aged at least 75 years - that the rapidity of change is most evident with an increase of over 20 per cent predicted among this group between 1981 and 2006. It is among the 'old elderly' that significant levels of functional impairment become evident and it is this group also who use a disproportionate amount of services. Not only are more people living into old age but there is an increasing tendency for elderly people to be living alone. While, in 1981, 18 per cent of the elderly lived alone, by 1986 this figure had increased to 21 per cent and projections for the period 1981 to 2006 predict a growth of 31 per cent.

In addition to the increasing number of elderly in the population there are other demographic changes which also have implications for future policy in relation to the older age groups. Factors such as the decline in family size, the increase in the number of women working outside the home and greater mobility leading to greater geographical distance, decrease the amount of family care and support potentially available to elderly people.

Need for Care
Stereotyped assumptions, which portray old age as one of inevitable decline, deterioration of mental abilities and increasing dependency, have been contradicted by research. Most elderly people especially the 'young elderly', live full and independent lives in the community (78%) with about five per cent needing institutional care. Among the 'old elderly', however, levels of disability and incapacity rise rapidly and, concomitantly, the need for care and support rises. Research shows, for example, that whereas about 10 - 15 per cent of the general population over 65 years suffers from dementia, the figure rises to over 20 per cent among those aged 85 years or more.

Recent research indicates that in the Republic of Ireland 66,300 elderly people are at least partially dependent on help and require some level of care. Some 36 per cent of these elderly
require 'a lot' of care and almost 77 per cent receive their care from a household member.

A Community of Caring
Current Irish policy with regard to the elderly emphasises community care. A distinction is often drawn between the 'formal' and 'informal' sectors within community care; with the formal sector referring to organised statutory services and some private and voluntary activities and the informal sector including care by family, friends, and neighbours. Ideally, a community of caring involves partnership between all those involved with the elderly; with the formal sector providing the necessary back-up and support services in the community for the informal carers who are the mainstay of community care. Commitment to community care would suggest that community-based services, such as social worker support, home-help, meals-on-wheels, chiropody and transport services and day care centres, would expand to keep pace with the increasing number of elderly. In practice, however, community care essentially means care in the community by families, friends and neighbours with little or no formal support or recognition. Female relatives, in particular, bear the major brunt of providing the support and care that enable elderly people to remain in their home environment.

The Policy Framework
Two major benchmarks in the development of policy in relation to care of the elderly are the Care of the Aged Report published in 1968 and The Years Ahead brought out twenty years later in 1988. Both documents emphasise that services for the elderly should be geared towards enabling them remain in their own homes for as long as possible. The first report put forward the following objectives for services for the elderly:

(a) to enable the aged who can do so to continue to live in their own homes;
(b) to enable the aged who cannot live in their own homes to live in other similar accommodation;
(c) to provide substitutes for normal homes for those who cannot be dealt with as at (a) or (b);
(d) to provide hospital services for those who cannot be dealt with as at (a), (b) or (c).

The emphasis on keeping the elderly in their own homes is again evident in *The Years Ahead* which lists the following as the appropriate objectives of policy in relation to the elderly:°

- to maintain elderly people in dignity and independence in their own home;
- to restore those elderly people who become ill or dependent to independence at home;
- to encourage and support the care of the elderly in their own community by family, neighbours and voluntary bodies in every way possible;
- to provide a high quality of hospital and residential care for elderly people when they can no longer be maintained in dignity and independence at home.

**The Elderly as a Heterogeneous Group**

Elderly people are frequently viewed in a way which lumps them together as if they formed one group. Research shows, however, that the elderly do not form a homogeneous group. It needs to be recognised that age differences between, for example, those aged 65 years and those aged 85 years are at least as significant as those between children and teenagers or between people in their twenties and those in their forties. Accordingly, a range of care options needs to be made available which caters for the varying needs experienced by those over 65 years of age.

**LITERATURE REVIEW**

To date, no research has been carried out in Ireland which specifically explores the extent of unmet need from the view of the elderly themselves. However, previous research on different
aspects of care of the elderly has indirectly identified various areas of unmet need. This section presents findings from the existing literature which have implications for care of the elderly with particular regard to the area of Family and Personal Support Services.

Overlap Among Needs

One of the impressions which emerges from the literature is the difficulty of neatly compartmentalising needs where the elderly are concerned. For example, in achieving the aim of enabling the elderly to maintain an independent life in the community, health needs and housing needs are very much interconnected. Clearly their state of health has major implications for the capacity of the elderly to remain in the community but health is greatly influenced by housing. Poor housing exacerbates problems arising through handicap and decreasing functional ability. In addition, since many elderly people spend a great deal of time in their own homes, the condition of the dwelling is likely to affect their psychological well-being as well as their physical health. The effect of disability and ill-health on the ability to get out and about may also be either alleviated or exacerbated by the elderly person's access to transport. It is also clear that isolation and loneliness may have deleterious effects on the elderly person's physical and psychological health and likewise ill-health affects their ability to meet their social needs. This overlap between needs requires a level of co-ordination and integration among different agencies involved in care of the elderly which, to date, has not been set in place.

