1991, the Scottish Spinal Cord Injury Association commissioned a survey of its members regarding their respite needs (Sandeman et al 1991). This study pointed up the varied requirements of people with physical disabilities and their helpers in terms of number and duration of breaks, extent of assistance required and preference for non-residential or residential respite placement.

1.8 Conclusion

The general issues surrounding residential respite services have been briefly over-viewed. The next chapter examines existing respite services in Ireland.

Chapter 2: The Irish Experience

2.1 Introduction

This chapter outlines the current problems of estimating the numbers of people with physical disabilities in the country. It gives a brief overview of general health and social welfare services for people with disabilities. It focuses particularly on respite services for people with disabilities. It includes the views of representative organisations for and of people with physical disabilities regarding optimal respite provision.

2.2 Numbers of people with disabilities

The development of coherent policies, of forward prioritised planning and of realistic funding projections have all been impeded by the absence of national statistics on physical disabilities. In the past number of years strides have been made in the fields of mental handicap and of the elderly needy. By contrast, to date there is no register or national database of people with physical disabilities. In 1984, a commitment was made in the Government green paper, *Towards a full life*, that a register of people with physical disabilities would be drawn up. It is uncertain whether baseline figures on the numbers and severity of physical disabilities will be available before the year 2000.

2.2.1 Current estimates of numbers

The current methods of obtaining figures on the numbers with disabilities are unsatisfactory. A total figure of 150,000 disabled people of all ages was quoted in the Government green paper *Towards a full life* in 1984. This gave a proportion of 4.28% of total population. To obtain figures for the number of people with *physical* disabilities, it is usually suggested that the known figures on mental handicap and psychiatric illness are subtracted from the total to leave a physical disability remainder.

The 1981 census of mental handicap (Mulcahy et al 1984) found 22,979 individuals with mental handicap living in the community or in residential units. This suggests a 0.67% incidence of mental handicap in the total population. In 1991, the numbers of inpatient admissions for psychiatric difficulties totalled 27,913 (Health Research Board sources). Of these 7,949 were new admissions and 450 were given a diagnosis of mental handicap. No information on people treated as psychiatric out-patients is available. As a result there is no complete figure for that year, or any other, of the total number of people with psychiatric difficulties as a proportion of population. As a result of subtractions it can be stated that upwards of 100,000 of the postulated 150,000 may have physical disabilities, psychiatric disabilities treated on an out-patient basis, or multiple disabilities of unknown variety.

2.2.2 Nature of disabilities

In the Government green paper *Towards a full life* (1984) the most frequent cause of mobility problems was identified as arthritis. This contrasts with figures used by the *Review Group on Physical and Sensory Disability* in its interim report (1992), which identifies 46,530 people "known to organisations working in the field of disability", and which, in contrast, lists epilepsy as the most common disorder (43% of total), while ignoring categories such as arthritis, head and spinal injuries. These figures beg questions as to primary versus secondary diagnoses and to the extent of day-to-day intrusion of given disabilities on individuals' lives. The method of information-gathering assumes incorrectly that all people with a given disability belong to representative organisations.

2.2.3 Disability payments

We may obtain some measure of the numbers of people with physical disabilities of sufficient magnitude to affect their lives by taking a head count of various disability payments made to individuals. This method is fraught with potential inaccuracies due to the selection and exclusion procedures for many payments. Two main payments are directed at people with long-term disabilities. The total number of people in receipt of the Disabled Persons Maintenance Allowance (DPMA) in 1991, was 26,397. There were, in addition, 37,034 recipients of Invalidity Pension in 1993. This gives approximate figures of 63,000 claims on both systems.

The government-based indicators of the numbers of people with physical disabilities range from 46,530 through approximately 63,000, to possibly 100,000 people. All of these are based on different criteria and assumptions and provide no bases for the planning of services. There is no information on the nature, the extent or the pattern of age or other variable distribution of any of these disabilities.

2.2.4 Comparison with international figures

The percentage of people considered to have disabilities in Ireland (4.28% of total population in the context of 150,000 people with disabilities) is lower than that put forward by the World Health Organisation, which suggests that 10% of a given population may have a disability. The European Commission estimates that between 8-12% of people have disabilities. These discrepancies probably arise from different criteria on the nature of included problems and the extent of cognitive, psychiatric and physical problems to be labelled as disabilities per se.

The services available to people with disabilities and their families are now briefly outlined with specific reference to issues of concern to people with physical disabilities.

2.3 Community health services for people with disabilities

Non-governmental organisations (NGOs) and directly staffed Health Board facilities provide a range of services for people of all ages and varieties of disabilities (Department of Health 1993). The focus of many of the services is on children, defined as people under the age of 16-18, when formal education typically ceases. Thereafter, adult services are less plentiful and in some areas of the country are quite limited. At the age of 65 a person is designated "geriatric" and becomes entitled to services for this group. The services may be divided into:

2.3.1 Financial assistance

There are a number of allowances and grants payable under specific circumstances. These include the Disabled Persons Maintenance Allowance (DPMA), the Mobility Allowance and the Domiciliary Care Allowance. Certain diagnostic categories of disabilities are entitled to free drugs. A subgroup of these is entitled to in-patient and out-patient services free of charge. In addition, there is funding from the Department of Social Welfare through the mechanism of the Carer's Allowance and the Respite Care Fund.

People's options are directly affected by their income or lack of it. People with disabilities are often unemployed and reliant on social welfare payments. The additional cost of living imposed by physical disability has yet to be meaningfully recognised, particularly in the area of exceptional transport costs and housing adaptation. The available State assistance is typically means-tested. There are widespread regional variations in the extent of services and application of the rules (Union of Voluntary Organisations for the Handicapped 1991 a,b, Disability Federation of Ireland pre-budget submission 1993).

2.3.2 Non-residential services

These include case management, social work, chiropody, occupational therapy, physiotherapy and speech therapy services. There are also day-care and activity centres, some of which have a training or work programme. Substantial funding of training of people with disabilities has come through the EU programmes. The National Rehabilitation Board (NRB) has a statutory role in this area. Home services include public health nursing and provision of home-helps. For people with physical disabilities there is assistance with structural alterations of their homes, the provision of aids, etc.

There is a general consensus that professionals providing community-based services are doing their best in the context of gross staff and equipment shortages. The medical focus of some of these services may not be relevant in certain cases of chronic disability. Home-help services which are means-tested are limited, of varying standard and effectively unavailable in certain areas. The interim report of the *Review Group on Physical and Sensory Disability* (1992) accepted that "the existing home-help and public health nursing services are aimed primarily at elderly people and only provide limited assistance to people with physical and sensory disabilities". Care attendant schemes are not available nationally. Day-care centres for people with physical disabilities aged 18-65 constitute only 4% of the total

provision. When day-care places are available their effective use is often marred by the absence of suitable transport for people with significant mobility difficulties. The different needs of this group from those of the elderly is often not appreciated.

2.3.3 Residential services

This includes residential respite care and long-term residential placement. Residential care waiting lists are lengthy, denoting both shortage and need. Accommodation trends are moving away from residential care for all groups. Many organisations now actively promote sheltered housing options, hostels and independent living facilities. Personal assistance schemes, in which the person with a physical disability employs an assistant are being devised and evaluated (INCARE 1992).

2.4 Perspectives of the different groups

None of the sectoral interests is satisfied with current levels of funding or with availability of services. There are a number of critical overviews of the services to different groups. These include the *Report of the Review Group on Mental Handicap Services* (1991), the *Community Care: People with Mental Handicap* (1989) policy document of the National Association for the Mentally Handicapped of Ireland and the *Green Paper on Mental Health* 1992 and the detailed reports commissioned by the National Council for the Aged (now the National Council for the Elderly). Studies focusing on people with physical disabilities include the profile of the membership of the Irish Wheelchair Association (IWA) undertaken by Faughnan (1977). Another study of the IWA membership has just been completed and is due for publication in May 1994. The reports of working groups at the UVOH Annual Conference of 1991 examined a wide range of services for people with disabilities.

2.4.1 Recent developments

In 1992, a *Review Group on Physical and Sensory Disability* was established by the Minister for Health:

- to examine current provision of health services for this group;
- to consider how best to meet their needs; and
- to make recommendations for service developments.

The impetus for this review stemmed, in part, from the provisions of the *Programme for Economic and Social Progress*. The interim report of the *Review Group on Physical and Sensory Disability* (1992) presents an overview of the existing situation and preliminary recommendations for improvements in existing services. The final report of the review group is due for publication in 1994.

The *Programme for Government* 1993-7 has given a commitment to significant improvements in the situation of people with disabilities. The *Commission on the Status of People with Disabilities* has been set up. New organisations of people with disabilities have been formed (the Forum of People with Disabilities and the Center for Independent Living). These developments have the potential to change the lives of many with physical disabilities and will challenge society's preconceptions about people with disabilities.

These moves have yet to affect the present circumstances of the majority of people with disabilities. The reality remains that "a large percentage of people with a disability are obliged to spend most of their time within the confines of their homes" (UVOH *Working Group on Respite Care* report 1991). Figures to support this contention are available from Faughnan (1977) who found that fully 55.2% of those studied had "no social life at all or a rather limited one" (p53). This "limits their social horizons, restricts their development and places a huge burden of responsibility and commitment on their carers." The calls for respite care come in the context of this reality. The remaining sections of this chapter discuss respite services in detail.

2.5 Respite care: its role in the Irish context

The exact role of respite care has never been defined in the Irish context. This is partly due to the plethora of approaches encouraged by the extensive NGO sector in the country. Some consider that respite care is there to provide a safety valve, indicating that crisis intervention is all that is considered. An overriding service aim is to provide respite care to limit the numbers seeking long-term residential placement. These views focus on the relief of carers and see their needs as paramount.

A view expressed by some of the health administrators interviewed for the present research was that residential respite care was no longer necessary because of the range and extent of services now provided to people in their own homes.

Despite these views, or perhaps because of them, respite care has become an issue in the Irish health service in the last number of years. The reasons for this are multiple. There has been a growing advocacy of respite care as a service for those who look after people with disabilities, broadly representing the carer's view. As the level of discussion has become more sophisticated, the role of respite care in providing productive experiences for people with disabilities has been promoted as an allied aim.

Current services for adults with disabilities are being documented by a working group of 20 NGOs under the aegis of Age Action, Ireland. A specialised data base of all respite services for adults in Ireland is being prepared by Age Action, Ireland, funded by the Respite Care Fund of the Department of Social Welfare.

For the purposes of the present review, the respite policies and solutions of the distinct services providing them will be discussed. The next sections deal with respite services for people with mental handicap and the elderly. A detailed examination of the respite services for people with physical disabilities completes this chapter.

2.6 Respite care and mental handicap

2.6.1 general considerations

The perception that respite care is to provide alleviation of stress to families with a mentally handicapped member is dominant (National Association for Mental Handicap in Ireland 1989). Calls for "respite" include other long-term measures which alleviate strain such as family aid from care attendants and home-help assistance. There is an appreciation that the person with mental handicap is entitled to a range of life experiences including meaningful day facilities and recreation (Hanrahan 1993). This has placed quality demands on respite care and the mental handicap associations have adopted positive approaches. Both residential and non-residential respite care are available to families with a mentally handicapped member.

2.6.2 Residential respite services

In terms of residential units, each Health Board may provide a range of facilities either through existing long-term residential units or in specific respite accommodation. A number of non-statutory organisations also provide residential respite services for people with mental handicap. Some of these are run by the NGOs providing other services to this group, some are run by religious groups (e.g. the Presbyterian Church in Ireland, Board of Social Witness). Remarkably, one of the residential respite centres for people with mental handicap is private-sector operated (Galtrim Private Respite House in Castleknock, Dublin). This facility is used extensively by the NGOs in the mental handicap field. Part of its success may lie in the guarantee of secure Health Board funding of all services for children with mental handicap up to the age of 16. Campus-based respite, within an enclosed residential environment, is provided by certain NGOs, such as the Daughters of Charity in Navan Road, Dublin and the Sisters of Jesus and Mary (Moore Abbey). A list of residential respite facilities for people with mental handicap is available in a National Rehabilitation Board (NRB) booklet on respite care (Murray et al 1990).

2.6.3 Home-based services

Family-based schemes dominate respite care provision in the field of mental handicap. Limited numbers of residential places, family preference and financial considerations make these attractive ventures. These schemes advertise for, recruit, train and support host families who will accept a person with mental handicap into their home as a guest. Some of the schemes focus on children, others have attempted to include placement of adults with mental handicap. Schemes are usually termed "breaks" rather than "respite", a linguistic marker for the perceived needs of both beneficiaries. A number of these schemes are operated by large NGO service agencies in the field (e.g. "Share a break", run by the Sisters of Charity of Jesus and Mary (Moore Abbey), funded by the Midland Health

Board, "*Homechoice*", run by Saint Michael's House, funded by the Eastern Health Board, and "*Home Sharing*" run by the Galway County Association for Mentally Handicapped Children and the Brothers of Charity (Western Region)). An inter-agency scheme called "*Breakaway*" has operated now since 1981. This permits a broader advertising and funding base while permitting local campaigns and recruitment.

The work involved in setting up and running these schemes successfully is extensive. Typically, prospective host families fill in an application form. A social worker visits and investigates the motivation and supports of the intending host family, and provides a general description of the nature of the experience. Selected applicants are expected to attend a training course. On successful completion of this, the family is matched with a child. Prior to placement, most agencies will organise meetings and short stays. The input required to obtain host families means that the agencies are keen to stress the long-term nature of the commitment by the host family. A training video and manual and a report on the *Homechoice* scheme are available (Boland 1991a,b). An extensive evaluation of another of these schemes, *Home Sharing*, is provided by Hearne et al (1992). Results showed that all placements were successfully completed and "provided a high quality of individual care, emotional security and enriching and new experiences for the child" (p92).

Some organisations provide in-home services which have a respite function, for example the *Link* project of Saint Michael's House, which is presently undertaking an evaluation of the uptake of its *Homechoice* and *Link* services. This involves compilation of a profile of users and interviews with the natural and host families. The Kare Association of Co. Kildare has recently completed a comprehensive survey of in-home support needs of their client group, to plan services. The Saint John of God's facility at Drumcar has recently completed a survey of family needs for in-home services (Hanrahan 1994).

The National Federation of ARCH Clubs provides recreation services for people with mental handicap through regular weekly and monthly social outings. One of the objectives of this service is to provide regular respite for families.

2.6.4 Respite houses

Another method used by the large agencies is "respite houses" staffed by professionals. For example, Saint Michael's House has two respite houses, one used at weekends and one used weekdays. A modification of this is found in the Caring and Sharing Association (CASA) approach. CASA invites selected people with mental handicap as guests into their respite house called a "breakhouse". There are two breakhouses in Dublin, one providing weekend breaks and the other week-long breaks. Some of the guests will have additional physical disabilities. The number of places available varies and is dependent on the number of helpers available. Each guest has a helper who has a 24-hour a day commitment to that person, even sleeping in the same room. Long-term commitment to the guest involves repeated invitations to stay at the breakhouse and continued contact by phone, social outings and visits to the person's usual home. A feature of the CASA approach is that it provides breaks for adults living in long-term residential care as well as people living at home.

2.6.5 Holidays

In addition to the designated respite services, many of the service providers in the field of mental handicap provide conventional holidays for their client group, usually in the summer. These may involve use of school facilities out of term as a holiday venue, or use of standard holiday packages such as renting a cottage or boating on the Shannon. A popular destination is Lourdes and CASA operates holidays to Lourdes, by invitation, often for people who have been guests in their respite breakhouse.

2.7 Respite care and the elderly

The criterion for provision of services for the elderly is age. Anyone over the age of 65 has access to whatever residential care is available for that group. As a number of disorders giving rise to significant physical disabilities occur in the older age groups the geriatric respite services are relevant for this group.

2.7.1 General considerations

The true extent of respite services provided to the elderly population is difficult to define. This is in part due to the large number of nursing homes operating privately and without statutory control. A directory of services and organisations for older people and their carers has been prepared by Age Action, Ireland.

Deriving from the extensive study of carers of the elderly (O'Connor et al 1988), the Council for the Aged adopted as policy that certain services, paramount of which was respite care, could assist families particularly when the need for assistance was great. Respite care in this context was viewed as a "sharing of responsibility of caring between formal services and the family" (O'Connor et al 1988, p10). A number of respite options were identified, including live-in arrangements, day-care centres, short-term family-based breaks, intermittent hospital admission and intermittent placement in nursing homes. Factors of importance were the provision of a range of options and information to carers and provision of a level of choice.

The role of respite services in the management of dementia is acknowledged by those NGOs in the field. The Alzheimer's Society identifies as one of its aims "to campaign for statutory day-care, short-term respite and long-term residential care for Alzheimer victims" (Alzheimer Society of Ireland promotional literature).

2.7.2 Non-residential respite services for the elderly

Day-centres typically include respite of carers in their stated aims. Relative to other groups, people with geriatric problems have substantially higher amounts of day services (Interim report of the *Review Group on Physical and Sensory Disability* 1992). Carer support groups are provided by Health Boards and NGOs.

2.7.3 Residential respite services for the elderly

The Eastern Health Board has a policy to provide residential respite care, this service being mainly provided in the geriatric homes and hospitals. A routine feature of hospital-based geriatric care is the use of "floating beds". These are places available for respite use if and when requested, but not dedicated to this use. Floating beds have been recommended by a number of professional bodies (e.g. social workers) as being a useful response to the existing situation. The Alzheimer Society of Ireland provides a day-care centre and a limited residential respite care service with 8 places in Blackrock, in co-operation with the Daughters of Charity.

A detailed analysis of the effectiveness of regular planned respite admission in a geriatric unit was presented by O'Mahony et al (1990). This study reported on a scheme set up in 1984 for elderly people normally cared for at home. The impetus for the establishment of this service came from the work of the National Council for the Aged. Over-viewing the scheme, the authors demonstrated that, for this group, the support of respite care permitted long-term maintenance in the community.

Respite care has been the topic of parliamentary questions. On 26 January 1994, information was requested on the current provision and possible increase in "respite beds" in Co. Meath, part of the North Eastern Health Board (NEHB) area. The Minister for Health in his reply gave data only for respite beds for the elderly, of which there are currently 18 in the area. The NEHB plans to increase this by a further "twenty five per cent" in 1994.

2.8 Respite care and physical disability

Respite services for people with physical disabilities are less developed than for other groups. The causes of this are explored in the present report. A critical overview of the present services and their rationales is provided. None of the comments is made to detract in any way from the enormous efforts and fund of goodwill of all professionals and others involved in seeking and providing services. The provision of residential respite care is based on the age of the person with the disability. The present review summarises the services provided for children and adults within the Eastern Health Board area. A guide to the available services was produced by the National Rehabilitation Board (Murray et al 1990).

2.8.1 Children aged 7- 16

The call for respite care for children with physical disabilities comes from their parents. Professional services dealing with children have set up a variety of services in response. These have been both home-based and residential. Host-family schemes such as those in mental handicap have not been developed. There are obvious problems associated with extensive physical, often intimate, assistance and most homes are not adapted to the needs of people with mobility or other physical disabilities.

i) Home-based respite services

The Central Remedial Clinic (CRC), a major NGO service provider for children with physical disabilities, has run a family aid scheme since 1986. This is a home-based family respite and support service for families of children attending the CRC, delivered by trained child-care workers. The actual numbers of hours provided per family often are small and seem to the outsider to be entirely insufficient. These schemes are popular and waiting lists are often long. This indicates that the service is addressing a need and that some service is better than none. Cerebral Palsy Ireland (CPI), the other major service provider for children with physical disabilities has recently begun to develop a similar service for its clientele.

ii) Residential respite services

There are virtually no residential respite places available within the EHB catchment area for children with physical disabilities. There are two places dedicated for short-term use by children with physical disabilities in Saint Mary's Hospital in Baldoyle, an EHB facility. These two places are widely considered to be respite in nature, but officially they are provided to assist children to attend the CRC for intensive treatment. Two further places in this unit are available for short-term use by children with mental and physical disabilities. Children with severe mental and physical problems are provided short-term accommodation in the Sunshine House in Bray. A number of other facilities including CASA, Home from Home and the Small Unit, Delgany provide a respite service for children with learning disabilities but will accept children with physical disabilities also.

Most of the units offering long-stay residential care for children attempt to provide respite places at times when their residential population may be away e.g out of term, over long weekends etc. For example, Cerebral Palsy Ireland uses its residential unit in the Marino Clinic in Bray as a respite service during off peak periods. Between 30 and 35 residential respite places are offered in July, during the summer school vacation.

iii) Holidays

A number of organisations providing services for children organise extensive summer holiday programmes. For example, the Irish Association for Spina Bifida and Hydrocephalus run a residential summer camp using their special school facilities, and residential independence training and social skills projects.

2.8.2 Adults aged 16-65

i) Non-residential respite services

A number of the NGOs provide home-based respite services for people with physical disabilities. Principal among these is the Irish Wheelchair Association's Home Care Attendant Scheme. This is designed to provide "relief for carers who bear continuous responsibility for caring for people with

disabilities in their own homes" (IWA promotional literature). The service uses trained staff, who spend a few hours each week with the person with disability thus providing the regular carer with time to do other things. The service is available and widely used at unsocial hours including weekends and in cases of emergency. A total of 146 care attendants are employed on this scheme, providing assistance to 205 families currently. The Irish Wheelchair Association pay the care attendant and ask for contributions from the families in receipt of service. Pay rates are low: staff are usually women. The taxation system is a negative force in recruitment and maintenance of staff. The Home Care Attendant Scheme operates throughout 18 of the 26 counties.

The services of private home-care agencies are used by certain groups to provide short-term home assistance for people with physical disabilities. One of the main areas for this service is in terminal care. These agencies report on-going difficulties in recruiting and maintaining staff due to taxation of low incomes and loss of social welfare and health entitlements at marginal rates.

ii) Residential respite services

The residential respite services provided to people with physical disabilities between the ages of 16-65 may be dedicated to this use or provided on an *ad hoc* basis. The NRB guide to dedicated respite places (Murray et al 1990) lists places for people with physical disabilities in the EHB area but gives no entries in this category for other Health Board areas in the Republic. The interim report of the Review Group on Physical and Sensory Disability (1992) stated that nationally there are "only about 30 designated respite care places available for people with physical disabilities" (p16).

The Minister for Health in reply to a parliamentary question on 5th May 1994 gave a list of "dedicated respite care beds for physically disabled people under the age of 65 years in each Health Board area". This list is presented in Table 2.1.

Table 2.1. Health Boards, centres and number of beds for people with physical disabilities under the age of 65.
(Source: answer to parliamentary question on May 5 1994, Minister for Health)

Health Board	Name of Centre	No. of beds
Eastern	St. Mary's Hospital, Phoenix Park St. Colman's Hospital, Rathdrum Wicklow District Hospital St. Vincent's Hospital, Athy Baltinglass District Hospital Barrett Cheshire House, Dublin 2 Cara Cheshire Home, Phoenix Park Richmond Cheshire House, Monkstown Ardeen Cheshire Home, Co. Wicklow MS Care Centre, Rathgar	32
Midland	Clochan House, Tullamore	4
Mid-Western	None	—
North Eastern	None	—
North Western	Community Hospitals (15 locations)	number varies according to demand levels
South Eastern	None	—
Southern	Abode, Cork	10
Western	Sacred Heart Home, Castlebar District Hospital, Swinford District Hospital, Ballina D'Alton House, Claremorris Plunkett Home, Boyle	6

From Table 2.1 it is apparent that the number of dedicated residential respite places for people with physical disabilities nationally is not known. In particular, with reference to the North Western Health Board figures, it is not possible to have a varying number of dedicated places. Places either are or are not dedicated i.e. used for only one purpose or used for many purposes.

In the course of this report, all of the Eastern Health Board facilities listed in Table 2.1 were contacted. A number of the facilities listed as providing dedicated places in fact do not provide such a specific service. In the case of St. Colman's Hospital in Rathdrum, Wicklow District Hospital, St. Vincent's Hospital in Athy and Baltinglass District Hospital there are no dedicated places provided for the sole use of people with physical disabilities under the age of 65. In each of these units there are respite places primarily designed for use by people over 65 years which can be used by younger people if required.

All of the facilities listed by the Western Health Board in Table 2.1 were contacted by the present authors. All are facilities providing geriatric care. Each unit stated that there were no dedicated places in their facility for people under the age of 65. Each stated that they had provided and would continue to provide occasional placement for this group if required. It is apparent that such places are "floating" beds, not designated places. Cloghan House in the Midland Health Board does provide dedicated residential respite care for people with physical disabilities under the age of 65.

Those residential respite places which are dedicated within the EHB area are the focus of the present research and are described and evaluated in chapters 3 and 4 of this report. There are 19 such places in total. It is apparent that this report examines a substantial proportion of existing designated respite facilities for adults with physical disabilities under the age of 65.

The non-dedicated provision consists of a number of different facilities. As part of the answer to the parliamentary question on dedicated respite places on May 5th, the Minister for Health noted that: "In addition to the dedicated beds for persons with a physical disability outlined, such persons are also provided with respite care in various hospitals and homes from within the normal bed complement". It is unclear whether this "floating" provision actually services any significant number of people. The results of the present study indicate clearly that non-dedicated facilities are not being used by people under the age of 65.

Nursing home placement may be available or short-term stay in a geriatric unit may be possible. The limitations of such services are obvious. The Health Boards have attempted to address some of the problems in this area by development of units for the "young chronic sick". Some geriatric long-stay facilities have quotas of young chronic sick long-term places which may be in a separate unit or be allocated throughout the geriatric wards. Some of the separate young chronic sick units may provide short-term placements (e.g. Saint Mary's Hospital, Phoenix Park).

2.9 Numbers availing of the current dedicated residential respite service

The interim report of the *Review Group on Physical and Sensory Disability* (1992) suggests that 10 people per year may avail of each residential respite place, giving a national provision, on the basis of their numbers, catering for 300 people. This infers that each person would obtain approximately 5 weeks residence in a single year.

2.10 Numbers with physical disabilities requiring residential respite care

The available literature is almost entirely anecdotal. Various organisations have presented figures on the numbers of people in need of residential respite care. None of these accurately examines the issue and all are methodologically inadequate. Statements regarding the extent of physical disability in certain diagnostic groups do not indicate that all of these individuals would require or even wish for residential respite care. Consideration of need in terms of level of on-going assistance required is equally not a measure of need of respite care.

In an objective consideration of need for any service, the question as to why any given group would seek a service should be explored. In the context of respite care where two distinct sets of people are involved, their mutual and disparate aspirations regarding provision of service should be considered. The possibility that other responses to the identified needs might hold benefits should be investigated. The benefits and drawbacks of the proposed service should be itemised.

To date there are no reliable estimates of the numbers of people with physical disabilities who would wish to avail of a residential respite service. The figures presented by the UVOH *Working group on Respite Care* in 1991, while undoubtedly a measure of the perception of neediness among members of representative organisations, do not give information on the numbers requiring or wishing to avail of respite places. Nevertheless, in the absence of true estimates, the figure presented by that report, of 837, has been used as a baseline by the interim report of the *Review Group on Physical and Sensory Disability* (1992) to propose a requirement of 80 further residential respite places. That report acknowledged that improvements in home-care and day-care facilities could reduce the demand for residential respite services. It tacitly accepted that current levels of provision fall well below that required.

2.11 Who uses residential respite facilities?

One study addressed the characteristics of residential respite service users. Deeney (1989) performed a survey of all 35 residents in the National Multiple Sclerosis Care Centre, a residential respite unit, over a two month period. The results showed that only 48.5% of residents came from the Dublin area. This figure lends support to the perception of an absence of local regional respite facilities.

Of the 35 residents, 85.7% were cared for by a relative, with all others either living alone or without assistance. Over 91% of the residents were wheelchair users, indicating substantial mobility difficulties. Nonetheless, 31.5% were in part/full-time employment. For the 68.5% who were unemployed, the days were long; of the total number of residents, 62.8% did not attend a day or rehabilitation centre or have any other opportunities of day-time relief. The figures provided by Deeney suggest that less than 6% of those unemployed had any form of concerted day-time activity.

Questions were asked regarding how often the residents had a break away from home. These breaks typically were of less than a week's duration. The resident's usual carer had typically only obtained a break from on-going assistance during these periods. The results are presented in Table 2.2.

Table 2.2. Number and frequency of breaks
availed of by residents surveyed
(Source: Deeney 1989)

number of breaks	% residents
1-3 times per year	28.5%
once or less per year	42.8%
once every 1-3 years	5.7%
once every 5-7 years	5.7%
once every 10 years	2.8%
never had a break until now	8.5%

The results indicate that some people with physical disabilities are availing of breaks, while others have limited options in this regard. The study did not address any relationship between employment or severity of disability and the availing of breaks. The absence of any comparative data from other centres precludes generalisation.

2.12 Attitudes towards residential respite services

The only substantial raw data available are those from the National Multiple Sclerosis Care Centre. These data are largely unanalysed, though for the purposes of the present study a section of figures relating to the perceptions of residents and their carers was subjected to analysis. The results are presented in chapter 3.

2.13 State policy towards residential respite facilities

A major statutory aim of respite care services is to keep people out of long-term residential care. This aim focuses on the needs and expectations of carers alone. The *Review Group on Physical and Sensory Disability* is ambiguous in the matter of residential respite care for people with physical disabilities. Respite care is equated with crisis intervention, yet its purpose is described as providing "care to people who may for a short time require more intensive treatment or therapy" (p16). A subsidiary priority is the enablement of carers to have a break (p16).

2.14 Holidays versus respite care

Many organisations working for and with people with physical disabilities have called for holiday facilities and opportunities to be available.

"A holiday for many physically handicapped people is the only break they get in an otherwise monotonous existence" (Faughnan 1977, p54).

Faughnan (1977) provided an overview of many of the issues regarding holidays for people with significant levels of physical disability. She pointed out that many people with physical disabilities are totally dependent on non-statutory organisations for holiday provision. There may be a number of reasons for this. Personal finance may be a constraint. The organisation of a holiday for a person with significant physical disability may pose such problems that independent arrangements are impossible. In this regard, the paucity of suitable available holiday venues for people with physical disabilities in the Republic of Ireland remains a problem to the present. This contrasts with the position in Britain where many tour companies specialise in holiday packages for people with physical disabilities and charities such as the Winged Fellowship Trust are devoted to provision of holiday breaks for people with significant physical disabilities. Trends in the past number of years have moved from the provision of group holidays for people with physical disabilities as these may stigmatise the people involved. For real integration in the life of the community issues of access and usability are to the fore. Current legislation requires that a certain percentage of hotel accommodation is usable by people in wheelchairs. It has been pointed out to the present authors that while bedrooms and bathrooms may conform to these standards, the access to these rooms may be inadequate.

The dearth of facilities has led many representative organisations to provide their own responses. The Irish Wheelchair Association provides group holidays and short weekend breaks and assists with individual holidays through its local branches. The Friedrich's Ataxia Society of Ireland (FASI) is one of many groups to run summer holidays for their disabled membership. The FASI also advertises a wide range of holidays for people with disabilities in Ireland and Britain in its newsletter. The Abode Centre in County Cork provides some residential short-term stays and is used by groups with physical disabilities as a summer holiday venue.

2.15 Respite services: views of interested groups

A number of groups have interests in the nature and extent of provision of respite services to people with physical and other disabilities. For the purposes of this review comments will be restricted to the issue of physical disability. Two groups are particularly vocal in their calls for respite services; the carers' associations and the service/lobbying organisations for people with physical disabilities.

2.16 Carers perspectives

2.16.1 General remarks

"The extent of informal care in Ireland has never been quantified despite recommendations that this be done (Duffy 1993, p325)."

Estimates on the number of informal, unpaid carers in the Republic vary. Winslow (1993) extrapolating from British figures, suggests that over 300,000 people in Ireland are involved in caring for an elderly or disabled person. The Soroptimist International Republic of Ireland group suggest that there are over 100,000 carers of relatives in the country.

Unpaid caring is exploitative (Duffy 1993). The literature on the effects of caring on carers uses phrases which indicate that people who care perceive themselves as "needy" as the people they care for. While certain people may be happy to adopt the often unexpected and typically unasked for role of a carer, it is probable that many people do not want to have to care for people they care about. The forfeit of employment to act as an unpaid carer and the consequent financial and personal repercussions have been recorded (O'Connor et al 1988).

Demographic, employment and attitudinal changes in society will eventually undermine the current position. The State's reliance on unpaid carers is increasingly being challenged. The statutory response has been to provide a Carer's Allowance but this has raised the usual problems of means testing and levels of payment.

2.16.2 Carers of people with physical disabilities

Winslow (1993) focused specifically on those caring for people with physical disabilities. She examined some of the intertwining forces which promote intense and singular reliance of and between the carer and cared for person. This often unspoken web of responsibility and indispensability creates ambivalence in relationships leading to strain on both parties.

"Community care policies say that family care is good. However they fail to recognise that the pressure is often on one person to care for all i.e. child, spouse and person with a disability" (Winslow 1993, p63).

2.16.3 Calls for respite services from carers groups

The Soroptimist International Republic of Ireland has been to the forefront of examination of caring since 1988. In 1991, it published the *Carers' Charter* which listed the rights of carers. Among these is the "right to respite care for both short spells, as in day hospitals, and for longer periods to enable them to have time to themselves."

In 1993, a seminar was held by Soroptimist International Republic of Ireland, in Galway, on the topic "How carers perceive their own needs". Respite services were viewed as an important need, both on a regular and crisis basis. In particular, the seminar identified home-based proxy care, using sitting services or care attendant schemes, as valuable services. Day-care services including sheltered employment, social clubs and day hospitals, short-term inpatient hospital services and carers' support groups were considered part of a respite package.

2.17 Representative organisations for physical disability perspectives

The calls for residential respite provision, which led to the commissioning of this report, have come in the main from NGOs of representative or lobbying interests in the field. The organisational view of these groups was investigated for the present research. A number of organisations were selected to complete a detailed questionnaire on residential respite care. The criteria for selection for this group were:

i) The organisation was a representative/lobbying organisation of or for people with physical disabilities;

ii) The organisation had previously expressed concern regarding respite facilities for its group.

Most of the organisations involved in this aspect of the study were members of DFI, but this was not a criterion of selection. A list of the organisations contacted is presented in Appendix II. A copy of the questions asked of each organisation is presented in Appendix III.

The main findings were that few organisations have any stated aims or objectives in the area of respite care provision. Despite this, a number of organisations provide services which may be classified as providing respite. These include carer support groups, and the provision of outings and social events. A number of the larger organisations provide extensive services which have as a principal aim the relief of the carer. Foremost among these groups is the Irish Wheelchair Association which provides an extensive service of home care attendance.

2.17.1 Groups with perceived special needs

In the course of the interviews a number of groups were repeatedly identified as having special needs, including possible residential respite placement. On the basis of the interviews no estimates can be given of the numbers in these groups who wish to avail of residential respite care, or of any other service. The categories are merely indicative of subgroups of people with physical disabilities who may require additional or exceptional servicing.

i) Families with two or more disabled members

A number of conditions are hereditary, genetic or for other reasons may affect more than one member of a given family. The living conditions of these families have never been systematically investigated. Existing services are not sufficient to allow for focusing of special assistance for this group. One group representing families affected by genetic inheritance of physical disability, the Friedreich's Ataxia Society of Ireland, has been seeking residential respite accommodation for its membership for some years.

ii) Severe mobility difficulty

Without exception, all organisations interviewed stated that significant mobility difficulty, combined with need for extensive routine personal assistance, created additional problems for their disabled membership.

iii) Terminal illness

People in the final stages of terminal illness were considered to require a host of services not now routinely provided, in particular home-based relief to usual carers. A number of the groups pointed out that the progressive nature of certain diseases required different responses at different times. It became evident in this regard that the close relatives of people with progressive or terminal illnesses are provided with no counselling or emotional support. This issue requires a response well beyond respite care.