Identified Unmet Needs of the Elderly

A previous study among the rural elderly has suggested that the concept of need is not one with which the elderly readily identify and, when asked, they find it difficult to specify those conditions that would make their life easier. A study of sheltered housing tenants also reveals low expectations of happiness among the elderly with comments of the following type
frequently expressed: 'I'm happy. At my age you're lucky to be alive'.

A review of existing literature suggests the following as some of the primary unmet needs among the elderly in Ireland:

- social contact
- appropriate range of housing and care options
- domiciliary support services
- transport
- security and freedom from fear
- day care centres

Need for Social Contact

It appears from the literature that financial and organisational problems which preoccupy service planners and managers have little to do with the major preoccupations of the elderly whose primary concerns revolve around isolation and loneliness. In the Mid-Western Region, Public Health Nurses pin-point loneliness, isolation and fear as among the most outstanding problems of the elderly. It has been found, generally, that loneliness is a common experience among the rural elderly and that lack of company and feelings of isolation remain the most significant problems of elderly people. Among elderly people living alone, loneliness affects two-fifths, at least to some degree. In particular, bereavement and the resulting loss of intimate companionship often lead to feelings of isolation and loneliness. Apart from bereavement, it has been found that the factors which contribute most strongly to frequent or persistent loneliness are a decrease in physical mobility, a feeling of being neglected by society, dissatisfaction with standard of living and a sense of unhappiness about life in general.

Housing Needs

Research shows that the housing of the elderly tends to be older than that of younger generations and often is in poor condition. Even in terms of basic amenities such as piped water
supply, internal toilet and bath or shower, homes headed by elderly occupants are considerably less well equipped than in the general population.\textsuperscript{19} The National Council of the Aged estimated that in 1980, 31 per cent of the elderly and 39 per cent of those over 80 years did not have an internal toilet and that 38 per cent of the elderly and almost 48 percent of those over 80 years had no bath or shower.\textsuperscript{20}

Since 1982, there exists a Task Force on special housing aid for the elderly which decides annual financial allocations to the Health Boards to carry out improvements to the homes of elderly people which are unsanitary or unfit. Two further schemes - the Essential Repairs Grant Scheme and the House Improvement Grant for Disabled Persons - are also available to the elderly for adaptations and repairs to their homes. However, as pointed out in The Years Ahead, all these schemes represent ad hoc responses to the needs of the elderly in poor accommodation, and, as a result, they are often inadequate to meet existing needs.\textsuperscript{21}

**Need for Range of Housing and Care Options**
It has been pointed out that in order to cater adequately for the diverse needs of the elderly, a continuum of housing and care options needs to be made available.\textsuperscript{22} Basically, five different options are required. The first option is that the elderly person stays put in his/her own home with the provision of appropriate improvement and home adaptation schemes along with a range of domiciliary support services. Where staying put is not viable, the elderly person should be offered the option of special small-unit housing with additional support such as an alarm system. If elderly people are experiencing difficulty in coping by themselves they may need sheltered accommodation with an on-site warden. Very frail or functionally disabled elderly need the option of residential care and for those not suitable for residential homes there needs to be the option of the hospital or geriatric ward.
Staying-Put
With regard to the first option of staying-put, as indicated previously, current schemes for repairs and adaptations are inadequate and need to be replaced by a more comprehensive and flexible scheme. Where sheltered housing is concerned, research shows that while the accepted yardstick for provision is five to ten per cent of the elderly population, in Ireland, however, just one per cent of the elderly are accommodated in this kind of housing. Service-providers indicate that there is a huge over-demand for this type of housing and, in addition, some parts of the country have no sheltered housing whatsoever.

Hospital Care
With regard to hospital care, service-providers involved in care of the elderly point out that due to reductions in financial resources, obtaining beds for elderly people is often very difficult and there may be considerable delay before the elderly person receives the needed care. In *The Years Ahead* the difficulties often experienced by elderly patients in gaining admission to hospital are also noted and the point is further made that only a minority of hospitals have a department of geriatric medicine. Because of shortage of beds in general hospitals, an acutely ill elderly person may be redirected to district and geriatric hospitals and nursing homes which are not equipped to deal with acute medical conditions.

Need for Domiciliary Support Services
With increasing age, elderly people are more likely to develop problems with mobility and to experience increasing difficulty with the tasks of everyday living. A survey of the economic and social circumstances of the elderly carried out in 1982 shows that those activities which cause most difficulty are getting on and off a bus, climbing stairs, walking half a mile or more and bathing without help. Among elderly people receiving care in their homes, climbing and walking also present difficulty for the majority and the majority also need help with bathing, dressing
and cutting toe-nails. In addition to difficulties with the tasks of everyday living, older people also tend to experience more medical problems and to suffer from chronic diseases. It has been found that six out of ten elderly people suffer from a long-standing illness, compared with one in ten among those aged 18 to 29 years.