2.17.2 Perspectives on current provision of residential respite places

The vast majority of organisation representatives were scathing in their condemnation of the absence of services generally for people with physical disabilities and for respite places in particular. Terms such as "dreadful", "not really available", "very inadequate", "appalling", "very limited" were routinely used to describe the existing level of residential respite places.

Views varied regarding the quality of services currently available. Individual units were often highly praised. Some groups considered the facilities of the units did not meet the needs of their group. A number of specific criticisms were made of existing services. Some of the groups considered that there was insufficient nursing care available to their disabled respite users. This points up the need for different levels of response to different levels of disability and illness. Some of the units were felt to be inappropriate because of the absence of other people of a similar age. Opportunities to go out, particularly at night were cited as a high priority for certain young people. Their agreement to use respite facilities seemed, in part, based on the additional opportunities they would have to participate in ordinary life while in residential respite placement. Only one group considered the provision of residential respite services was acceptable. This organisation caters for a relatively older age group and uses Eastern Health Board facilities.

Of interest was the finding that there was only limited systematic use of private nursing homes to obtain respite placement. Many of the respondents noted that such placements were often unsuitable for the individual involved.

2.17.3 Perception of aims of respite care

Generally the organisations interviewed focused on the value of respite care for both carer and the person being cared for. It was apparent that calls for respite care in the organisations came principally from the carer members. None of the organisations has investigated the views of its membership on the current level and nature of respite services or on services which would be of benefit in this area. In this regard, many of the organisations did not perceive a potential conflict between views of usual carers and views of members with disabilities. A number of organisations stated that they had not carried out research as they considered that they had nothing to offer and did not wish to raise expectations unnecessarily. Some organisations had compiled figures on potential numbers who would possibly benefit from respite placement but the views of the people identified were unknown.

All organisations indicated that home and residential respite options should be available. Some organisations expressed a general preference for home-based services to permit participation in everyday life rather than continued isolation. Some of these organisations identified this preference in terms of provision of individual personal assistance to people with disabilities. A number of the organisations representing disabilities which are of late onset and particularly those which are progressive and terminal, suggested that their disabled members would prefer to be left at home rather than placed in residential care for any time. This was considered to be particularly true of people with severe communication problems. People in the terminal stages of an illness often requested support to remain at home to die. For these groups a hospice-type home-care service was suggested to be preferable to residential care.

2.17.4 Suggested types of residential respite facilities

A number of the organisations stated that people with physical disabilities should be afforded appropriate residential respite placement. The inclusion of people with unique physical disabilities with people with severe mental handicap or diseases of old age was criticised. Many organisations, across a spectrum of age ranges stipulated that age was a factor in residential accommodation. A further area of agreement was in the preference for a location which was well serviced by transport. Transport availability to and from and during residence was also considered by many. Many organisations referred to charges for the service. All were agreed that charges should be kept to a minimum and preferably not paid directly by the residential users. Beyond this level of agreement, the organisations varied in their views of size, staffing and focus of any further residential respite facilities.

2.17.5 Funding of respite services

Many of the representative organisations provide services or funding to avail of existing services. The Department of Social Welfare Respite Care Fund was seen as a positive measure, and most of the organisations had received funding through this channel. It is noticeable in the funding allocations under this scheme that little of the money has gone to residential services. All organisations expressed positive views regarding the establishment and possible continuation of this fund.

2.17.6 Other services which would alleviate stress

A substantial number of groups stated that increased financial assistance to people with disabilities would decrease the stress of everyday life. Modifications of the home environment, with appropriate telephones, communication aids, hoists and lifting equipment, suitable mattresses and cushions were itemised as being effectively unavailable without independent means. Additional local support services, particularly in-home assistance for the family and opportunities to participate meaningfully in the community for the person with disability would dissipate the sense of need for respite services generally. There was general agreement that all services were understaffed and underfunded. Specific services most requested were home-help, day activity centres, and aids and appliances for use in the home. Issues of use of public transport, of access to buildings, of appropriate footpaths, of public toilets and phones, of the grim realities of rural living for people with disabilities were raised by almost all people interviewed for this study. Providing a real response to these issues would decrease the perception of need and the current demand for respite services.

2.18 Views of people with physical disabilities

An entirely different perspective on all aspects of disability is provided by lobbying organisations of people with disabilities. In Ireland, the two principal examples are Forum of People with Disabilities and the Center for Independent Living.

The Center for Independent Living has an integrated philosophical and political perspective on the requirements of people with significant physical disabilities living in existing residential units and in the community (McGettrick 1994, Center for Independent Living 1994, Naughton et al 1994). Within this approach, the existence of respite services is seen to demonstrate the failure of current policies to address the rights of people with disabilities. People with physical disabilities should have the same options in life regarding education, training, employment and social outlets which other people take for granted. For people with significant disabilities routine tasks, which able-bodied people take for granted, can impede participation. The Center for Independent Living promotes an alternative to this dependency through employment of personal assistants by people with physical disabilities. The relationship of employer to employee inverts the traditional dependency role of cared for by carer, in to one of leadership and self-empowerment of people with disabilities. The philosophy of independent living is acknowledged by many of the NGOs as a major step forward in social policy. To what extent existing services can rise to the demands of such organisations remains to be seen.

The philosophies of these organisations remain unknown to many people with physical disabilities. For many people with physical disabilities residential respite care is something they want. It provides a break from the humdrum existence of a partially adapted home; it gives them an opportunity to take "time-out", it may relieve the on-going strain of living alone or of relationships marred by the intrusion of continuous care.

2.19 Present research

This chapter has presented an overview of the many issues which surround the provision of respite services for people with physical disabilities. Statutory and non-statutory perspectives have been considered. The potentially conflicting, and perhaps frequently coinciding, views of people with physical disabilities and their relatives who provide on-going assistance have been noted. The perspectives of the NGOs in the field have been examined and the issues of concern to them elaborated.

It is within the context of these different perspectives on services, on needs and on participation that the current research in to the provision of dedicated residential respite care places in the EHB was undertaken. The 19 dedicated residential respite places for adults with physical disabilities, under the age of 65 were surveyed. The description of the facilities is presented in chapter 3 and discussed in chapter 4. The methodology of this research is presented in Appendix IV.

Chapter 3: Description of Facilities

3.1. Numbers of facilities and places

There are six facilities located in the Eastern Health Board (EHB) area providing dedicated residential respite services for adults with physical disabilities under the age of 65. Of these only one facility is directly controlled and staffed by the EHB. A total of nineteen dedicated respite places are available for people within these facilities. Of these four are provided by the statutory service, fifteen by non-statutory bodies. The locations are;

EHB facilities

1. Saint Mary's Hospital,
Phoenix Park,
Dublin 20. 4 places

NGO facilities

2. National Multiple Sclerosis Care Centre,
Rathgar,
Dublin 6. 8 places
3. Barrett Cheshire House,
Herbert Street,
Dublin 2. 2 places
4. Cara Cheshire Home,
Phoenix Park,
Dublin 20. 2 places
5. Richmond Cheshire House,
Monkstown Road,
Co. Dublin. 1 place
6. Ardeen Cheshire Home,
Shillelagh,
Co. Wicklow. 2 places

In addition there are a number of respite places provided directly by the EHB within the geriatric service which may be used for people under the age of 65, but which are not solely for such use. It will be observed that these hospitals provide the additional 13 places counted as dedicated in the parliamentary reply discussed in section 2.8.2.ii) of chapter 2.

7. Wicklow District Hospital, 1 non-dedicated place
Wicklow, also beds allocated on demand
Co. Wicklow.
8. Saint Colman's Hospital, 2 non-dedicated places
Rathdrum,
Co. Wicklow.
9. Saint Vincent's Hospital, 6 non-dedicated places
Athy, also beds allocated on demand
Co. Kildare.
10. Baltinglass District Hospital,
Baltinglass, 4 non-dedicated places
Co. Wicklow also beds allocated on demand

3.2 Description of existing facilities

Each of the dedicated facilities responded to the questionnaire. A description of each facility is presented in turn. Issues arising are discussed in chapter 4.

The description of each facility is considered under the following headings;

- i) Policy of the residential respite service
- ii) Nature of placements
- iii) Number of placements in a year
- iv) Criteria for placement
- v) Characteristics of users
- vi) Type of facilities
- vii) Services available
- viii) Meal arrangements
- ix) Visitors
- x) Going out and transport
- xi) Staffing, social employment schemes and volunteers
- xii) Costs and charges
- xiii) Measures of satisfaction
- xiv) Other respite services on offer
- xv) Role of service within the overall respite strategy.

3.2.1 Saint Mary's Hospital, Phoenix Park

Saint Mary's Hospital, Phoenix Park (St. Mary's) is the only one of the six facilities directly controlled by the EHB. A unit within St. Mary's, called *Cuan Aoibhean*, is devoted to people with physical disabilities under the age of 65. Up to 1992, this unit comprised thirty eight long-term residential places and ten respite places. Because of the low usage rates of these ten respite places the Steering Group for respite admissions in St. Mary's reduced the respite bed complement to four.

The reasons for this low rate of take-up of respite places are unclear. It has been suggested that the facility was under-advertised. In an attempt to rectify this, an open day was held for public health nurses, general practitioners and social workers. In addition, Saint Mary's Hospital wrote to general practitioners and superintendent public health nurses reminding them of the respite facility as this was not being fully utilised.

Another possible reason is the location of St. Mary's, which is peripheral to the city and poses transport and access problems. A factor identified in the present research is that most of the people availing of respite places in St. Mary's have severe physical disabilities. A large percentage of the long-term residents in the unit also have severe physical problems. This combination may mean that people with less severe problems may opt for other respite services. The major reason cited by the hospital authorities was the pressure to obtain an increase in long-term places within the unit. A number of requests for respite were from spouses or partners who could no longer carry the burden of caring and hoped that once the resident was admitted into respite placement then he or she would remain an in-patient. This was also true of the people with disabilities living alone who were seeking respite placement in St. Mary's. The six additional places obtained from the decrease of the dedicated respite places have gone some way to address long-term demands.

St. Mary's is currently considering a system of "floating bed admissions" to facilitate people with disabilities living in the community. This system would permit the person with a disability to be admitted for a set number of days each week and to receive an in-depth medical and nursing review of their situation while in hospital.

The four dedicated respite places are the focus of the remarks which follow.

i) Policy of the residential respite service

The primary goal of the service is to provide a temporary relief service for families or primary care-givers and to provide something positive for the people with disabilities.

ii) Nature of the placements

Both crisis and planned, repeated placement are available. The average length of stay is two weeks, although durations of one week to one month have occurred. There is no waiting list for placement at the moment, but it is likely that there will be one soon because of constant referrals to the unit.

iii) Number of placements in a year

In 1993, 26 individuals obtained a total of 47 placements in the facility. This indicates a high level of repeat visits to the unit. Of the four places available, two are designated for women and two for men.

iv) Criteria for placement

There are medical, social and personal criteria which must be fulfilled to obtain placement. Application for a place in residential respite may be made by medical, nursing or social work professionals or by family members. There is a standard admission form which has three sections, one each for family/carers, the family doctor and the community physician. The information sought covers routine personal details, diagnosis of the disability, medications and special problems, the identity and frequency of visits of the public health nurse and details of nursing problems. In addition, there is an admission slip which the family/carer sign which states that the admission is for a two week period and that discharge of the person from the unit will be facilitated. The facility is not publicised, but voluntary and other EHB hospitals and health professionals would be aware of the service.

v) Characteristics of users

St. Mary's keeps records of the people availing of the residential respite service. The average age of users for the year 1993 was 53 years. Of the total 26 users, there were 14 women and 12 men. When repeat admissions are analysed, 22 were of women and 27 of men. Of the total 26 users, fully 21 lived with their spouse, 4 with an older carer and only 1 with their child or children. Of the total number of users 11.5% were considered to have moderate physical disabilities and the remainder (88.5%) were designated as severely physically disabled. The principal medical diagnostic categories were multiple sclerosis, stroke and motor neurone disease with some cases of brain injury, road traffic accidents and syringomyelia.

vi) Type of facilities

St. Mary's is a purpose-adapted building with full disabled access and use. The accommodation within the *Cuan Aoibhean* unit is in individual rooms, 4-bedded rooms and 3-bedded sections. There are 4 bathrooms and toilets with washing facilities in each section or room. There is a day-room, two sitting-rooms, a computer room and verandas used as sitting areas.

vii) Services available

Basic physical, medical and nursing consultations are carried out each time a resident is admitted. Should a patient in respite care become seriously ill the medical officer attached to the unit will be available. Respite admissions bring in their own medications which are administered while in hospital. Physiotherapy may be available if required. Speech therapy and dietetic services are not available. Chiropody is sometimes available, depending on the time of admission. There are no counselling, yoga or other similar services. Counselling services would be a positive addition to assist people in long-term and respite care. Occupational therapy is provided and arts and crafts are part of the service. A diversional therapy programme is available. A hairdresser may be available at certain times. There is a shop and a prayer room and a reading room but no coffee dock. The unit also provides recreation activities and outings. Some of the long-term residents are involved in computer training programmes.

viii) Meal arrangements

Breakfast is served at 9.00am, dinner at 1.00pm, evening tea at 5.00pm. In addition, there are mid-morning, afternoon and night drinks provided. The meals are served in the dining-room or on the wards. There is a choice of menu. Food and beverages are available throughout the day if required.

ix) Visitors

Rooms to receive visitors are available. There are no time or other restrictions on visiting.

x) Going out and transport

There are opportunities to go out shopping, to the cinema and theatre and to the pub. Transport would be available for expeditions if long-term residents were involved. Transport is available to residential respite users coming to and from the unit, through the EHB ambulance service. The Barrett Cheshire Home loans its bus for use by St. Mary's on a regular basis.

xi) Staffing

Specific staff numbers dealing with people in respite places are not available. The staffing of the unit is considered as a whole. For the 48-bedded *Cuan Aoibhean* unit there is a nursing sister, 13.5 staff nurse full-time equivalents and 13 care attendants. For night duty rosters there are 2 staff nurses and 2 attendants each night. Rostering of staff assists busy times. Staff are assigned to individuals during their stay, given normal flexibility of the system.

In general, the staff feel that the staffing levels are inadequate to meet the physical, psychological and social needs of the people with disabilities and to deliver individualised care. At times, the staff can be under pressure and find themselves in stressful situations. Because the physical needs of people in the long-term and respite places are demanding, their psychological and social needs are not always met. The nursing administration is aware of these on-going problems and continues to strive for more staff.

Staff are employed on social employment schemes and volunteer helpers are used.

xii) Costs and charges

The Health Board pays the full costs of the unit. The cost of each respite place is £550 per week, or £78.57 per day.

There are no charges as the unit is a public facility. The Voluntary Health Insurance scheme does not cover public facilities.

xiii) Measures of satisfaction

At present, St. Mary's does not have a tool to measure user satisfaction. The unit utilises a detailed nursing assessment and evaluation of each patient including measures of progress while in the unit.

xiv) Other respite services of offer

St. Mary's also provides dedicated residential respite placement for people over 65 years.

xv) Role of service within the overall respite strategy

The role of St. Mary's is viewed positively. The respite places are considered to contribute effectively to the overall respite strategy in the area. This is because respite care plays a major role in the support of people with disabilities and carers in the community. It can mean the difference between home and permanent institutional care. It was stressed, by the respondent, that residential respite care does not, on its own, provide the answer to caring for people with disabilities in the community. Instead it should be seen as one link in a support chain for people with disabilities plus their families or primary care-givers.

St. Mary's has produced no written documents regarding residential respite services. A booklet and a video on the *Cuan Aoibhean* unit in St. Mary's are available.

3.2.2 The National Multiple Sclerosis Care Centre

The National Multiple Sclerosis Care Centre (MS Care Centre) is the first and only unit in the country to provide respite services uniquely. It is a project of the MS Care Foundation which was founded in 1987. The MS Care Centre was set up as a pilot project with capital funding from the Department of Health. There was a place on the Board of the MS Care Foundation for a representative of the Department of Health and subsequently for a representative of the Eastern Health Board. However, the position has never been taken up.

The MS Care Foundation views its role as giving practical expression to the need for care in the community by providing a range of support services, one of which is residential respite care. The MS Care Centre, in focusing solely on respite provision believes it can offer a quality and range and choice of service, a level of staffing and a commitment to on-going improvement not possible in other general residential units. One of the principal aims of the MS Care Centre is to promote self-help and independence. This has repercussions on staffing level and policy.

i) Policy of the residential respite service

The MS Care Centre views its function as to:

"act as a physical and emotional load bearer at times of individual and family difficulty, to address such issues as personal independence, integrity of personality and maintenance of dignity and well-being while sustaining hope and effort by virtue of the fact that the services of the centre are readily accessible if required (MS Care Foundation, 1989).

ii) Nature of placements

The average length of stay is two weeks. This varies and stays as long as one month and as short as overnight have occurred. Crisis placement is rare and depends on a cancellation, or delay in take-up of planned residence. Many of the planned respite residents are considered to be "in crisis", in the sense of being under considerable on-going strain. Up until recently planned repeated placement was available throughout the year, up to a maximum of three placements a year. Due to growing numbers, repeat visits in a single year will have to cease, with a maximum of two weeks per year for each resident. There is a lengthy waiting list for placement, stretching 7 months in advance. This places constraints on the centre in fulfilling its mandate. As a result, the MS Care Centre is considering increasing the number of residential respite places it provides. The centre is publicised mainly in the *MS Newsletter*, but publicity has decreased as a direct attempt to stem further growth of waiting lists.

iii) Number of placements in a year

In 1993, a total of 260 residential placements were provided for 217 people.

iv) Criteria for placement

Acceptance of a resident depends on their need and availability of a place. The MS Care Centre is run according to a non-medical model of care although it is recognised by the VHI as a hospital. The MS Care Centre accepts people with different care level needs but in general three of the eight residents at any one time need 'total care'.

There is no age criterion per se in the MS Care Centre. Because each of the resident's rooms is separate, there are no requirements regarding gender. The centre accepts residents with a wide variety of mobility difficulties, though the main group, given priority, are people with multiple sclerosis. The MS Care Centre also provides special niche periods for people newly diagnosed, for younger people etc.