Decreased mobility among the elderly, difficulties with the tasks of everyday living and chronic illness highlight the need for domiciliary support services if elderly people are to remain in the community. The major domiciliary services include the Public Health Nurse; home-help, meals-on-wheels; chiropody; physiotherapy and occupational therapy.

Public Health Nurse Service
The Public Health Nurse plays a key role in enabling elderly people remain in the community. However, research shows that while the services offered by the Public Health Nurse are highly valued by their elderly clients, their visits are seen as not being frequent enough or long enough. While the elderly form just one of 12 groups considered to be targets of the Public Health Nurse Service, they account for by far the largest proportion of patients on their visiting lists. Within the Mid-Western Region, Public Health Nursing returns show an increase of around 10 per cent over the period 1985-1989 in the number of geriatrics on the live register. In particular, the increase in the number of 'old elderly' means that nurses in the region are required to devote more time in surveillance and curative nursing with little time for preventive work. The nurses in the Mid-Western Region also express concern about lack of expertise in the management of incontinence and highlight the need for education and training in this area. In The Years Ahead it is pointed out that, because of the low ratio of Public Health Nurses to population, the service is not in a position to cope with the current need for nursing advice and nursing care at home and cannot deal with the demands of a rapidly ageing population.
Occupational therapists, chiropodists and physiotherapists also have an important role to play in preserving and facilitating the mobility and independence of elderly people. However, current arrangements for these services appear haphazard and inadequate and in some areas there is virtually no physiotherapy, chiropody or occupational therapy available to elderly people at home\(^{36}\).

**Home-Help and Meals on Wheels Services**

With regard to assistance with the tasks of everyday living, a study carried out by the St. Vincent de Paul Society found that only five per cent of the elderly living alone received the services of a home-help\(^{37}\). In a study of dependent elderly cared for at home, the provision of a home-help service was found to be practically non-existent\(^{38}\). The provision of home-help appears, however, to vary according to region. For example, four per cent of the elderly in the Mid-Western Health Region are in receipt of home-help compared to two percent in the South Eastern Health Board. Despite the importance of the service in supporting elderly people at home, overall just three percent of the elderly population benefit from home-help services\(^{39}\). Provision of a meals service is even less frequent than that of home-help and, outside of urban areas, is practically non-existent\(^{40}\).

**Transport Needs**

The ability of the elderly to meet many of their needs – for example, medical care, social contact, shopping and recreation – is very much influenced by their access to transport services. Deteriorating mobility in later years increases the critical role which efficient and suitable transport plays in enabling the elderly gain access to essential services. While all persons over 65 years of age and their spouses are entitled to free travel on public transport this concession is often of little use to elderly people. One study found that 70 per cent of the rural elderly in the area surveyed had never used their free travel pass\(^{41}\). A study of the rural elderly carried out in 1984 suggests that the free
transport scheme is not relevant to the lives of those in remote areas because regular public transport services are simply not available. A later study specifically on transport and access to services reveals a major problem of access to transport among elderly people in rural areas: with bus services in some cases infrequent and confined to a couple of days per week. In addition to infrequency, public transport may also not meet the needs of the elderly because time schedules do not correspond with the times of out-patient departments or day care services. A further problem is that the design of buses, which often involves high entry and exit steps, makes them difficult for elderly people to negotiate and accordingly curtails accessibility of transport.

Security and Freedom from Fear

The importance of security in the lives of older people is highlighted in several studies, both by the elderly themselves and by service-providers involved in their care. One study of the rural elderly noted the climate of fear which almost all respondents appeared to live in and to which they spontaneously drew our attention. In this study, doors were frequently found to be bolted and chained even in broad daylight. Similarly, service-providers emphasise how elderly people suffer from fear and speak of experiences where 'we were standing on doorsteps maybe two or three minutes and all you could hear was the clank of three or four bolts being pulled back'. A study of the tenants of sheltered housing again reveals the importance of security in the eyes of the elderly themselves. When asked what they considered to be the best aspects of sheltered housing, security emerged among the top three items reported. Fear affects the elderly in several adverse ways: it makes them less open to involvement with neighbours; it curtails their freedom to come and go as they wish; it affects their health and psychological well-being; and poses a threat to their independence.
Day Centres
Potentially, day centres play an important role both in enabling the elderly to remain in the community and, in the case of dependent elderly, providing a respite to carers. However, a study carried out in the Eastern Health Board in 1987 indicated that, to date, day centres have not achieved anything near their true potential in assisting the elderly. It was found that provision of day centres is at a minimum level, coverage is uneven and inequities exist in access to services, the facilities made available and the fees charged for attendance. The fact that many elderly people are unable to avail of day centres because of unavailability of public transport is highlighted in the study of Public Health Nurses carried out in the Mid-Western Region.

METHODOLOGY

This section outlines the procedures employed to explore unmet needs among the elderly. It describes the general characteristics of the people interviewed and indicates the themes around which the interview was structured.

Profile of Elderly Interviewees
Overall ten elderly people - eight women and two men - were interviewed. Two of these may be regarded as 'young elderly' being less than 75 years of age. The remaining eight belong to the group frequently referred to as 'old elderly' being older than 75 years of age. The youngest person interviewed was aged 72 while the oldest was 93 years of age. Urban and rural areas were equally represented among those interviewed with five being from Limerick city and surrounding areas and five from rural areas of County Clare. All but two of the elderly group interviewed are living alone and most have problems associated with mobility. All are receiving old age pensions. Three of the ten people in the group are in receipt of a home-help service.
Means of Contact
Contact was made with the elderly people involved in the study through Social Workers and Public Health Nurses working in the Limerick and Clare areas. The elderly people had been informed of the study and had been told that staff from the SRC would be in contact with them to invite them to take part. It was emphasised that the study was being carried out by an independent agency and that participation in it was absolutely voluntary. The initial contact made through the Social Workers and Public Health Nurses was then followed up by visits from SRC fieldworkers. The interviews explored the perceptions and experiences of elderly people through the qualitative accounts of the ten interviewees.

Location and Duration of Interview
All of the elderly people involved in the study were interviewed in their own homes. In all but one case, nobody else was present at the interview except the elderly person and the fieldworker. During one of the interviews the home-help was present in the room for some of the time but continued with her household chores.

Interviews ranged in duration from 14 to 24 hours; these being among the longest interviews held with any of the client-groups. In view of the safety concerns of the elderly, all interviews were carried out during the day-time. Despite this precaution, however, several of the elderly people interviewed were hesitant about opening the door to the interviewer. In some cases this hesitancy arose because the elderly person had forgotten that the interviewer was to call despite having been reminded of this several times previously by the Public Health Nurse. Many of the elderly interviewed were suspicious of the tape-recorder and required much reassurance and time to get used to it.

Topics Covered in Interview
The emphasis of the interview was in allowing the elderly people an opportunity to give their views on their main needs and concerns at this stage of their lives and their perceptions of the
extent to which their needs are currently being met. Within this context of open exploration of needs, the interviewer ensured that the following themes were covered:

- general needs
- housing
- physical health and well-being
- finance
- social
- emotional
- transport
- work and continuing education

**FINDINGS: MOST FREQUENTLY MENTIONED UNMET NEEDS**

One of the most outstanding impressions arising from the interviews conducted with the elderly is the central importance in their lives of social contact. Apart from having someone to talk to, the second most frequently mentioned unmet need is the provision of an adequate transport system. Both of these unmet needs are discussed more fully below.

**Need for Social Contact**
The extent to which social contact affects the quality of life among the elderly emerges again and again in the course of the interviews. Where the elderly person has contact with others, it can contribute greatly to their emotional well-being as is illustrated in the following comment:

'The Legion of Mary visit regularly..... they cheer me up..... they sit down and chat to me..... I think that's really nice. The social worker comes as well. It's nice to see somebody is around'.

Conversely, where there is lack of social contact, the feeling of
isolation and loneliness can be very distressing. According to one of those interviewed:

'Loneliness is the worst sickness you can have...... a bit of company would help a lot. I'd like for someone to come in and talk..... make a cup of tea...... ask me if I had anything for dinner'

When asked what they perceive to be their greatest need, most of the elderly pin-point contact with others. This is illustrated in comments such as the following:

'I think the only thing that would make me happier is if I had some person that I could rely on to stay with me. I'd like somebody to be here...... when I go to bed at night and when I get up in the morning there is nobody here'.

According to another elderly person 'all the elderly want is a bit of company... it can be terrible lonely when you are on your own'.

The central importance of contact and company is vividly illustrated in the comments of an elderly woman who found hardship and suffering in the company of another more endurable than loneliness:

'I was alright when Tom was alive even though I suffered an awful time with him. He had arthritis and then he got incontinent. It was hard but all the same it was better than this..... at least I had someone to make a noise in the house'.

Among those who live alone, feelings of loneliness and isolation are particularly common. As one elderly woman pointed out:

'When you are alone it is very hard. I find the day and night long. I'm here alone now since yesterday..... since I came in from the centre at half past three, I didn't see anybody until half past nine last night. Then the lady next door just dropped in to see how I was and she put a few pins up in my hair'.
It appears that social contact is an unmet need most particularly among those who have been bereaved and have lost their partner and accordingly, as they see it, have lost someone with whom they could talk. As one elderly woman says ‘when your husband is around you can say things you wouldn’t say to others’. Loneliness following bereavement and the effect it can have on the elderly person’s well-being are very evident in the following comment:

‘I haven’t anybody to talk to... I miss that, I used to talk to my husband when he was alive. I feel sad and depressed when I start thinking back, and even then I have nobody to talk to... only talk to the four walls... sometimes I just talk to myself. I feel lonely especially at night... I hate the winter nights... they are so long... I find I cannot sleep.’