The initiation of contact with the centre can come from any source, but the centre deals directly with potential residents. This is a policy. A detailed reservation form must be completed by or on behalf of the prospective resident. This serves as an application which can be refused, on medical grounds. The form asks for personal data relating to level of independence and requirements in terms of personal and equipment assistance. The prospective resident is asked to state the main reason for

wanting to use the centre. There is also a section on financing of the stay. A medical report to be completed by the prospective resident's general medical practitioner must be completed. This gives data on diagnosis and current medication.

v) Characteristics of users

The average age of residents is about 50 years. The ratio of men to women using the centre is 1:2. This reflects the higher incidence of multiple sclerosis among women in the general population. Of the total, 85% were diagnosed as having multiple sclerosis. The other main medical diagnostic categories were Friedreich's ataxia, motor neurone disease and Parkinson's disease.

Most of residents live with their spouse. This is reflective of the natural history of multiple sclerosis which tends to appear in the twenties and thirties.

vi) Type of facilities

The centre comprises both purpose-adapted and purpose-built disabled access and use. Sleeping arrangements are in individual rooms with en suite facilities and direct dial telephones. Each bedroom and bathroom has a call bell system. The centre has a reception area, sitting-room/TV room, a dining-room and a library. There is a patio area and each of the resident's bedroom's leads directly in to the gardens.

vii) Services available

The centre provides full nursing care at all times. There is a general medical practitioner on call in case of emergency. Occupational therapy and physiotherapy are provided routinely. Speech therapy is provided when required. Chiropody and counselling services are also available. In addition there are arts and crafts sessions, yoga and massage on offer. A dietitian gives advice during certain of the residential special interest weeks. During certain weeks there are talks by dietitians, neurologists, continence advisors etc. A hairdresser is available within the centre. An outline of the objectives of each of the services provided directly by the MS Care Centre is given to each resident.

viii) Meal arrangements

Breakfast is available from 8.00 - 10.30am and is taken in the bedroom, if desired. All meals may be taken in the bedrooms, an option often preferred by people with swallowing difficulties. Lunch is available from 1.00pm and the evening meal is available from 5.30 - 7.00pm. There is choice of menu, with flexibility for personal preference. Wines and beer are available at meals.

ix) Visitors

Visitors are usually entertained by residents in their own rooms. There is a sitting-room available. There are no time or other restrictions on visiting.

x) Going out and transport

Opportunities to go out depend largely on transport availability. On Wednesday afternoons the Cara Cheshire Home loans a bus to the MS Care Centre and excursions are arranged for that day. Arrangements are also made for church attendance locally. Transport to and from the centre is not available.

xi) Staffing

A total of 8 full-time and 32 part-time staff including sessional staff and social employment scheme (SES) workers are employed at the centre. There are 6 full-time care staff and 2 half-time care staff. Night staff are part-time employed. The staff rostering is designed to give maximum staffing at times of maximum demand, for example morning rising, bathing, meal times and evening retiring. Staff are not assigned to individual residents for the durations of their stay. This is due to small numbers and individual variations in need of assistance. There is on-going staff evaluation support and training. Staff involvement in policy and service review is routine.

Some staff are employed on social employment schemes (SES). There are 12 such staff employed throughout the facility, including garden, laundry and administrative duties and 6 provide additional assistance to the care staff. These workers are given 2 days training to familiarise themselves with the centre as well as on-going training. Volunteers are also used, primarily in the provision of transport and entertainment. They are not used to provide standard services.

xii) Costs and charges

The Voluntary Health Insurance Scheme (VHI) will pay a maximum of £74.40 per day for those residents covered by its scheme. Health Boards pay varying amounts; between £11.93 and £15.00 per day for their medical card holders. Some residents receive financial assistance for their stay from their local MS branch. The MS Care Centre seeks to avoid any elitism of residential placement. This is confirmed by figures indicating that a substantial percentage of residents are medical card holders (See Table 3.4 in this chapter).

There is a substantial shortfall of funds from receipts. The MS Care Centre receives substantial direct funding from the Department of Health, and also from the National Lottery via the Departments of Health and Social Welfare, and from fundraising through the Friends of the MS Care Centre, who run a "Carnation Day" each year.

xiii) Measures of satisfaction

The MS Care Centre is the only facility in this study which seeks extensive feedback from its consumers. This is done through a post-residence survey form systematically sent to all ex-residents. It includes a section for the usual carer of the person involved. These data are collected on a two or three monthly basis. These are reviewed on a regular basis by the Board.

The present research analysed the post-residence surveys for 1993. There were 163 survey forms completed (62.7% of all residences). There was a possible seasonality factor, with responses slightly lower for the March/April period and slightly higher for August/September/October.

Results of the post-residence survey of the MS Care Centre for 1993

Residents were asked to indicate whether their stay was their first or had they stayed previously. The figures indicate that at least 55.1% of respondents were second or more frequent ex-residents. This has interpretative implications and potentially skews all results. The present report does not provide a critical analysis of the results.

Method of analysis

Measures of satisfaction were obtained on the facility and various services. For the purposes of the present analysis those aspects which involved all residents (food, bed and bath facilities, personal care) were examined separately from those which were optional (for example the services of therapists, counsellors etc). The survey form asked residents to indicate on a 5 point scale their level of satisfaction. For the purpose of the present research, a test of satisfaction, as opposed to acceptability, was preferred. Satisfaction levels of excellent (scale 5) or good (scale 4) were combined and this was considered a measure of satisfaction.

Measures of satisfaction of residents

The results of the analysis of those aspects of the facility experienced by all residents are presented in Table 3.1. These figures indicate overall respondent satisfaction with the facility.

Table 3.1: Satisfaction rating (scores excellent or good) expressed in percentage terms of total number of respondents, on aspects of the service in the MS Care Centre for the year 1993. (N=163).

Item	% satisfaction
Food	94.5%
Bed and bath facilities	94.5%
Level of personal care	95.1%

Some residents did not participate in certain activities or certain measures were irrelevant to them. For the purpose of the present research, the analysis of optional services was confined to people who had participated and who had scored the service as excellent or good. Participation rates vary substantially. Massage is the most popular and most satisfactory experience for these respondents. Physiotherapy and counselling are popular, with yoga also a frequent choice. The satisfaction level with these services (excepting massage) is relatively uniform. The results are presented in Table 3.2.

Table 3.2: Satisfaction rating (scores excellent and good), expressed in percentage terms of all participants, on aspects of the optional services provided by the MS Care Centre in 1993. (N=163).

Item	% participation	% satisfaction
Leisure and entertainment	unknown	80.3% of total respondents
Massage	95.7%	92.3%
Physiotherapy	84.7%	71.7%
Occupational therapy	68.7%	71.4%
Music and Movement	59.5%	72.2%
Counselling	83.4%	73.5%
Yoga	74.8%	66.4%
Art	37.4%	68.8%
Promotion of self help	81%	78.8%

Carers' perspective

The post residence survey also examined the perceptions of the residents' usual carers along a number of parameters. Of the 163 returned forms, 119 had completed carers' sections. This gave a putative overall response rate of 45.8%, given that all residents have a usual carer. Considered in terms of the total numbers of completed survey forms, 73.0% included a completed carer's section.

Carers were asked to indicate whether they considered the length of stay adequate, too long or too short. Most respondent carers were satisfied with the length of stay, which is typically two weeks. This may in part be explained by their use of their time to go on holidays. Three out of ten of the carers found the break too short, indicating on-going strain in their everyday lives not fully alleviated by this support service. The results, in percentage terms, are presented in Table 3.3.

Table 3.3: Adequacy of the duration of stay in the opinion of the carer, expressed in percentage terms for 1993. (N=119).

Perception of length of stay	% of carers who responded
Adequate	61.3%
Too short	28.6%
Too long	2.5%

The carers were asked to rate the value of the stay to the ex-resident and to themselves on a five point scale. For the present research, only those scores of excellent and good were included. Of the total number of carer respondents 77.3% considered the stay at the MS Care Centre to have been of significant value to the ex-resident. A large percentage (16%) of respondents left this section blank. Regarding benefits to themselves, 74% considered the break of significant value, with 16.8% leaving the section blank. Comparative interpretation of these figures is not possible as equivalent questions were not asked of the ex-residents.

Funding sources of residents

The survey also investigated the funding sources obtained by the residents. The main sources of funding were from the VHI scheme, from Health Boards, from MS Society branches and from other private insurance schemes (garda, ESB etc). The figures show that more people are assisted by the VHI than by all Health Boards combined. The percentage of people covered by VHI is only slightly higher than that of the entire population (36.6% of national population, in 1991).

The results are presented in summary in Table 3.4.

Table 3.4: Sources of funding of residential stays at the MS Care Centre in percentage terms for 1993. (N=163).

Funding source	% of residents availing
Voluntary Health Insurance	40.5%
Health Board assistance	31.3%
MS Society branch	9.8%
Other	18.4%

Summary of post-residence findings

In summary, the MS Care Centre provides a service which is highly valued by many residents. The centre obtains detailed feedback from its residents which potentially permits the centre to modify its service to client need and preference.

xiv) Other respite services on offer

The MS Care Centre also provides regular carer support groups.

xv) Role of service within the overall respite strategy

Reference is made to the point in the introduction regarding the pilot and initial funding from the Department of Health and the pilot nature of the project.

3.2.3 The Barrett Cheshire House

The Barrett Cheshire House (the Barrett), a city centre facility, is primarily a long-term residential unit for people with physical disabilities. There are 26 long-term residential places in the Barrett. As a result of pressure from those caring for people with physical disabilities at home and from services such as the public health nurses and social workers a number of respite places have been provided. There are two places for respite stays in the Barrett.

i) Policy of the residential respite service

The respite service is viewed in terms of relief for the carer. The role of short-term stay to acclimatise potential long-term residents is also stressed. The Barrett seeks to respond to the individual needs of all residents regardless of their length of stay. Increasingly, home and community-based assistance is being requested and the Barrett is attempting to respond to these calls.

ii) Nature of placements

If a place is available due to delays in uptake or temporary absence of a long-term resident it is used for crisis placement. This service is seen as separate from the on-going provision of respite places. Planned repeated placement is routine in the Barrett, with many people using respite facilities intermittently prior to eventual long-term stay in the house. Two weeks is the average length of stay. There is a two month waiting list for respite placement. Over 200 people are on the waiting list for long-term admission.

iii) Number of placements

A total of 52 placements were made in planned residential respite in 1993.

iv) Criteria for placement

The criteria for placement are medical, psychiatric and social stability. The nature of the available accommodation means that 1 male and 1 female resident may be accommodated at any given time. Initial contact regarding respite placement can come from any source. A reservation/admission form is in preparation. The facility is not publicised, because the consequent flood of demand could not be addressed. People get to know of the facility by word of mouth.

v) Characteristics of users

The average age of people using the service is approximately 30 years. Typically, residential respite users live with an older carer, usually a parent. The demand for "respite" is seen to reflect the needs of aging parents and the gradual preparation for long-term residential care. There are approximately equivalent numbers of men and women availing of the respite service. The majority require total care. The principle medical diagnostic categories are cerebral palsy, spina bifida and multiple sclerosis.

vi) Type of facilities

The Barrett Cheshire House is a purpose-adapted building with full disabled access. The sleeping accommodation comprises individual and 2 bedded rooms. The bathroom and toilet facilities are shared. The house has large reception rooms, a sitting room, dining-room, reading room, conservatory, occupational therapy and computer room and a physiotherapy room.

vii) Services available

A routine medical review is available to people in respite care. Physiotherapy and occupational therapy services are also provided routinely. There is no speech therapy, chiropody or dietitian service. A part-time counsellor is available. Arts and crafts are provided by the occupational therapy department. Alternative therapies including yoga, aromatherapy and massage are provided. These services are popular. Other potential services such as hairdressing and shops are all available locally and residents are encouraged to go out. There is a kitchen available for residents to do their own cooking, if they so wish.

viii) Meal arrangements

Breakfast is served whenever people get up. Lunch is served at 1.00pm and the evening meal is served

at 5.00pm. There is considerable individual flexibility in providing meals at any other time. Any special dietary need or preference is catered for. Meals are taken in the dining-room.

ix) Visitors

There are no restrictions on visiting. There are numerous places where visitors may be entertained.

x) Going out and transport

The location of the Barrett means that a wide variety of opportunities exist to go out. Residents can avail of expeditions to shops, cinema, theatre and pubs. The Barrett has a bus, but no full-time driver. However the bus is used for expeditions. There is no transport to and from the facility for people availing of a respite placement.

xi) Staffing

There are 30 staff employed by the Barrett Cheshire House, 25 of whom work full-time. There are 13 care staff, 3 of whom are nurses. Numbers of male and female care staff are equal. Staff rostering is used to ensure additional staff at busy times. Staff are not assigned to individuals during their respite stay. This is not considered relevant in view of numbers.

The Barrett Cheshire House is located in a designated area-based response to long-term unemployment (ABR) area. This has allowed the Barrett to be involved in a Community Employment Development Programme (CEDP) funded by FAS. The scheme in the Barrett involves the training of care workers. This training programme will be certified to City and Guilds standards. The Barrett recruits its own staff from this pool of trained care workers. Further co-operative development with FAS is envisaged in setting up an outreach scheme to train people to provide home liaison and companion services, with live-in options. The Barrett actively encourages volunteer helpers. There is a Director of Volunteers. This is considered necessary as there is no local community base around the Barrett to provide supports.

xii) Costs and charges

The cost to the Barrett of each place, regardless of whether for long-term or short term placements is approximately £450 per week, or £64 per day. Over 90% of the running costs of the house are provided by Health Board subvention.

No standard charge is applied. People give what they can, ranging from no contribution to £50 per week, the equivalent of the DPMA. Most people using the Barrett are medical card holders, because the diagnostic classification of their disability entitles them to free inpatient and outpatient services.

xiii) Measures of satisfaction

There are mechanisms to consider the views of long-term residents, but no system addresses the views of people in respite places.

xiv) Other respite services on offer

The Barrett Cheshire House offers some day-care facilities which may be classified as providing respite. These are not used extensively, probably because there is no transport available to and from the House.

The Cheshire Homes within the Cheshire Foundation operate a scheme of holiday exchanges between their residents. The Barrett Cheshire House residents avail of exchange arrangements with Cheshire Homes in England.

xv) Role of service within context of overall respite strategy

Statutory strategy is seen to be absent. Development of cohesive policies need to include sheltered housing options, outreach services and to tackle the need for integration in the community. The Barrett Cheshire House would like to modify its role to that of a centre of service, in which a variety of responses to people with disabilities could be provided. The dependence and de-motivation of people in longterm placements need to be challenged.

4.2.4 The Cara Cheshire Home, Phoenix Park

The Cara Cheshire Home (the Cara) is primarily a long-term residential with 50 long-term residential places. It has also provided a residential respite service for the past number of years. There are 2 places available in toto, 1 male and 1 female. The vast majority of users of the service are under 65, and any exception is referred to the admissions committee.

i) Policy of the residential respite service

The primary goal of the respite service in the Cara is to satisfy the reason why respite was required in the first instance. The limitations of the building are acknowledged. The fact that many people in long-term residence are middle-aged suits an older age group in respite also. A major concern for the Cara is that people on respite breaks are getting sufficient stimulation and change of environment. Needs in this regard vary between individuals.

ii) Nature of placements

Crisis placement is not available, unless a booked respite admission is delayed. Planned repeated placement is the norm, with an average of two stays per year. The minimum length of stay is two weeks and the maximum is one month. There is a waiting list of 6 months for residential respite admission.

iii) Number of placements

There were 53 placements in total in 1993.

iv) Criteria for placement

Acute medical illness precludes placement. Anyone may initiate contact regarding respite placement. There is a standard reservation/application form. This covers personal data, nature and extent of disability and need for general and nursing assistance. A GP and social worker's report are required. The facility is not publicised because of the potential demand created.

v) Characteristics of users

There are approximately equal numbers of men and women, with an age range of 45-60. The average age is mid-50s. Over half of the people availing of the residential respite service are considered to have high care needs. Cerebral palsy is the principle medical diagnostic category, followed by stroke and spinal injuries. The numbers of people with multiple sclerosis availing of the service has dropped due to their use of the MS Care Centre. Most respite users live with parents. A substantial minority live with their children.

vii) Type of facility

The facility was purpose-built in 1974 with full disabled use. The sleeping arrangements are in separate rooms. The toilet and bathroom facilities are shared and their physical location means that the unit is divided into male and female corridors. It is a large building, with substantial reception areas, a TV room, a dining-room and a quiet room.

viii) Services available

On admission to a respite place there is a drug review and any other medical problems can be addressed. Physiotherapy and occupational therapy are routinely available. There are no speech therapy or chiropody services. There is a dietitian on call. Counselling can be arranged privately. Arts and crafts are available. Yoga was introduced but the long-term residents did not like it and it was discontinued. Massage is provided by the physiotherapist. Other services such as hairdressing or shops are provided in the local area and residents are encouraged to go out. A computer room is available. Swimming is provided in Clondalkin.

viii) Meal arrangements

Breakfast is served between 9.00 - 10.00am. Lunch is available from 12.00 - 1.30pm and tea is served between 5.15 - 6.15pm. Meals may be taken in the dining-room or room service is always available. There is always a choice of menu.

ix) Visitors

Visitors are usually entertained in the person's room or in one of the communal rooms. There are no restrictions on visiting.

x) Going out and transport

Residents go out shopping, on various expeditions and to the cinema and to the pub. The Cara has a large bus for group outings, a minibus for smaller groups and a car for single passengers. Transport to and from the facility is available for the respite user, if the person lives locally.

xi) Staffing

A total of 40 staff are employed by the Cara. There are 14 care staff, 7 of whom are male. Four of the care staff are State Registered Nurses (SRNs) and 2 are State Enlisted Nurses (SENs). There is relatively little turnover of staff. There is an in-service training programme which covers aspects of lifting and handling, first aid, basic nursing care, incontinence management and permits day release for course attendance. Extra staff are not available at busy times and there is a shortage of staff.