Some of those interviewed have families but because of geographical distance there is little contact. As one woman explains:

‘I never see anybody. Often I don’t see anybody for the whole day. My family are far away and a lot of the people around here are young and they are working..... and so they don’t have time.’

Apart from bereavement, retirement too can contribute to feelings of loneliness. According to one elderly man:

‘I find retirement awful. I sold my land to the Land Commission... I used to go out in the morning to the top of the hill and milk the cows. I miss that... having my land taken over and being confined more or less to the house. I really miss the work and just being able to go out into the fields’.

One of the women interviewed also indicated a connection between retirement from work and feelings of isolation:

‘I was working all my life but I had to stop when my husband
was really sick to look after him. So I missed out on the chance to meet other people.'

In the view of the elderly what is most needed is more companionship. As one woman says 'If somebody only came in and out, then you would feel a bit better... somebody to talk to and rely on.' Similarly another says:

'I think it should be there for the elderly that someone would come in and stay a couple of hours a day... the lady who comes into me now stays about ten minutes... what good is that. I'd like a bit of company... someone to stay longer and talk to me.'

The fact that having someone who calls is frequently an unmet need among the elderly interviewed is illustrated in comments such as the following:

'Nobody like that calls..... that's what I'm saying. There is nobody that would sit down and talk to you. I like the company..... I'd like somebody to talk to me'

With regard to visits from social workers, one woman remarks:

'Only one social worker called ever....she was here in March....she said she would be out the following month but I didn't see her at all. She just sat down chatting with me.'

The interviews clearly indicate that the elderly people who have somebody to talk to and confide in are more content with their lives and less inclined to feel depressed. This is illustrated by one woman who says:

'Yes I am able to confide in my niece. That helps a lot to be able to talk to somebody you feel understands..... I don't ever feel down or sad although I get frustrated sometimes..... especially about not being able to move around like I used to.'
Need for Adequate Transport System

The importance of transport and the extent to which an adequate system is, at present, an unmet need emerges as recurrent themes throughout the interviews with the elderly. When asked, for example, whether or not they perceived the elderly as getting a fair deal, some of those interviewed pin-pointed transport as their main problem. Typical comments on the absence of transport are as follows:

'First of all they have no transport to get anywhere'
'There is no transport at all..... it's awful..... you get nothing here..... there isn’t even a hackney around here'  
'There are no buses..... it’s a big problem. I can’t afford a taxi, they are too expensive'.

Under these circumstances, it is clear that the provision of free transport is of little value to the elderly people interviewed. Even where admission to hospital is required, getting there is often a problem as illustrated by the following comment:

'There was a time when the ambulance would bring people to the hospital if they needed it but they don’t have that anymore around here. So an old person living alone has no way of getting to the hospital unless they have a kind neighbour who will offer to take them there. I have no way of going to the clinic were it not for my niece’s husband. He has to take time off work to take me there and bring me back'.

Even where a bus service is available, it may be of little value because as one woman pointed out 'I’m not able to get up on the bus anyway'. From the interviews, it appears that as a result of lack of public transport, most of the elderly people are obliged to rely on friends, relatives or neighbours to get wherever they want to go. As one woman points out:

'I have to rely on a lift from a neighbour if I am really desperate..... I always pay for it..... I wouldn’t have it any other way'.
Others attempt to walk if they need to get somewhere, while some hitch lifts:

'When I was able to look after myself I used to have to go and thumb a lift in the morning if I wanted to go anywhere.... I used to be alright when the school bus was on.... I could get a lift on that but there was nothing otherwise.'

In discussing health-related issues the effects of unmet transport needs again emerge. One woman described her problem as follows:

'At the best of times you might have to wait hours for a doctor to come... what can you do but wait when there is no transport to get to the surgery'.

A similar problem is voiced by another of those interviewed:

'I do have problems because sometimes there is no answer from the doctor's. Then when you do get him he often says 'come down' but I couldn't go down. The worst of this is that it is coming on the winter and I'm getting very fed up of this'.

Difficulties with travel also arise in relation to attendance at day-care centres. The following comments from an elderly man encapsulate the problem:

'I would go to a day centre if they had one here. I don't know if it is of much benefit because senior citizens around here are too far apart to be able to benefit from it. Most of them couldn't walk and who is going to transport them there. I think what is really needed around here is a bus'.

ADDITIONAL PERCEIVED UNMET NEEDS

While social contact and transport emerge as the most frequently noted unmet needs, the elderly people interviewed identified a number of other needs which they perceived as being also unmet. While not all of those interviewed were in agreement that these were unmet needs, they were remarked upon by a sufficient number
to warrant attention. These additional unmet needs are discussed below.

Adequate Financial Support
When asked whether elderly people get a fair deal generally, a number of those interviewed indicated that the financial support they receive is not adequate to meet their needs. As one woman points out:

'I just barely manage with what we get in the pension...... if we got an increase it would make life easier for me.'