There are 6 people employed on social employment schemes (SES) at the Cara, whose duties are mainly in maintenance, driving and social involvement with the residents.

The Air Corps provides regular outings to swimming and other venues and also fund-raises. The Legion of Mary members perform letter-writing and shopping tasks for residents. The senior cycles in the local secondary schools usually have some involvement and students in Bolton Street also act in volunteer capacities.

xii) Costs and charges

The overall cost of a place in the Cara Cheshire Home regardless of the nature of that placement, is £326.30 per week or £46.61 per day. Funding is over 90% from the EHB. The respite care fund has assisted in the maintenance of respite places in the past year.

There is no set charge for residential respite places, but donations are requested.

xiii) Measures of satisfaction

No formal measurement of satisfaction is performed for people using the respite places. The fact that people are eager to come back again is seen as evidence of satisfaction.

xiv) Other respite services

No other respite services are provided by the Cara. For long-term residents a holiday is provided every year. This may be a group holiday with NGOs such as the Friedreich's Ataxia Society, Multiple Sclerosis Society, Irish Wheelchair Association or the Caring and Sharing Association. There is an exchange scheme with the Cheshire Home in Jersey, in the Channel Islands. Individual holidays with a care assistant are also provided.

xv) Role of service within the context of overall respite strategy

The contribution of the Cara to the respite strategy in the area is unclear to them as they accept people from all over the country.

3.2.5 The Richmond Cheshire House, Monkstown Road, Co. Dublin

The Richmond Cheshire House is the most modern of the Cheshire Homes in the EHB area. There are 18 long-term residents, and one residential respite place.

i) Policy of the respite service

The role of the residential respite service is a dual one, providing the person with a disability with a break and thereby giving the carer a break.

ii) Nature of placement

Crisis placement is not available. Planned repeated placement is available with a maximum number of two placements in the year. There is no minimum stay, the maximum stay is 1 week. There is a waiting list of 30 people for the single respite place. As a result, the use of a waiting list has been suspended and placements are now obtainable month to month.

iii) Number of placements

There were 40 residential respite placements last year.

iv) Criteria for placement

All sources of initial contact are accepted. There is a standard form to fill in. This requests information on medication, dietary requirements, nature and level of assistance required routinely, preferential day activities and general personal data. Respite placement is available to people between the ages of 18-55. Many of the long-term residents are young and this means that young people availing of respite places may feel more comfortable than an older age group. This is not always so and the older influence may also be positive. This single respite place may be used for male or female residence. The facility is deliberately not publicised due to inability to meet demand.

v) Characteristics of users

There are more men than women using the respite facility. The average age is about 30 years. The level of assistance needed varies, approximately half of the people on respite placement require total assistance and on occasions additional staff have been brought in to satisfy this need. The principal medical diagnostic category is cerebral palsy. Features considered of relevance in this regard are the onset of cerebral palsy from birth, leading to on-going life-long care by parents. This becomes more difficult with time and respite may offer a break. The high concentration of services for children with cerebral palsy is not continued into adulthood, leaving many people without anything to do. The other principal medical diagnostic categories are multiple sclerosis and stroke. Many people availing of respite places live with their parents or with siblings.

vi) Type of facilities

The Richmond Cheshire House is purpose-built with full disabled access. Sleeping arrangements are in individual rooms, grouped into clusters of four, with in-room washing facilities and with shared bathroom and toilet facilities between the four bedrooms. The general accommodation, although open plan and spacious, lacks enclosed private space.

vii) Services available

The Richmond Cheshire House considers that most people with chronic physical disabilities are healthy people. The Richmond Cheshire House does not subscribe to a sick role model of disability. As a result there are limited therapy services available to residents. If comprehensive therapy is required by any resident it is obtained within the local community service as it would be for any other person living in the community. The Richmond Cheshire House does not provide traditional activities such as arts and crafts. The Richmond Cheshire House aims to develop independence and to give real opportunities of employment to their residents. This is done through a substantial vocational training project, funded by the EU Horizon initiative. Residents study child-care to City and Guilds levels, horticulture and art and design. These courses are not available to people on respite placement.

Some services are provided to people on respite, including counselling and reflexology. There is an aerobic exercise group. Art therapy and drama workshops are used to challenge both residents and staff in their underlying assumptions and expectations of disability. A transport service is provided to assist in independent use of other community services.

viii) Meal arrangements

There is no set time for breakfast. A main meal is served at 1.00pm; at 5.30 tea is served. These arrangements reflect residents' wishes. Any meal, at any time of the day, is available. The dining-room facilities are excellent. The menu is devised in consultation with residents and special diets are catered for.

ix) Visiting

There are no restrictions on visiting. Communal areas are poor and visitors usually are entertained in the residents' rooms.

x) Going out and transport

Opportunities to go out are plentiful and this is assisted by use of staff on SES schemes to provide personal assistance. Transport is provided. Transport to and from the facility can be arranged within the catchment area.

xi) Staffing

There are 22 full-time staff and 4 part-time staff. There are 2 nursing and 11 care staff. There is no nursing cover on night duty. The numbers of male and female care staff are approximately equal. Figures are not available for the proportion of staffing used by the single respite place.

There is an extensive care staff training programme carried out in the Richmond. This includes two weeks intensive induction and needs-based training on a six weekly basis. Refresher courses are run throughout the year.

There are staff employed on the Horizon projects and 14 people are employed on SES schemes, including 10 personal assistants.

Volunteerism is approached cautiously by the Richmond Cheshire House. Many residents dislike the patronising behaviour of some volunteers. Some people perform useful volunteer roles and are accepted by residents.

xii) Costs and charges

The estimate of the cost of a respite place in the Richmond Cheshire House is £190 per week or £27.14 per day. The range of services routinely available to long-term residents is much wider than that for respite. The overall cost per week per resident (regardless of status) is £435 or £62.15 per day.

Until recently there was no fixed charge, but donations were accepted. Recently a minimum charge of £30 per week, with a maximum of £60 per week has been instituted. The respite facility is not covered by VHI. No distinct funding of the respite service has been provided except for the respite care fund of the Department of Social Welfare.

xiii) Measures of satisfaction

The satisfaction level of people in respite is routinely examined in the course of general evaluation of the residential service. In 1993, the satisfaction level with the standard of care and facilities was high, but there was a sense from some of people who had availed of the respite service that they were not made welcome by people in long-term residence. This is apparently a reflection of the view of some long-term residents who find it intrusive that new people are constantly coming and going. As a result, the respite service is constantly reviewed and appraised by the management.

xiv) Other respite services

No other respite services are provided by the Richmond Cheshire House. It is the policy of the Richmond Cheshire House to provide a holiday every year for each of the long-term residents. This can be a group holiday arranged by the residents. There is an exchange arrangement with Ardeen Cheshire Home, Shillelagh. Individual holidays are also arranged.

xv) Role of service within the context of overall respite strategy

The Richmond Cheshire House is not aware that it fits into any formalised respite strategy but it would welcome a more generalised and structured approach to respite provision. The Richmond Cheshire House would acknowledge that its contribution to the overall respite provision is very small.

3.2.6 Ardeen Cheshire Home, Shillelagh, Co Wicklow

The Ardeen Cheshire Home (Ardeen) is rurally located. It is a long-term residential unit for 25 people. It provides two dedicated residential respite places. These are for use by adults of any age. In practice, they are usually used by people under the age of 65.

i) Policy of the residential respite service

The primary goal of the respite service is to respond to peoples' needs. Ardeen has not designed the service; it is a direct response to what people ask for. The usual reasons for respite placement are to alleviate the care burden in cases of progressive illness, to give families a break, or because of illness of the main carer.

ii) Nature of placements

Crisis placement is available. This is additional to and separate from the on-going respite service. The crisis service places a substantial burden on staff and resources. The problems leading to crisis requests are never simple and involve Ardeen Cheshire Home in problem-solving at many levels. One of the main problems is that community services are virtually absent.

The main focus of the residential respite service is on planned repeated placement. There are no minimum or maximum lengths of stay, which have varied from overnight to 5 months. There is no waiting list. When seeking a respite place in Ardeen, dates are given and if Ardeen can be of assistance it will agree.

iii) Number of placements

About 40 people availed of the service in 1993.

iv) Criteria for placement

There are no criteria for placement. As a result, some people on respite placement have had very serious psychiatric and social problems. This can be disruptive of the lives of others and place strains on staff relationships.

Any source of initial contact is accepted. There is a brief standard application form used for all short and long-term placements. This requests information on the nature of the primary medical condition, the nature and extent of assistance required and the means of mobility. The facility is not publicised because it is over-run with requests as it stands.

v) Characteristics of users

There are approximately equal numbers of men and women availing of the service. The average age is in the late 30s. There is quite a range of level of physical disability. The principle medical diagnostic categories are cerebral palsy, multiple sclerosis, stroke and Huntington's disease. Most respite users live either with their mother or spouse.

vi) Type of facilities

The respite accommodation is purpose-adapted with full disabled access and use. The sleeping arrangements are in individual, 2- or 3-bedded rooms. The bathroom and toilet facilities have been improved but are insufficient. There are large communal living spaces and a workshop which provides employment for some of the residents. In addition, in the grounds there is a sheltered housing project for long-term residents of Ardeen.

vii) Services available

There is no medical review, physiotherapy, speech therapy, dietetic or chiropody service. The occupational therapist provides arts and crafts and supervises the workshop. Counselling is available and there is a coffee dock. Services such as yoga are not provided and residents may not wish for these. There is sufficient contact between the residents and the people living in the small town of Shillelagh.

viii) Meal arrangements

Breakfast is served from 9.00am, lunch from 12.30pm and tea from 5.30pm. As in all of the Cheshire Homes there is considerable flexibility regarding times of meals. Meals are served in the communal dining-room, but residents can eat in other locations if they wish. There is a choice of menu, which is devised each week by two long-term residents.

ix) Visitors

There are no restrictions on visiting and there are many areas in which visitors may be entertained.

x) Going out and transport

Excursions are arranged regularly. Due to the location of Ardeen transport is a vital necessity. A substantial portion of the annual budget is devoted to transport and allied costs. Transport is available to and from the facility and the drivers routinely go to Dublin and back to pick up people.

xi) Staffing

There are 24 full-time staff employed in Ardeen Cheshire Home. Care assistants number 12, 8 of whom are women. Extra staff are available at busy times. Staff are not assigned to an individual during a respite stay.

There are 26 people employed on social employment schemes (SES). Many of these people provide personal assistance to residents. Volunteers are welcomed and used in all capacities.

xii) Costs and charges

The overall cost per place, regardless of duration is £210 per week or £30 per day.

There is no set charge for respite services. Donations are expected and are based on means. The respite facility is not covered by the Voluntary Health Insurance scheme (VHI).

xiii) Measures of satisfaction

No attempt is made to measure consumer satisfaction in the residential respite service. Repeated stays are seen as an indication of approval. The staff have voiced distress at times regarding the respite service. The additional work-load has been considered excessive.

xiv) Other respite services on offer

Ardeen Cheshire Home has as a policy to respond to need. Advice, day respite, social activities and transport are all provided to people with physical disabilities in the area. In addition, equipment is loaned out and repaired. Lobbying for services and entitlements is undertaken.

xv) Role of service within the context of overall respite strategy

The absence of any coherent statutory policy to deal with chronic disability is seen as the primary problem, which Ardeen merely responds to as well as it can.

3.3 Additional EHB facilities

The additional EHB facilities, which are part of the Board's hospital geriatric service, listed at the start of this chapter, provide residential respite facilities which may be used by people under the age of 65. For the purposes of the present study these facilities were of peripheral interest as none of the places are dedicated for use by people under the age of 65. The questionnaire used in the present study was sent to each of the hospitals to obtain information on the use of the existing places.

Saint Vincent's Hospital Athy has 6 respite places in total for all ages, but primarily for geriatric use. **Baltinglass District Hospital** has 4 respite places in total, primarily for geriatric use. The administrator of both of these hospitals reported, for this study, that in the past year, no person with physical disability under the age of 65 was given respite placement in the respite facilities of either hospital. This did not indicate policy, but an absence of applications. Both hospitals are eager that people under the age of 65 would avail of their respite service. No publicity of the service is undertaken. Referrals to the unit are typically obtained through public health nurse or general practitioner recommendation. Both units have a commitment to provide residential respite placement for applications above and beyond their respite quota.

The administrator of **Wicklow District Hospital, Co. Wicklow** has reported for this study, that there is a single place dedicated to respite care regardless of age of the person in the hospital. There is flexibility, in that additional places can be allocated on the basis of demand. Any source of initial contact is accepted by this unit. The accommodation is based on 6-bedded and 4-bedded wards. No person under the age of 65 obtained a residential respite place in Wicklow District Hospital in 1993.

Saint Colman's Hospital, Rathdrum Co. Wicklow has two residential respite places which may be used for people with physical disabilities under the age of 65. In addition, there are 12 residential respite places, (8 for female and 4 for male users) in the hospital dedicated to people over the age of 65. Crisis placement is not available. In general placements are of two weeks duration. This facility accepts contact from public health nurses, general practitioners and medical consultants. The residential places are in a 6-bedded ward. A total of 4 people with physical disabilities under the age of 65 used the residential respite service in Saint Colman's Hospital Rathdrum, Co. Wicklow in 1993.

3.4 Summary

This chapter has detailed the number and nature of dedicated residential respite places located within the EHB area for use by adults, under the age of 65, with physical disabilities. The facilities have many features in common and some distinguishing features. Chapter 4 is devoted to a discussion of the pertinent issues.

Chapter 4: Discussion of Results

4.1 Introduction

This chapter focuses on the results of the survey of dedicated residential respite facilities within the EHB area. Comparison of the units, in so far as possible, is undertaken. General policy issues are discussed. Specific recommendations deriving from this discussion are presented in chapter 5.

4.2 General remarks

There are six facilities providing nineteen dedicated respite places for people with physical disabilities within the EHB catchment area. Almost four-fifths of the places are provided by the five non-governmental service agencies (NGOs). The provision of these dedicated places is merely a partial response to existing demand, with resulting gross over-subscription to most of the services available. This places strains on all aspects of the dedicated residential respite service provision.

4.2.1 EHB facilities

Reliance on NGO service provision is routine within the EHB. The present research highlights problems of partial use of direct EHB dedicated respite places, and non-use, or under-use, of the non-dedicated respite places based in EHB geriatric hospitals. In the face of mounting and sometimes overwhelming pressure on the NGO facilities, this is a matter of concern. In particular, **the fact that the non-dedicated places in EHB facilities are virtually unused, by the group in question, in the face of lengthy waiting lists at other facilities, requires immediate attention.** It is remarkable that none of these units advertise that they provide a service for the under-65s, although each is a geriatric hospital, with consequent supposition that the services apply to elderly people only.

It is of substantial concern that the Eastern Health Board and many other Health Boards apparently do not have a working definition of the term "dedicated" when used in the context of a residential or hospital bed. This is aligned to an under-development of the concept of residential respite placement generally within many Health Board policies. The Department of Health has a co-ordinatory role in this regard and should seek to obtain an agreed definition.

4.3 Overall numbers

There are nineteen dedicated respite places for adults under the age of 65 with physical disabilities located within the catchment area. Numbers of places for men and women are essentially equal. Elementary consideration of population variables leads to the conclusion that this number of places **is completely inadequate to provide any meaningful level of consistent service to this group.** This number of places can provide residential respite places for only a small fraction of people who might wish to avail of such a service. It is not an answer to respond to such criticism by noting the potential of use of additional non-dedicated places. This report shows categorically that such additional **non-dedicated respite places are quite simply not used for people under the age of 65 with physical disabilities.**

4.3.1 Number of places within the Eastern Health Board area

The places within the MS Care Centre are used by people from other Health Board areas. The respite services in the Cheshire Homes are available only to people within the EHB catchment area. So, although these 19 places are provided within the EHB catchment, the number of dedicated placements for adults with physical disabilities living in the EHB area is less than 19. In fact, given Deeney's (1989) data, in which over half of the sample from the MS Care Centre were from outside the Dublin region, there may be a few as 15 effective places for people with physical disabilities being used by EHB residents at any one time. Given the virtual total absence of dedicated residential respite facilities in any of the other Health Boards, serious questions must be asked about the realistic access that most people with physical disabilities in the country have to residential respite services.

The current demand for residential respite places in the four Cheshire Homes strains management and care staff and can disrupt the long-term residents. This may eventually limit or cause cessation of the

respite services in these units. It certainly places a restraint on further respite service development. The reason for these problems is that the respite service is an imposition, often taking places out of the long-term system to dedicate them to respite use and lacking realistic funding. The Department of Social Welfare Respite Care Fund is the first real attempt to address the costs of existing respite places or to encourage further development of residential respite places. **Funding of residential respite places needs to be addressed if facilities are to provide worthwhile services.** Specific recommendations are made in this regard in the chapter 5 of this report.

4.3.2 Age range inequities

In addition to the strains on places within the EHB as a result of use by people from outside the catchment area, **there are age imbalances in placements.** Specifically, while most facilities do not operate lower or upper age range criteria, extrinsic to the geriatric age division, many more of the users are over 40 years of age than under. This has serious repercussions for younger people who might wish to avail of a residential short-term break.

4.3.3 Diagnostic group inequities

Certain diagnostic groups are much more likely to obtain service than others. Of the 19 dedicated respite places available, 8 are within the purpose-run unit in the MS Care Centre. Its policy, naturally, is to give preference to people with multiple sclerosis. It is possible that, with current pressure on places in the MS Care Centre, a clinical diagnosis of multiple sclerosis will become an admission criterion. This has serious implications for equitable service provision for all groups. It is a direct result of policies which allow NGOs to provide services for specific groups, unfettered by overall health objectives. This issue needs to be addressed at statutory level.

The groups with special needs identified in chapter 2 are not well represented in residential respite placements. These include people with terminal illness, young people to the age of 30 and people with hereditary progressive disabling conditions. The reasons why these groups, reported as having special needs, are not using the service are unclear. Perhaps policies regarding medical stability or level of care-need operate to exclude certain diagnostic groups. This issue was not considered in the present research but should be addressed in any future study on residential respite services.

4.4 Throughput of users

Given an average two week stay, the 19 dedicated places give a total number of 494 dedicated single placements in a year, or 247 twice yearly placements. If the MS Care Centre maximum of three respite breaks per years were applied, 164 people with physical disabilities could have an optimum service. If the figures put forward in the interim report of the *Review Group on Physical and Sensory Disability* are used, a total of 190 people can avail of this service in any given year. It is obvious that any of these estimates fall substantially below the number of people with physical disabilities in the EHB area who might wish to avail of a respite service.

In fact, on the basis of the figures supplied for this report, some of which were estimated, a total of 516 placements were achieved in a single year in the NGO sector alone, and 563 placements in total. This shows clearly that **the existing facilities are being used to their maximum and that individual users are not receiving the on-going planned repeated placement which is to be preferred.**

The shortage of facilities, combined with absence of publicity means that many places are obtained by personal contact. This encourages channels of placement through certain sources and not others, compounding the inequities of the system. This is not a criticism of the service providers but of the overall system which allows for this underprovision to continue. There is an obvious need for co-ordination by the statutory sector.

All of the dedicated facilities have a policy of accepting all sources of contact. Admission/reservation forms are used almost universally and there is a growing appreciation of the range of information which would be of assistance in service planning. In particular, the reasons for seeking residential respite placement are of considerable potential value in long-term planning.

4.5 Nature of placements

The statutory body, the Eastern Health Board, provides a limited dedicated residential respite service for the group in question. It might be expected that this is because of underlying assumptions of the role of this service as a crisis intervention mechanism. The provision of "floating beds" in the geriatric hospitals gives credence to this view. However, the policy of the residential respite places in Saint Mary's Hospital, Phoenix Park is not substantially different from those of any of the five NGO facilities. Whatever confusion exists in central policy definition of residential respite care, all facilities providing a dedicated residential respite service are clear about the fundamental goal to be achieved.

This goal is two-pronged; temporary relief of the carer and temporary activation of the person with disabilities. The perspectives of all six facilities accept that, for this client group, usual carers are under pressure and people with physical disabilities are not involved in on-going activities. The residential respite services respond to both sets of people's needs in the best way they can. To plan services effectively in the long-term it will be necessary to ask what each group is looking for from the service and to examine how to maximise gain for both groups.

None of the NGO facilities regard crisis short-term residential care as part of their on-going respite service. It is distinct from planned respite. This indicates that the rationales for the two responses are discrete. Crisis intervention is precisely that: a response to an unexpected problem. Respite care is a response to an on-going difficulty. The service providers seek to provide an on-going reliable repeated service which people availing of it can count on in the long-term. The two distinct objectives need to be encompassed in policy and agreed by all of the facilities.

4.6 Policy of the services

Although many of the facilities do not have a stated policy on respite care, their criteria for placement give definition to their views of residential respite. These views are remarkably similar across the various different organisations and across the statutory and NGO sectors.

i) Respite care is provided to people with physical disabilities who need support and assistance but who are not acutely ill. This may well act to rule out people in terminal illness. A distinct service may be required for this group. Discussion of requirements for this group should be undertaken with the appropriate representative organisations and with such bodies as the Irish Hospice Foundation and other organisations providing home-based support to people in terminal stages of illness. In the first instance a survey of the extent of unmet need in the area should be undertaken.

ii) Severity of physical disability is not the sole or even always an important criterion for placement. Individuals vary in their ability to cope with certain problems at certain times and these variations are reflected in the care-needs and the expectations of people in respite care.

iii) Certain factors may lead to requests for residential respite placement. These include:

- the trauma of diagnosis of many conditions,
- the nature of progressive disease, whether relentless or faltering,
- the age of onset of disability, familial circumstances, age and health of main carer,
- the absence of social outlets for people with physical disabilities, a problem intimately connected with the absence of a viable transportation system.
- the impossibility of "taking a break" or holiday without personal assistance, access, transport etc.
- the planned eventual entry into long-term residential care.

Each of these different factors requires a specialised response. Staff working directly with people in respite placement should be given specific training in each of these areas.

4.6.1 Planning of services

The role of the MS Care Centre has been positive by placing residential respite services in a framework and by addressing the service as a unique entity. The approach of the MS Care Centre is one of a number of possible routes in this area. Saint Mary's Hospital, Phoenix Park collates useful personal data on their respite users. The other NGOs are aware of the need to keep figures and to

collate data on their users. Each facility is attempting to address this matter in a systematic fashion. It would be valuable, given the dearth of information in the general area, if organisations were to liaise on the information sought, so that a common data-base could be established.

The MS Care Centre is the only organisation to examine and formally present their role in respite services. All other services respond to need, but have neither the time, the staff nor the resources to consider the respite services other than as an addition to their main function. In the context of facilities examined in this report, specialisation of respite services is seen as a positive feature.

4.6.2 Statutory regulation

When almost four-fifths of any service is provided by non-statutory organisations, there should be statutory concern regarding the objectives, service requirements and control mechanisms in place. This is not the case. In fact, no concerted statutory policy is observable to the NGOs providing these services.

4.7 Characteristics of users

The findings show distinct patterns of characteristics of users. These are examined under a series of headings.

4.7.1 Age

Distinct age groupings of users were observed in the present study. There was evidence to suggest that different facilities in the Dublin area cater to different age ranges and interests.

i) Many people using respite facilities are in mid-life. They are often married, perhaps sharing the emotional strains of child rearing and problems of adolescent children. Their needs are for a quiet time out, a period of reflection, a sense that they can focus on themselves and their lives without the pressure of their usual environment. Many may rely on their spouse to provide routine personal assistance, which may place strains on both parties in the marriage. An opportunity to be apart is positive. Some of these people have developed disabilities recently; they may need to come to terms with altered circumstances and expectations. Other have progressive diseases; their time in respite care may act to assist them to adjust to gradual alterations of their physical abilities. The two larger facilities, MS Care Centre and Saint Mary's Hospital, Phoenix Park, effectively cater for this older age group.

ii) Another group are young people with disabilities. A number of factors operate to make their perceptions different from the older group. They are part of the general youth culture. Their interests are those of the young. Their views are informed by current social norms, reflected in their view of their disabilities. This group may want freedom from the restrictions of parental control or the on-going nuisance of confinement to home. Yet many of these young people have few realistic opportunities to be involved in every-day life. Their horizons are confined by absence of usable public transport, inability to get into many buildings, lack of financial resources to avail of accessible recreational or other facilities and by unemployment. The problems are particularly acute in rural areas. While residential respite care may be required for certain young people at certain times, the reality is that many young people require a range of realistic life options and services which do not include respite care. There is an urgent need to investigate the perceptions and requirements of young people with disabilities in order to plan useful services for their future.

4.7.2 Usual living arrangements

Many facilities did not keep record of this factor. Saint Mary's Hospital, Phoenix Park presented collated data for all users for 1993. This showed clearly that most people availing of their services are married. None live alone. This picture is also seen in the users of the MS Care Centre. Of interest in this regard is that the primary diagnostic group availing of the St. Mary's service is multiple sclerosis. The main users of these two facilities differ from the people using the four Cheshire Homes. For the Cheshire Homes generally, cerebral palsy is a more common diagnosis for the people using respite places.

4.7.3 Level of required personal assistance

The level of personal assistance required by people in respite places varies but is often significant. The figures from the four Cheshire Homes are representative, with about half of all respite users requiring extensive personal assistance. The level of assistance required by people in Saint Mary's Hospital, Phoenix Park suggests that this facility is virtually a specialist unit for severe disabilities. There is evidence to suggest that all facilities view extensive personal assistance need as one criterion for admission. There is an appreciation that provision of on-going assistance of this nature is a physical strain on the person providing it, often a relative, often older, often a woman, sometimes with health problems of their own. There is also a realisation that there are staffing concerns unique to the provision of service for people with severe physical disabilities.

4.7.4 Diagnostic criteria

The major groups serviced by residential respite care are people with multiple sclerosis and cerebral palsy. The natural history of these diseases is entirely disparate. It may be that facilities are providing services suited to these groups. This may leave other groups less well catered for, e.g. young people with acquired physical disabilities. This entire area needs further investigation.

4.8 Type of facilities

Each of the facilities is purpose-built or purpose-adapted. All provide wide-ranging access and use for people with disabilities. The facilities are designed to give a sense of comfort, ease and security to people in wheelchairs and with other mobility difficulties.

A number of the respondents commented that specialised equipment was not the most important factor, rather design, space and access were the keys to providing an acceptable environment for people with substantial mobility difficulties. This raises questions regarding the acceptability of the home conditions of people in wheelchairs or with other mobility difficulties. Grant assistance is provided for modification of a room and provision of bathing and toilet facilities. The rest of the house, with door-widths insufficient for wheelchairs, room sizes inadequate for turning, impossibility of gaining access to upper floors, can mean that moving around at home potentially becomes an obstacle course. The statutory assistance to people with disabilities should take account of this and make a serious financial commitment to improving the living conditions of people with substantial physical mobility disabilities.

4.8.1 Services available

The facility providing the largest range of services is the MS Care Centre. People using the MS Care Centre utilise the choices open to them. None of the facilities provides acute medical services, reflecting the underlying ethos of the respite service and the requirements that the person availing of the residential respite place is not ill. Provision of physiotherapy, occupational therapy and other paramedical services is routine in many of the facilities. Service users consider these therapies worthwhile. This begs the question as to whether people with disabilities receive or wish to receive on-going therapy while they are at home. The evidence from the present study indicates that few people receive on-going therapy while at home.

There is a growing trend away from the "sick role model of disability". The non-medical orientated approach to disability will become increasingly prominent in the next number of years, with ramifications for all existing services. This approach is likely to gain ground with younger people with physical disabilities with consequences for the future of many existing services.

4.8.2 Flexibility of the regime

i) Meal arrangements

The times of breakfast in the residential respite facilities are best described as civilised. The early evening meal times are apparently preferred by many people with disabilities. Views vary regarding the benefits of room service meals or dining-room facilities. This is partly related to age, with young people often enjoying a shared meal more than other older residents. Clearly, the extent of eating difficulties is relevant in this regard also. There is flexibility regarding different food preferences in all of the facilities.

ii) Visiting

All of the facilities have an open policy on visiting. This does not give rise to appreciable difficulties.

iii) Going out

Many people with physical disabilities are confined to their homes due to access and transport difficulties. All of the facilities make efforts to include excursions as part of the residential respite service. For many of the respite users it is true to say that they go out more when in respite than when in their homes, giving an indication of their poor quality of every-day life. A feature of the Cheshire Homes is their organisation of annual holidays for their long-term residents.

iv) Transport

A major lack in many of the NGO services is transport to and from the facility for the respite user. This is an issue which requires remedy. Transport for expeditions is not always available in the facilities. The Cheshire Homes, in particular, address this issue for their long-term and respite users, with funds, vehicles, volunteer and paid drivers. As a general remark, transport is cited again and again as an overwhelming constraint on the lives of many people with physical disabilities.

v) Overview

Each of the facilities attempts to provide a relaxed atmosphere in which a range of options is available for daily activities. Models of good practice exist and valued features should be incorporated in any future additional respite places.

4.9 Staffing

Exact comparison of staff ratios between the various units is complicated by the fact that the operation of most facilities does not allow for discrete measurement of staff time devoted solely to residential respite users. Only one unit is a respite unit uniquely (MS Care Centre). All other units use their general staff to cover the respite facility. It is apparent that staff in the long-term residential units provide assistance to all residents on the basis of schedules and needs. As a result, it is not possible to make direct comparison between services on the provision of staff. Alternative means of examining this general issue should be considered in any further research.

4.9.1 Care staff

In almost all of the units there is a relative balance of female and male care staff. All of the units make some effort to roster staff to provide additional peak-time cover. Saint Mary's Hospital, Phoenix Park is the only unit which assigns individual members of staff to individual residential respite users. A number of the units stated that there were staff shortages. In addition to the need for adequate numbers of staffing, the training and support to care staff should be maximised. Providing care to people with severe physical disabilities can be a demanding role for staff. All of the units were aware of the need to train and continue in-service development of staff skills. Training and in-service development should be mandatory for all respite care staff, to encourage a comprehensive care ethos and a consistent practical implementation of underlying philosophy in each unit.

The Richmond Cheshire House provides personal assistants to some of its long-term residents to facilitate training and employment. The use of such a scheme for short-term residence hold substantial possibilities and should be investigated. Issues arising include training and certification of personal assistants, employment models and ranges of options open to people in utilising such schemes.

4.9.2 Social employment schemes

An interesting finding of this research was the large number of people working on social employment schemes (SES) in the sector. In total over 70 individuals are involved. Additional services and personal assistance are provided through these schemes to people in respite placement. The potential of these schemes in the general area of disability and in respite service is enormous. Consideration should be given to training of respite service workers within present programmes of care assistant training.

4.9.3 Volunteers

All of the units are aware of potential privacy, dignity and legal problems associated with volunteer involvement. Some of the organisations are more reliant on volunteers than others.

4.10 Costs and charges

Many of the costs cited in this report are notional estimates, based on the figures for entire units.

The range of costs is wide. There are many reasons for these discrepancies. Principal among these are the range and frequency of services and staffing levels in the different facilities. Ranges of services are typically more extensive in the more costly units and many of the services employ relatively specialised staff, with consequent increased costs. A number of the units specifically commented on staff shortages. Adequate staffing levels in these units would clearly lead to increased costs.

The facilities vary from old buildings to new purpose-built accommodation. The standard of accommodation varies but is only one consideration in terms of cost.

It is apparent that provision of residential service per se (as opposed to extensive optional services) can be provided at reasonable cost within the context of moderate-sized residential units. The fact that residential respite care is being provided at this cost begs questions as to the range and extent of other services which could be provided for a similar cost. Residential respite care of the type provided by the Cheshire Homes may be an inexpensive option for health service planners, in addressing certain of their objectives. The present report has shown that acceptable residential respite services may be considerably less expensive than is often suggested.

4.10.1 Comparative costs of other services

Having obtained costings on residential respite services, the costing of other services should be addressed. What are the relative costs of short-term residential placement in comparison to other non-residential services, respite-focused or otherwise? This important issue requires consideration in the debate on further provision of residential respite places.

Pilot projects of alternative service provision should be contemplated, perhaps confined to certain age groups or within a geographical area. In this regard, the groups identified as particularly in need of services might be targeted. For example, a small project using personal assistants for short periods to give young people with physical disabilities experience of everyday life would be valuable. Such an approach could act as a baseline investigation of this approach. The bases for training for such a scheme exist both within the residential service and external to it. The positive potential for employment of assistants is obvious. The European Union programmes of Horizon and Helios may offer access to suitable models. National, regional and local innovation may be equally appropriate. Initiatives organised by people with physical disabilities should be actively promoted. It is time for innovative responses to the on-going problems of people with disabilities.

4.10.2 Funding of residential respite places

All of the residential respite places examined in this report are funded in substantial measure, if not in entirety, by statutory funds. Yet, particularly in the Cheshire Homes, this funding is not dedicated to respite services, but comes from general budgets designed to fund long-term residential care. The respite care fund of the Department of Social Welfare is the first attempt to provide funding for residential respite care in these facilities. The NGO facilities described in this report received a combined total of £35,000 from the Respite Care Fund, £20,000 of which went to the MS Care Centre. This amount should be increased in future allocations if the operation of the fund is to have a genuine impact on residential services for people with physical disabilities. Separate budget headings within the Respite Care Fund for residential and non-residential services may be valuable in future.

4.10.3 Charges to residential respite users

All of the facilities are aware of the potential burden of costs on people using the residential respite facilities. Nonetheless, all of the Cheshire Homes have introduced or are considering basic weekly charges for their respite service. This reflects growing costs and inability to rationalise using funds

supposed to be for other services for respite. The only service which is free at the point of delivery is in Saint Mary's Hospital, a directly funded EHB facility. This creates an inequity within the overall service. The role of the Voluntary Health Insurance scheme is limited, confined to the MS Care Centre. Individual representative organisations contribute varying sums to assist their members to avail of existing services. Their commitment to residential respite service needs to be recognised.

4.11 Measures of satisfaction

The MS Care Centre is the only unit which collects extensive raw data on measured levels of satisfaction. It is apparent from their figures that they provide a popular service which satisfies the need of residents at a number of levels.

It is acknowledged that for many of the units the compilation of data poses an additional administrative burden. Nevertheless, it is recommended that an organised approach to measuring satisfaction should be instituted in all the units. Statutory funding should be sought for this. The financial outlay is relatively small, comparative to the gains in baseline information. Without such information it is not possible to provide a comparative analysis of level of satisfaction with the various units. This limits discussion of value for money of the various facilities and impedes planning of any future services.

4.12 Policy issues

The individual perspectives of administrators of the facilities are observed in the general comments on policy and on the contribution of the facilities to an overall residential respite strategy within the EHB area. It is apparent that the role of the service in Saint Mary's Hospital, Phoenix Park is seen as being integrated into a coherent approach to community service to people with disabilities. This sense of place is virtually absent from the NGO facility administrators. **Many of these facilities view their service as a minimal exercise in containment of a potentially explosive situation.** Their perception of isolation needs to be addressed at Health Board policy level.

A notable absence of objective documentation pervades the subject. **There is an urgent need for baseline research,** of which the present report is an initial example.

4.13 Examination of extent of current demand for residential respite services

4.13.1 Estimates of current demand

No estimate of the percentage of people with disabilities availing of the service can be provided as national or individual Health Board area figures on the numbers of people with disabilities are unavailable. The extent of desire to use the facilities can be measured, on the basis of present knowledge, only by the length of the waiting lists. In a number of cases waiting lists are not kept because they become too long. Lengthy waiting lists probably mean that some people do not bother to place their names on the lists. Most of the facilities deliberately avoid publicity fearing a deluge of requests. This suggests that people seeking respite placement at the moment are by no means the only people interested in the service. It is apparent that **existing dedicated residential respite facilities are unable to cope with demand.**

4.13.2 Number of places required for current demand

The number of places available at the moment is totally inadequate. No-one knows how many residential respite places are needed to cope with present demand. Existing services are not addressing the problem in any consistent way and increased provision is required immediately to satisfy demand.