Similarly, others note that 'a bit more money in the pension would help a lot'. It is interesting that even among those who declare themselves 'happy enough' with the financial support they receive, their comments, nevertheless, often reveal limitations due to lack of money. This is illustrated in the following quote:

'I have enough money...... and we will be getting a bit more soon. There is no point in looking for any more. I have free E.S.B. and phone as well. I'm happy with the money situation the way it is. I have enough for food and clothes but I'm not able to go out at all'.

The fact that the money received barely covers necessities without allowing any for social activities is again raised by one of the men interviewed:

'I haven't enough money...... the pension barely keeps me going...... most of what I'm getting goes on food. I have no money over for any sort of social activities. I'd like to have money for clothes.... that would help'.

Others speak of how lack of money limits their ability to go out and meet people. One woman, for example, related how she could not go on organised day-trips:

'They go to Lahinch but you have to pay £25 for it. I don't think I could afford that'.
The comments of one of the men interviewed reveal how even basic needs go unmet because of perceived lack of adequate finance:

'I don't have electricity..... It would cost me more than £500 to get it in..... that's a lot of money'.

Activities such as getting to the shops or getting to the G.P. are also curtailed where public transport is not available, because, as one woman points out: 'I cannot afford a taxi because they are too expensive'. The problem for one man and his wife is that all of one of their pensions goes towards the cost of her hospital care and there is nothing left over for clothes or social activities. In this regard, another interviewee suggests that 'there should be a good insurance for elderly that would cover all sorts of illnesses for them'.

Generally the needs for which the elderly would like more money may be considered very modest. They speak of items such as 'water rates', 'electricity', 'turf', or 'shoes'. For some, the primary concern is with having money for a proper burial as is evident from the following comments:

'Well my grave is paid for and that's all I am worried about..... I have enough money to get by. More than anything I'm worried about being buried. When I buried my husband I bought a double grave and I got a headstone as well for him'.

A similar concern is expressed in the following quote:

'A person would need to have a fair bit of savings or security to bury them. It would cost you at least £2,000 to bury a person and put up a headstone'.

The lack of sufficient financial support and the worry about future financial security experienced by several of those interviewed are vividly expressed in the following comments from one woman:

'When I have everything paid for I don't have any money left over. We get a bonus for turf but that only lasts for a few
months of the winter... after that we have to pay for it. I'd like to have money to get the lawn done... I have to pay for that because I'm not able to do it. I don't want to put too much of a strain on the services either. I worry about money because sometimes I feel I don't have enough to keep me going... if you have to buy shoes or something the odd time you have barely enough money to pay for it.'

Need for Appropriate Housing
The majority of the elderly interviewed indicated that they would definitely prefer to remain living in their own homes for as long as possible. One man, for example, has lived in his present home for almost forty years and sees it as being suitable for his particular needs:
'I still do some work on the house - painting and decorating. I got a man to do some work. I got a back boiler and radiators in, and aluminium windows as well. It's very snug... I'd prefer to live and end my days here because I love the country air.'

The importance of being able to stay-put where social networks have been established is clear from the following comment from one of the women interviewed:
'I couldn't live anywhere else... I am too long here. The neighbours come in and out now and then. I like to see people... I never shut the door to anyone and I never will.'

One man interviewed points out the benefits of staying-put not just to the elderly person but also to the Government:
'I think it would save the Government money in the long run. People are much more content in their own home environment'.

For many, the greatest problem associated with staying-put in their own homes is having to cope with isolation and loneliness. For these interviewees, the most important help that could be
given in staying-put is the provision of companionship. However, as indicated previously, this need for companionship among the elderly is one which frequently goes unmet.

Many of the comments highlight an unmet need for adaptations to make their homes more suitable to their present levels of health and mobility. One woman, for example, who is quite satisfied staying-put envisages that she will not be able to do so much longer because of ill-health:

'I have thyroid trouble as well as bad arthritis. I feel okay one day and terrible the next..... I never know when I might fall or something'.

One of the men interviewed spoke of the adaptations that would be needed to accommodate his wife's return from hospital:

'Even in the bathroom... I'd say she would have a problem if she wanted to wash or something. If they could do something with the bathroom... like to build a frame. I have a shower but it's over the bath... I was thinking that if they could have it set up on the toilet and connect it in some way then it would make it easier for her'.

For another interviewee, the problem is that her house is too big for her to maintain:

'It's two storey..... I cannot manage the stairs..... I just don't use that part of the house. I don't even bother about all the rooms downstairs because I am not able'.

With regard to alternatives other than staying-put, many of those interviewed were unaware of other possible options. Several, for example, had never heard of sheltered housing. The importance of taking the elderly person's individual preferences into account in offering options is evident from the following response in relation to a question on sheltered housing:

'I don't know at my age because I am a very bad mixer. I even hate going out for dinner today with my nephew. I
suppose it's being from the country and working there a lot... I never mixed that much'.

Likewise, another woman noted her reservations about moving to a different type of housing:

'I don't know..... I don't really think I would like to move. I wouldn't like a flat because there are a lot of complications. I have a sister in one and she was attacked'.

Many feel that, in the event of dependency, nursing home care is not available to them as an option because of the expense involved. As one woman points out:

'There are nursing homes alright..... but you couldn't go to most of them because they are too expensive..... especially if you are surviving on a pension'.

According to another woman, living with her sister, if she became ill she would have to go to a welfare home:

'I'd have to go into St. Camillus'..... I couldn't afford to pay a nursing home.

Need for Safety and Security
Safety in their homes appears to be a constant source of anxiety for some of those interviewed. The consequences of suffering a break-in are illustrated in the following comments:

'I was broken into. I wasn't in that particular room though. Now I am frightened at night if I hear noises or anything'.

One suggestion put forward as meeting the need for security is the installation of some kind of alarm system:

'I think there should be some sort of alarm attached to the phone. If anything happened then you could set off the alarm so that somebody next door would hear it or whoever'.
Others suggest the establishment of a Neighbourhood Watch Scheme would alleviate fears about security:

'You can imagine a person living alone.... you will never know when you might have a break-in. I feel very safe since I came here to live with my sister but I was often really nervous when I was living on my own. I had a neighbour close by but that isn't much good to you. What is really needed is a Neighbourhood Watch..... the police should parade the roads a bit more than they do'.

Need for Adequate Hospital Services
Several of the elderly interviewed expressed concern about what they perceived as the inadequacy of hospital services. One man expressed his concern as follows:

'If you were really bad the chances of getting a bed in hospital, well, you would want to be lucky there too'.

Similarly, one of the women interviewed spoke of the effects of a reduction in resources on waiting-lists for hospital beds:

'Certainly I don't agree with all the cut backs - for elderly or anyone else. Like getting into hospital... they may be very urgent cases but they might have to wait months and months and maybe a couple of years. I don't believe in cut-backs... it makes life very hard... you know the way you read things in the newspapers like people dying from want of an operation.'

Need for Domiciliary Support: Public Health Nurse
The help received from the Public Health Nurse is perceived to be very important to the elderly people. While, by and large, those interviewed appear to be satisfied with this service, some comment on the heavy workload of the Public Health Nurse, and the fact that this reduces the time available to her to spend with individual people. As one woman explains:

'I find her good but she has an awful lot of things to do and people to visit. Like she usually comes in and asks me how I
am getting on.... that kind of thing.... and then she has to go again’.

Some are critical of the fact that the Public Health Nurse calls so infrequently:

'She is okay but she doesn't come often enough. She is helpful.... like she gives you advice..... she called herself the last day but the time before that I had to send for her. That's not good enough really I think'.

There also appears to be some disparity with regard to who receives the Public Health Nursing Service. One man interviewed mentioned that such a service would be helpful but he never sees the Public Health Nurse. Similarly a woman comments that:

'She doesn't come usually..... she came to do the ulcer on my leg when it broke out but then I didn't see her after that'.

Need for Domiciliary Support: Home-Help and Meals-on-Wheels

As with the Public Health Nurse Service, there appears to be some disparity with regard to who receives home-help. Some of those interviewed had not even heard of the service as the following comment shows:

'I don't think that service is available in this area... I never heard tell of it anyway... it would be good though if it was... definitely... to have someone to do a few things for you.'

Others are unsure of the conditions for entitlement to home-help:

'I don't have that... I don't think they would give that to you if you were able to move around... maybe if you were bed-ridden or something you might be entitled to one then'.

Some of those who receive home-help are critical of the service. As one woman comments:

'She only comes in and makes a fire and puts the ashes in an old bucket.... then she leaves it there. I have to get
somebody else to throw it out and sweep the house after it. The tea she makes is awful... I throw it out because I don’t like it. She really only stays for 10 minutes... she is no use.’

With regard to meals-on-wheels, few of those interviewed receive this service. Some see that such a service would be very useful: ‘There are no meals-on-wheels in these parts. It would be good if we did have them alright.’

One man points out that he could not manage without meals-on-wheels but the service is not always available: ‘I find it’s a necessary service alright... I’m not able to cook for myself... its great to have these meals from Monday to Friday but then there is nothing on Saturday and Sunday.’

The importance of taking note of individual preferences is, however, again illustrated with regard to this service. As one woman points out: ‘I get my meals myself. They take a lot of old folks to the day centre... these old folks either walk it or a lot of them are collected... If I wanted to go now I would be collected. I wouldn’t want to go... not for a while anyway... I’d prefer to manage myself. We do get our dinner every Christmas over there... that was very good last year.’

Need for Domiciliary Support: Physiotherapy

Presently, none of those interviewed are receiving physiotherapy. Some of the elderly people acknowledge the importance of this service and are aware that it is available at the regional hospital in their area. Others state that it is not available on the G.M.S. and are critical of this fact: ‘I didn’t get anything like that. There is a woman about six miles away and she is good but you have to pay her. I think there should be more of them and have them paid by the Government’.
Similarly, another of those interviewed points out:
'I should be getting physiotherapy. When I lived in my home place I used to go to the local hospital and get it done for my back... it was great. I even went on a holiday to London after that'.