4.13.3 Reasons for seeking placement

The reasons why people seek residential respite places have not been examined systematically. It is apparent that reasons affecting carers and the people with disabilities may or may not coincide. Research into who seeks residential respite, and the reasons why, simply has not been done.

4.13.4 More places now?

One of the questions asked of this report was whether more residential respite places are needed. The answer is an unequivocal yes. How this should be achieved is less clear. Who can provide places of a calibre of those already in existence? Which groups are best served by these types of placement? Would some groups find other types of services more or less successful? What are the features that distinguish successful youth-based or other services? Answers to these questions are tentative.

The problem is, as always, that no-one knows what people want because no-one has asked them. The suggestions of the interim report of the *Review Group on Physical and Sensory Disability* that additional respite places should be "dedicated" within selected nursing homes etc. may be suitable in some cases of physical disability. We do not know. This plan should not be recommended until an identification of which groups affected by physical disabilities would benefit from and wish for such service.

Use of places in designated nursing homes is entirely unsuitable for many of the groups under discussion here and should be opposed by and for them. That places should be dedicated for use, in units not designed to cater for the needs of people with physical disabilities, brings the issue back to where it began; the provision of temporary relief to the carer regardless of the experience of the person using the respite place. High-minded evocation of principles of independence or self-determination are refuted utterly by broad-stroke proposals of this type. The pressures which lead to proposals of this kind ignore the fact that unsatisfactory services create a momentum of frustration and demand which in turn will need to be addressed. To advocate more places regardless of their nature shows elemental incomprehension of the problem.

The interim report of the *Review Group on Physical and Sensory Disability* acknowledges that at least some of the pressure to provide respite services results from lack of supports to the people in question. Rather than stop-gap solutions, the underlying cause of the current demand should be tackled. In the short-term, targeting of resources to people not receiving any assistance at the moment should be a priority. This should be associated with baseline data collection. In the short- to medium-term, alternatives to and variations of residential respite placement should be examined. This should include promotion, adaptation and use of holiday facilities. Non-residential options of provision of personal assistants on a limited basis should be investigated.

A systematic investigation of the situation of people with a wide range of physical disabilities across a varied age range should look at preferred options of both people with physical disabilities and people who usually care for them in terms of respite care and its alternatives. This should permit accurate figures for the first time of numbers wishing to avail of respite services and provide data on the extent and type of services desired.

4.14 Future demand for residential respite services

4.14.1 Inability to predict numbers

There is no objective database which permits prediction of the numbers of people potentially seeking residential respite services in the EHB or the country at large in the next decade. This does not preclude statements as to potential scenarios and likely outcomes.

4.14.2 No change, more demand

Calls for residential respite services are, in part, a direct result of absence or insufficiency of non-residential services and of realistic opportunities to participate in the social life of the community, for two different client groups, people with physical disabilities and people currently expected to provide on-going unpaid physical, emotional, financial and social assistance to them. If non-residential services and levels of integration remain at their current level, then calls for residential respite services will become uncontainable.

4.14.3 Two potential sources of progress

There are two key groups in this debate, the Health Boards and the NGOs. Each of these may decide to respond to existing demand for residential respite services in a number of ways. Each may decide to do nothing. However, the problem will not go away.

Each may decide to provide more of the existing services. This will require up-grading and dedication of existing facilities and provision of attendant services for respite users.

Each may decide to adopt new policies aimed to target the cause of calls for respite services.

4.14.4 Possible statutory responses

Statutory bodies may decide to continue to allow the circle of demand to bulge. This may lead to political pressure which will result in decisions designed to appease rather than address the problem. Statutory bodies may act on their own analysis that current demand for residential respite services stems from lack of non-residential services. This may lead to increased provision of non-residential services. An economical response is to identify the requirements of people with physical disabilities and to address them directly.

4.14.5 Possible NGO responses

Only one of the existing NGO residential respite services is likely to increase the number of places, namely the MS Care Centre. It is possible that a number of NGOs might provide additional residential respite places. Such residential places could be funded either privately or through statutory means. However, there are a number of negative aspects. Such provision might be limited to particular groups. Weaker, smaller groups may never be able to provide residential respite services for their members. Such service(s) may be geographically inequitable, since economies of scale may be perceived to be possible only in Dublin. Further inequity in the system is to be avoided. Most important, concentration on this form of respite care may mean that other responses to the needs of the carer and of people being cared for will be overlooked. **It is vital that any further services are an effective use of limited resources, providing services required by all people directly affected by substantial physical disability.**

4.15 Policy choices

For statutory services and NGOs there is a clear policy choice. More respite services can be provided. This will continue the existing cycle of demand and provision. Alternatively, serious recognition of the wider issues and positive moves forward in terms of integration and provision of required services may decrease overall need for residential respite services while increasing the quality of life of both the people currently expected to care and the people society expects to be cared for.

The driving force behind health policy in the last 25 years has been to avoid residential care because it is so expensive. The present report shows that providing an acceptable quality of life to people with physical disabilities and to those people who care for them requires substantial expenditure. This financial outlay has benefit in terms of social gain. Policy makers and service providers have two options - to increase existing services in partial response to demand or to move forward into a new era in which people with physical disabilities are no longer shut up at home.

Chapter 5: Recommendations

5.1 An agreed definition of residential respite care

Much of the confusion regarding the quality and delivery of respite services stems from the absence of a clear agreed definition of the nature and purpose of residential respite placement. *The Commission on the Status of People with Disabilities* should address this issue with the intention to create a comprehensive definition of respite services, including residential respite care to give effect to the perspectives of people with disabilities and carers and to set standards for service provision. The present report provides a descriptive framework for the formulation of such a definition.

The matter of a clear definition of respite services should also be addressed by the *Review Group on Physical and Sensory Disability* final report. It is important that this group clarifies its view of the purpose of residential respite care. If there is to be real improvement in the delivery of respite services then the current linguistic and service obfuscation of the importance of dedicated services for this group must be clarified.

Any revised definition must be accepted by all Government departments involved. The implications of the definition for the type, extent, funding principles and rationale of services need to be identified. In particular, the Department of Health must insist on clarity of definition within all the Health Boards so that basic information such as the number of dedicated respite places for any given group can be obtained.

5.2 Structures in respite care

At the moment respite services are controlled through the Department of Health, are operated by Health Boards and NGOs and who in some cases are part-funded by the Department of Social Welfare. It is important that these bodies tease out their various motivations and come to a coherent structure which focuses on the social gain to be obtained through effective targeting of respite care. Specifically, it is important to decide whether respite care is a health, community care, social welfare or common good issue. This debate is timely in view of the notions of partnership between statutory and NGO operators.

5.3 Places and options

The Eastern Health Board needs to re-evaluate its position regarding its purported respite service provision. In particular the virtual total absence of use of all the places in the geriatric hospitals should be reviewed. If these places are to be a response to the existing situation, they must target their supposed users ie people with physical disabilities under the age of 65. On the basis of the present study it is probable that these places would suit a relatively older age group, perhaps from 55 years upwards. The EHB should advertise these places, not only in the locality but also further afield. People on the waiting lists for existing facilities should be offered immediate accommodation in these units, with transport to and from their homes. For these places to be of any relevance or they must be used.

The Eastern Health Board should immediately address the inequities of service provision in terms of age range distribution, types of disabilities and geographical spread. It may be preferable to focus on non-residential services to these groups in the first instance. This would allow for identification of the target group and examination of their requirements in terms of residential or other respite services.

Each Health Board should immediately identify a number of places within suitable accommodation and with appropriate services as dedicated residential respite places for people with physical disabilities under the age of 65. Health Boards need to address the requirements of people with physical disabilities as a unique group. Central to any analysis must be plans to provide an effective transport service for people with physical disabilities. An important issue is the active promotion by all Health Boards of their existing respite facilities and services.

Statutory requirements regarding training and qualification for care staff, with specialist respite training should be initiated. The **Department of Health** has a central role to play in this area. The **Department of Enterprise and Employment** also has a role in terms of training within the ABR areas.

5.4 Financial matters

5.4.1 Funding of residential respite services

It has proved difficult to assess the current level of investment in residential respite care due to the absence of separate budgeting for the scheme by providers. Funding of services in the long-term is dependent on the Health Boards;

- i) devising policy on respite care;
- ii) devising a programme of provision to give effect to this policy; and
- iii) devising a package of provision, grants and incentives to support the service over time.

Each of these requirements demands action from the statutory sector.

5.4.2 Department of Social Welfare involvement

The **Department of Social Welfare** in setting up the Respite Care Fund has, in part, cushioned **Health Boards** from their responsibilities in terms of funding of both residential and non-residential respite services. The **Department of Social Welfare** should seek to develop a niche for itself with respect to funding of projects designed to alleviate the burden on *carers* in the first instance. This would give the Department an important and discrete role, in keeping with its mandate. In the first instance, the projects under the first scheme of the Respite Care Fund should be analysed in terms of how the money was spent, value for money and focus. This analysis should be published as soon as possible in order to assist an informed debate. Deriving from that a series of overt aims for the fund should be set up. Separate funding of residential and non-residential schemes should be considered. In particular, the **Department of Social Welfare** should consider funding holiday schemes run by the NGOs in the field. There is a need to address holiday provision for people with physical disabilities.

5.4.3 Voluntary Health Insurance involvement

The Voluntary Health Insurance Scheme (VHI) should make clear its policy on respite funding and include facilities not currently covered. Voluntary Health Insurance input to residential respite services could be valuable in identifying optimal services standards and encouraging a range of choice.

5.5 Non-residential respite services

A clear outcome of the present research is that demand for residential respite services is, in part, the result of gross inadequacy of non-residential service, both respite-focused and otherwise, for people with physical disabilities. The services most requested are that of home care attendance and home-help. The **Eastern Health Board** should address this matter immediately by the provision of home-based assistance to people with physical disabilities and their families. Specific targeting of uniquely needy groups should be considered, particularly families with more than one member with a disability and people in terminal stages of illness. This recommendation applies equally to all other **Health Boards**.

5.6 Research priorities

The questions surrounding one small facet of services for people with physical disabilities, namely residential respite provision are wide-ranging, numerous and almost entirely unanswered. On the information/research side we must have baseline quantitative and qualitative information.

5.6.1 Numbers of people with physical disabilities

The number of people with physical disabilities must be counted. Data must be obtained on the numbers within diagnostic categories and on the individual extent of necessary personal assistance in order to plan realistic services for the different life patterns of people affected by physical disabilities. We must be able to identify families and individuals with exceptional problems. The number of people involved in on-going unpaid care must be obtained.

5.6.2 Optimal respite services

In the context of the present study, information is required on the attitudes of people with physical disabilities to residential respite placement. What do the different age groups want to do and how do they want to do it? Information is also urgently required on the preferences of carers regarding respite services. The **Department of Health**, the individual **Health Boards**, the **Department of Equality and Law Reform**, the **Department of Social Welfare** each have a potential involvement in commissioning research. Research should also be undertaken of other countries' responses to the problems associated with physical disability.

It should be observed that a number of the Health Boards have commissioned in-depth reports on current and potential services for groups such as people with mental handicap. Each of these **Health Boards** should be encouraged to provide an equivalent analysis for people with physical disabilities in their catchment area.

5.6.3 Specific projects

The number of possible specific research projects of is so vast as to preclude presentation here. A number of suggestions were presented in chapter 4 of this report:

- i) Pilot studies of the use of personal assistants for people with physical disabilities;
- ii) Investigation of relative access of different groups to existing respite/general services;
- iii) Comparative costings of residential and non-residential services to people with physical disabilities;
- iv) National baseline research of respite services.

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Appendix I

List of all individuals and organisations contacted in the preparation of the present report

Kevin Barrett, Winged Fellowship Trust
 Vera Manning Barrett, Saint Mary's Hospital, Phoenix Park
 Winifred Bligh, Alzheimer's Society of Ireland
 Ger Boland, Saint Michael's House
 Claire Brazil, Abode Hostel and Day Centre, Cork
 Edward Buckingham, Rathfredagh Cheshire Home, Newcastle West, Limerick
 Kieran Buckley, St. Vincent's Hospital, Elm Park
 Veronica Canning, Arthritis Foundation of Ireland
 Aine Casey, National Multiple Sclerosis Care Centre
 Anne Colgan, Department of Equality and Law Reform
 Sheila Collier, Polio Fellowship of Ireland
 Clare Creedon, Friedreich's Ataxia Society of Ireland
 Tim Creedon, Friedreich's Ataxia Society of Ireland
 Carol Cuffe, Eastern Health Board
 Mary Darragh, Irish Association for Spina Bifida and Hydrocephalus
 Theo Davis, Volunteer Stroke Scheme
 Jim Doyle, Eastern Health Board
 Mary Doyle, Saint Mary's Hospital in Baldoyle
 Derek Farrell, Disabled Drivers Association
 Mary Fox, CASA breakhouse
 Eithne Frost, Irish Motor Neurone Disease Association
 Frank Goodwin, Carers Association
 Nora Greene, Eastern Health Board
 Des Hanrahan, Saint John of God's, Drumcar
 Pat Healy, Building Control Section, Department of Environment
 John Hempenstall, Eastern Health Board
 Catherine Hickey, Muscular Dystrophy Ireland
 Eamonn Hunt, Eastern Health Board
 Judith Ironside, Soroptimist International Republic of Ireland
 Angela Kearns, Rehabilitation Institute
 Noreen Kearney, Department of Social Studies, Trinity College Dublin
 Eleanor Kelly, Saint Michael's House
 Mark Blake-Knox, Cheshire Foundation
 Joe Larragy, Council for the Elderly
 Vicki Lloyd, Multiple Sclerosis Society of Ireland
 Christy Lynch, Kare Association
 B. Maguire, Cystic Fibrosis Association of Ireland
 Bay Manally, Central Remedial Clinic
 Eamonn Martin, Focus Housing
 Eddie Matthews, Eastern Health Board
 Catherine McCann, Baggot Street Community Hospital
 Bernie McDonnell, Richmond Cheshire House, Monkstown
 Pauline McHugh, Cara Cheshire Home, Phoenix Park
 Mary McMahon, Soroptimist International Republic of Ireland
 Laura McQuillan, Caring and Sharing Association
 Geraldine McSwiney, Social Work Department, Royal Hospital Donnybrook
 Tom Mernagh, Eastern Health Board
 Bernie Moran, Huntington's Disease Association of Ireland
 Brian Mullen, Department of Health
 Barbara Murray, National Rehabilitation Board
 Martin Naughton, Center for Independent Living, Carmichael House,
 Elizabeth Nicholson, Elizabeth Nicholson Home Care Agency
 Paddy O'Brien, Headway, National Head Injuries Association
 Maurice O'Connell, Barrett Cheshire Home
 Bryan O'Flaherty, Headway, National Head Injuries Association
 Frederick Oluwele, Center for Independent Living, Carmichael House

Erica O'Meara, Volunteer Stroke Scheme
 Gregory O'Reilly, All Ireland Children's Hospice
 Jane Perrin, Cerebral Palsy Ireland
 Eileen Quinn, Social Work Department, St. James Hospital, Rialto
 Suzanne Quinn, Department of Social Studies, University College Dublin
 Alison Ryan, Abode Hostel, Cork
 Gerry Ryan, National Association for the Mentally Handicapped of Ireland
 Cherry Sleemann, Cerebral Palsy Ireland
 Frances Spillane, Department of Health
 Tom Stevens, Polio Fellowship of Ireland
 Pauline Synott, Marino Clinic, Bray
 Mervyn Taylor, National Social Service Board
 Jarlath Tunney, Ardeen Cheshire Home
 Maria Walls, Saint Michael's House
 Patricia Noonan Walsh, Saint Michael's House Research
 Robin Webster, Age Action Ireland
 E. Weir, Superintendent Public Health Nurse, Eastern Health Board
 John Wilson, Irish Hospice Foundation
 Anne Winslow, Irish Wheelchair Association

Organisations contacted for general information

Baltinglass District Hospital
 Bru Chaoimhin, Cork Street
 Clochan House, Tullamore
 Clonskeagh Hospital, Vergemount
 District Hospital, Ballina
 District Hospital, Swinford
 Forum of People with Disabilities
 Lorrequer House, Goatstown
 National Council for the Blind
 Order of Malta
 Open Door, Bray
 Sacred Heart Home, Castlebar
 Saint Brigid's Home, Crooksling
 Saint Clare's Home, Griffith Avenue
 Saint Colman's Hospital Rathdrum
 Saint Vincent's Hospital Athy
 Wicklow District Hospital

Appendix II**List of the representative organisations contacted in the course of the present research to complete the questionnaire on residential respite services, policy and development**

Arthritis Foundation of Ireland*
Cystic Fibrosis Association of Ireland*
Friedreich's Ataxia Society of Ireland
Headway
Huntington's Disease Association of Ireland
Irish Motor Neurone Disease Association
Irish Wheelchair Association
Multiple Sclerosis Society of Ireland
Muscular Dystrophy, Ireland
Polio Fellowship of Ireland
Volunteer Stroke Scheme

- these organisations did not view residential respite services as relevant to their membership and did not complete the questionnaire

Appendix III

Questionnaire used with selected representative organisations to ascertain their views on respite services, policies and potential development

NAME OF ORGANISATION:

1. Numbers

How many members does your organisation have?

Is this a national spread?

Are there regional groups or regional contacts?

2. Representation

Is your organisation an organisation of carers or people with disabilities?

3. Funding

Where do you obtain your main source of funding?

Do you receive flag day donations

corporate donations

Health Board

Department of Social Welfare

National Lottery

People in Need

other funds (please specify)

How much do you have available to spend in toto each year?

How do you spend it? (accounts if available)

4. Staffing

Do you employ any staff?

fulltime

part-time

Do you run an office/secretariat?

5. Aims and objectives

What are the stated aims of your organisation?

6. Publications

Do you have available?

general information

publicity material

newsletters

annual reports

policy reports

other documentation

(please supply copies)

7. Activities

What do you do to further your aims?

lobbying groups (which ones, by what means)

general public information

seminars

provide services:

counselling

financial assistance

research

other

8. Respite care:**a) Policy**

Does your organisation have stated objectives on respite care?

Has your organisation investigated the perceived need for respite care among your members?

If so, what were the results?

What is the function of respite care?

How does your organisation view the current provision of respite care for your group?

b) Utilisation of current services

Do members of your organisation use currently available dedicated residential respite care facilities?

What residential services are utilised?

(Information which you wish to remain confidential will not be published).

Health Board places

Cheshire Homes

MS Care Centre

Abode (Co.Cork)

Other dedicated respite facilities (if possible please specify which ones)

Other non-dedicated facilities (if possible please specify which ones)

What is your organisation's view of these services in terms of availability, appropriateness, cost, etc (confidentiality of criticism is guaranteed).

c) funding of respite care services

Does your organisation contribute to the costs of respite care of your group?

To what extent?

For what services? residential and non-residential

How does the provision of respite care compare with provisions of other services?

home-help

occupational therapy

appliances and aids

counselling

day activity centres

NRB services

d) Planning:

The need for respite care is accepted. For your members is this a need for domiciliary/ out of home respite?

Which groups represented by your organisation are most in need of respite?

e.g people living alone, people with severe mobility problems etc.

What are the specific needs of those groups in the context of respite care?

medical

physical environment: size, location etc.

age related

financial

other

Please set out any issues of importance for you regarding the nature of any residential respite care.

It has been suggested that calls for respite care are linked with levels of stress in everyday living of people affected by chronic disability. What measures, excepting respite care, does your organisation feel would be of assistance to alleviate this burden of stress.

Any other comments

Appendix IV

Research design and methodology

Research design

The aims of the study were:

- i) to identify the facilities providing dedicated residential respite placement for people with physical disabilities within the EHB area;
- ii) to assess the scale, nature and quality of the existing services in these facilities; specifically to;
 - identify the policy objectives of each service;
 - to find out the current number of places available in each facility;
 - to estimate the throughput of users over a given period;
 - to examine the type of respite service provided;
 - to make a profile of the clients using the services;
 - to describe the accommodation and services available to respite users;
 - to measure current levels of staffing and support;
 - to examine the costs and charges associated with respite placement;
 - to overview client satisfaction;
 - to examine the role of the existing services in the overall respite strategy and obtain any policy documents on respite care; and
- iii) to examine potential future demand for these services.

Methodology

Each of the aims of the study required methodological development. This section describes

- i) the criteria used to select facilities for inclusion in the study;
- ii) the format and underlying rationale of the investigation of the services in these facilities; and
- iii) the parameters used to consider future potential demand.

Identification of facilities

To identify the facilities of interest it was necessary to decide on the categories to be included in the research. The nature of the facilities on a number of parameters, the methods of obtaining placement and characteristics of the clientele were factors in the decision to include facilities in the present survey.

i) Residential facilities

Only those facilities providing all-year respite services were included. Other services were considered to be holiday schemes or to have idiosyncratic procedures of selection.

ii) Respite care

Designated (dedicated) respite care places for people with physical disabilities are few in number. All other places are provided on the basis of emergency, perceived need, at the discretion of authorities, on the basis of good will, or through personal contact. For the purposes of the present study, only dedicated facilities, not used for other purposes, were of primary interest. The Eastern Health Board provides respite places for use by the under 65 age group in certain of the Board's geriatric hospitals. The present study considered these in relation only to their use by people under the age of 65.

iii) Physical disability

The study differentiated between:

- a) facilities which cater for people with physical disabilities;
- b) facilities which cater for people with multiple disabilities, (physical, mental, sensory, learning);
- c) facilities which cater for people with mental disability, including dementia, but which permit use of their facility by people with physical disabilities.

The present research focused solely on facilities for people with physical disabilities.

iv) Age range

The structure of the health services separates children, adults and the elderly. As a result, services to these three groups are different. There are almost no dedicated residential respite facilities for children in the EHB area (see chapter 2, section 2.18.1). The situation regarding respite placement for the geriatric population was not of primary concern. The present research focused solely on those services for adults between the ages of 16 and 65.

This permitted identification of six facilities in the EHB area providing residential respite placement for adults with physical disabilities under the age of 65. These are listed in chapter 3.

Description of facilities

i) Method

A detailed questionnaire was devised for use with the administrator of each facility. The questionnaire used is reproduced in Appendix V. The administrator of each facility was contacted directly and the questionnaire was sent by post. The questionnaire was completed with a discussion regarding respite care.

ii) Information sought

The questionnaire centred on a number of discrete areas. The information sought and the underlying rationale are presented.

Number of places

The numbers of residential places provided, whether dedicated/floating, and whether confined to use by either sex was required as a baseline. The precise use of the places was examined to ensure that only those dedicated to people with physical disabilities were included. Due to the health service differentiation of people on the basis of age, it was deemed relevant to ensure that the residential respite places surveyed were used uniquely for adults under the age of 65.

Quantification of use

The questionnaire sought information on numbers of people availing of the places in the past year and any other figures available. Information was also requested on the extent of use over a period of a year, the length and extent of waiting lists. These measures gave some indication of the numbers availing of respite placement in a given year and of the throughput of the facilities. They permitted some preliminary estimation of future requirements.

The referral sources accepted, method of admission, form-filling and reasons for refusals of care were examined. The nature of any publicity of the service, and at what groups it was aimed, was examined. A sense of the operation of the facility was obtained in this way.

Nature of placements

The questionnaire asked whether crisis placement and planned repeated placement were available, and the average duration of placements. This gave indications as to the policy of the services.

Characterisation of users

The gender, average age, usual living arrangements, level of physical disability and principal medical diagnosis were of interest. This information gave a preliminary sketch of the characteristics of those people using residential respite facilities. Some of this information was used to identify relevant lobbying organisations whose members use residential respite services.

Type of facilities

This section of the questionnaire focused on physical characteristics of the buildings, wheelchair accessibility and disability adaptation. The sleeping arrangements, bathroom, toilet, and washing facilities were described. The questionnaire investigated meal arrangements, opportunities to go out and transport availability. In addition, the questionnaire sought to identify all the main services available to people on residential respite placement at each of the facilities. This information gave a picture of the accommodation and the services in each facility. The range of services provided in each facility gave an indication as to the ethos of the establishment. The range of services also provided a sense of the daily activity possibilities for people in residential respite placement at any given time. A question regarding other non-residential respite services provided by the facility was included.

Staffing

The numbers of staff, the use of social employment schemes and volunteers were investigated. The provision of extra staff at peak times was of interest, due to the potential assistance requirements of many people with substantial physical disabilities. This information gave insight on the level of care and general services in the facility. It was of assistance in considering the costs of the facility.

Funding issues

Costs to the facility of provision of the respite places, the source of any subventions, and the charges made to people using the places were investigated. The present research sought to obtain data on the cost of residential respite, the typical contributions made by people who avail of the service and the role and extent of statutory financing.

Measures of client satisfaction

All facilities were asked whether they measured client satisfaction for the respite service and if so, in what way. Such information gave a sense of the acceptability of the service from people who use it.

Policy issues

The primary goal of respite care service of each facility was examined. Differences between services were reflected in the different perceptions of aims. The sense of the organisation's part in the provision of respite care was considered. This sought to give a coherent view of the service as a whole. Any policy documents on respite care were requested, to contextualise the work of the various facilities. A further concern was to collate as much information as is available.

Anticipating future demand for services

The final aim of the study was to estimate the need for residential respite places for this group of people in the next 10 years. This aim involved addressing a number of discrete issues. These were:

- reasons why respite placement is sought and by whom;
- identification of other residential and non-residential services which, if available or more prevalent could decrease existing demand;
- enumeration of given categories and groups of people with physical disabilities. The time constraints of the present study, coupled with absence of baseline data precluded appropriate investigation of all of these variables.

At any early stage, it became apparent that data on any of these areas are either non-existent or when available, anecdotal or otherwise unsatisfactory. Aspects of this problem have been presented in chapter 2. Within the limits of the present study it was not possible to indicate numbers wishing to use residential respite services in the next decade. Estimation of present or future need for residential respite services required information which went beyond the scope of the present study. The absence of coherent figures was a major obstacle in achieving the final aim of the study.

A number of contingency sources were used. These were:

- i) The representative/lobbying organisations known to have an interest in respite provision were contacted and their views on a variety of issues were sought. This, in turn, raised questions as to the nature of optimal care for any particular group. A number of people with physical disabilities, individually or through their lobbying groups were asked their views on residential respite services. All of these contacts posed questions regarding services which may be required by people with physical disabilities. The outcome of these contacts has been presented in this report in section 2.17 of chapter 2.
- ii) The results from the questionnaire used with the facilities in the present study gave indications of the factors which bring about residential respite placement and the categories of people who avail of placement.

The research described in the present study was carried out between January and May 1994.

Appendix IV

Questionnaire used to examine the existing dedicated residential respite services for adults with physical disabilities in the EHB area

This questionnaire focuses on residential respite care facilities for people with chronic physical disabilities under the age of 65.

A. General information

1. Does your organisation provide residential respite care for people with physical disabilities under the age of 65?
2. a) How many places are available **in toto** for this type of care in your facility?
b) How many of these places are **dedicated**, i.e. never used for any other purpose?
c) How many are floating, i.e. sometimes used for another purpose, including geriatric respite?
3. How many are for male/female users?
4. How many individuals under the age of 65 availed of the respite service in the last year?
(If figures are available for other years please include.)

B. Nature of placements

5. Is crisis placement available?
6. Is planned, repeated placement available?
7. Are there minimum and maximum lengths of stay?
8. Is there a waiting list? of what length?
9. Are there any medical, social or personal criteria which must be fulfilled to obtain placement?

C. Characteristics of users

10. In the last year in which figures are available (please specify year)
 - a) How many men/women used the facility?
 - b) What was the average age of users?
11. Of the total numbers of users, how many, in percentage terms would have physical disabilities classified as: moderate / severe?
12. What was the principal medical diagnostic category?

<i>multiple sclerosis</i>	<i>motor neurone disease</i>
<i>Parkinson's disease</i>	<i>cerebral palsy</i>
<i>stroke</i>	<i>other (please specify).</i>
13. Of the total number how many would?

<i>live alone</i>	<i>live with mother or other older carer</i>
<i>live with spouse</i>	<i>live with child/children?</i>

D. Administrative information

14. What sources of referral are accepted by your facility?

<i>self referral</i>	<i>family referral</i>
<i>public health nurse</i>	<i>social worker</i>
<i>general practitioner</i>	<i>medical consultant</i>
15. Is there a standard admission form? (if so please provide a copy)
16. Is the facility publicised? where?

E. Type of facilities

17. Please indicate the **type of accommodation** available:
 - a) *purpose-built/ purpose-adapted buildings with full disabled access and use or other*
 - b) *sleeping arrangements: individual rooms, 2-bed rooms, larger sharing (specify)*
 - c) *bathroom, toilet, washing facilities, private or shared*
 - d) *general physical accommodation.*

18. Please indicate the **services** routinely available to people in respite care:

medical review	physiotherapy
occupational therapy	speech therapy
chiropracist	dietitian
counselling	arts/crafts
yoga	hairdresser
coffee dock/bar	shop
prayer room	reading room/library
other (please indicate any other service your facility provides).	

19. **Meals arrangements**

times of meals
where are meals served
choice of menu.

20. **Visitors**

availability of visitor's rooms
time or other restrictions on visiting.

21. **Opportunities to go out**

shopping, cinema, theatre, pub, other.

22. **Transport**

availability to and from your facility/for expeditions.

F. Staffing

23. How many staff (or time equivalents) are employed in the respite care facility?

full-time part-time

24. Are extra staff available at busy times, e.g morning and evening?

25. Are staff assigned to individuals for the duration of that individual's stay?

26. Are any staff employed on social employment schemes?

27. Are volunteer helpers used?

G. Funding - costs, charges and subventions

28. What is the cost to the user of the respite care service?

29. Is the respite care facility covered by VHI?

30. What are the typical means of subvention from Health Boards or other sources?

What is overall cost to you?

H. Measures of satisfaction

30. Does your facility try to measure the level of satisfaction of the cared for person/
of the carer?

J. Other respite services on offer

31. Does your facility provide other respite care services for adults with physical disabilities?

If so, please specify.

32. Are you aware of any other facility in your area which provides residential respite care for people with physical disabilities under the age of 65?

K. Policy issues

33. What do you view as the primary goal of the residential respite care service provided by your facility?

34. How do you feel this contributes to the overall respite strategy in your area?

35. Has your facility produced any written documents regarding respite care policy, research or service?

Any other comments

REPORT OF ATTENDANCE AT LAUNCH OF D.F.H. REPORT Eastern Health Board

TARA TOWERS HOTEL

7 JUN 1994

7th June 1994

Received Secretariat

1. There were approximately twenty people present consisting mainly of representatives of the various voluntary organisations, such as Irish Wheelchair Association, Centre for Independent Living, Cerebral Palsy Ireland; only one identifiable press person in attendance. One representative from the Department of Health.
2. Top table consisted of Brian Harvey, Judith Kiernan and Roger Acton.
3. In my presence there were about eight questions from the floor. The principle areas addressed were :-
 - a) The lack of facilities for persons in respite care e.g. transport, counselling, training.
 - b) The lack of respite care facilities in rural areas.
 - c) The small number of places available in the Eastern Health Board area.
 - d) The lack of a data base to enable proper planning of facilities.
 - e) The need to ask the physically disabled what services they required and the subsequent provision of this service (empowerment of the physically disabled).
 - f) The need to address the relative merits of a community based service as against residential respite care.
- 4) Irish Wheelchair Association Comment :-

"Not much hope that this report will make any difference in light of previous experience."

There is no strategic plan for services for the disabled and this report should be used to agitate for a planned approach to the service.
- 5) Top table commented that this report's main aim is to influence the Review Group Report on Physical and Sensory Disability.
- 6) No direct references to the Eastern Health Board.

Tom Mernagh

7th June 1994.

Eastern Health Board

7 JUN 1994

Received Secretariat



Disability Federation of Ireland

2 SANDYFORD OFFICE PARK, DUBLIN 18.
TEL: 01 - 2959 344/5 FAX: 01 - 2959 346

PRESS RELEASE - TUESDAY 7 JUNE 1994

SHUT UP AT HOME ?

Major Study launched by Disability Federation of Ireland

A major study on Respite Care for people with physical disabilities has been published by the Disability Federation of Ireland. It is entitled 'Shut up at Home?'

This report was commissioned by the Disability Federation of Ireland as the first in-depth overview of this service area in the country.

While the primary focus of the study is the Eastern Health Board area, many of the findings could be projected to reflect the situation in the Country as a whole.

The main findings and recommendations of the report are as follows:

Findings

- those residential Respite places which are available to people with physical disability are grossly oversubscribed and inconsistently funded,
- many people with severe physical disability are confined to their homes when not in residential respite care,
- dedicated respite facilities are virtually non-existent with the result that many people must make do with services which are not designed with them in mind,

Recommendations

- an agreed definition of Respite Care is required,
- Government Departments and Agencies must develop coherent structures which will effectively target Respite Care,
- funding issues need to be clarified,
- greater development of non-residential Respite services is needed, i.e. home care attendants or home helps,
- further research is required on the requirements and preferences of people with disabilities.

Further information from:

Roger Acton
Chief Executive, DFI
Tel. 01-2853099 (h)
01-2959344 (w)

or

Judith Kiernan, Co-Author
2, Rathdown Crescent
Terenure, Dublin 6W
Tel. 01-4903039

Eastern Health Board

Further to the launch of the 'Shut up at Home?' report by the Disability Federation of Ireland the Eastern Health Board is concerned that some of the recommendations contained in the Report might mislead members of the public. Because of this and for the purpose of clarification our Board makes the following comments:-

1. The Eastern Health Board adopts a flexible approach to the provision of in-patient respite care for persons in need of the service as against having a specific number of dedicated places. Our Board considers this as the most effective and efficient way to meet the service need for respite care as it fluctuates throughout the year. In any event it would not be feasible to have dedicated respite places in small scale facilities such as in Athy, Baltinglass or Wicklow.
2. The age factor is not a criterion in the consideration of applications for in-patient respite care.
3. The Report recommends that 'the Eastern Health Board should advertise its non-dedicated respite places not only in the locality but also further afield'. Our Board is of the view that respite care should be provided as close as possible to their own homes for those in need of the service.

Our Board also wishes to point out that all the community based staff, e.g. community care personnel, General Practitioners, etc. are fully aware of the various types of respite care (e.g. in-patient, day, home based) currently being provided by or through our Board. In this way people in need of respite care are directed to the most appropriate level of care to meet their need at any particular time.

4. The Report recommends that 'the Eastern Health Board should target non-residential respite assistance specifically home care attendants and home-helps to the needy groups identified'

There is an inference in this recommendation that these home-based community services are not being provided. The full range of community support services, including public health nurses, social workers, physiotherapy, home-helps, etc., are available to all persons in need including persons with physical disability. These services are in fact 'non-residential respite' services and, needless to say, are critical in meeting the respite service needs of disabled persons.

Eastern Health Board

7 JUN 1994

Received Secretariat

5. The Eastern Health wishes to point out that it's directly provided day-care services throughout the Board's area are open to disabled persons.
6. Throughout the Report, focus moves from the Eastern Health Board area to other Health Board areas and as a consequence may prove confusing to some of it's readers. There also appears to be some confusion in the Report in relation to the approach to be taken with regard to the provision of respite services to physically disabled person in the over 65 age bracket.

- The Report is apparently based on the findings of a questionnaire only. It is not therefore considered to be sufficiently comprehensive and as a consequence must be regarded as somewhat flawed (e.g. no reference made to the Irish Wheelchair Association day care facility on the grounds of St. Vincent's Hospital, Athy or the Fr. John Sullivan Centre in Clane, Co. Kildare).
- The Eastern Health Board has always welcomed positive constructive criticism. However this Report is regarded as falling somewhat short in this regard.
- The Report is not very helpful in the identification of unmet needs in our Board's area.