Need for Day-Care Centres
While the importance of social contact is emphasised by all those interviewed, some point out that their ill-health prevents them from participating in social events. This is illustrated in the following comment:
'I cannot go out... I cannot walk. I suppose they have socials and that in the centre but I cannot travel... that's because of my chest. I used to go to Mass but I had a few blackouts there. Then the priest told me not to go out. Now I sit here all day by myself.'

Similarly, others point out that although day centres exist in their areas, they are not appropriate to their needs. According to one woman:
'I don't go many places... We have an old folks dinner... that's okay... I don't really care that much for planned activities but I think it's very good for people who can go out to them. They have just built a day centre here but I don't think I'll avail of it... I'm very stiff you see....'

Another woman describes her disinclination to use the day centre as follows:
'I do go to the day centre... a man with a van called for me... I find it depressing... I'll tell you why... because the rest in the group are able to go around and I am sitting there.'
Several of those interviewed are critical of the lack of activities for elderly people in their area and would certainly avail of a day centre if it were available:

'I don't think enough is done at all for old people. I think when you are so isolated like I am here you miss out on a lot of what's going. I wouldn't mind going to the Day Centre... it would pass the time away.'

According to one woman:
'There is nothing around here for old people. We have no day care centre. It would be great because you would at least have some company. I often get lonely... I think the time I am most lonely is during the day... at least at night you can pick up a book and read it and it takes things out of your mind'.

Similarly, another woman perceives the benefit of having a centre for old people, as follows:
'It would be good to have a centre for old people. The Wheelchair Association... I was in that... the head lady there came down to me one day and said: 'you will have to go out' and I said 'How can I walk? For God sakes leave me alone'. So after that she used to bring me out in her car to different places. I used to enjoy that but there isn't a word about it now for the last two years'.

Information on Keeping Fit and Healthy
All of the elderly people interviewed suffer some debilitating effects as a result of ageing. Most are resigned to this and adopt an attitude of 'sure what can I expect at my age' or 'I could be a lot worse at 88 years of age'. Some, however, are less well able to cope with decreasing ability and comments such as the following suggest a need for advice and counselling in this regard:

'I feel really tired all the time... old age is really dragging me down... I feel really down in myself.'
It appears that information on keeping fit and healthy is not made available to those interviewed even though all indicate that they would find such information useful and valuable.

**INFERRRED UNMET NEEDS**

Apart from those needs specifically noted, the experiences and perceptions recounted by the elderly people interviewed point to further unmet needs. These inferred unmet needs are discussed below.

**Need for Advice on Planning for the Future**

The need for advice on planning for the future is most evident in the elderly people's responses to a question on what they would do in the event of a serious illness. It appears that the elderly interviewed have not thought or planned in advance in relation to this event. Some of those interviewed assume that their relatives would care for them. This is illustrated in the following quote:

>'If I needed somebody I could call my niece. I think she would be here for me for as long as I needed'.

Some rely on the neighbours helping out:

>'If I was sick the neighbours would help me. All I would have to do is hit the wall and someone would be in to me.'

Others believe that the medical services would take care of them in the event of serious illness. Prayer is the solution to worry adopted by one woman:

>'I worry a bit about getting sick though... when I go to bed I pray to Jesus, Mary and Joseph to keep me and I think they do... I have faith.'

According to one man, he does not consider the event at all:

>'I don't really know what would happen to me. I suppose my nephew would look after me, or I would have to go to hospital. But I don't worry about it... what's the point?'
The negative consequences of failure to plan for the future are illustrated in the following comment:

'I didn't ever worry when I was younger. My husband had a good job until it closed down and he was idle for a while. Then he thought he would get back again somewhere... I thought the sunniest days were in the future... but they are turning out to be the hardest days'.

Need for Understanding From Others
Several of the comments of those interviewed point to a need for greater awareness and understanding among the general public of the situation of the elderly. As one woman says:

'As far as I can see there is nothing for the elderly. You are just a nuisance when you get old... nobody is interested in you anymore'.

Others feel they are not listened to as the following quote shows:

'I feel some people listen... some more don't... they just say: 'Snap out of it'. People who are not old or who don't have anything wrong with them cannot believe it or understand it'.

Another woman puts forward a similar view when she says:

'I don't think people really understand - even though they would usually listen... everybody has enough to do for themselves'.

Need for Advice on Active Retirement
The outstanding impression received from the interviews is that these elderly people are unaware of any concept of 'active retirement'. The overall perception relates to the idea that the elderly are 'redundant' or 'defunct'. Those who had previously worked now perceive quite a gap in their lives but cannot see themselves becoming involved in anything else as the following quotes from a man and a woman respectively show:

'I wouldn't be able for that now. I would like to be working
if I was able. I found it hard to pass the time when I was no longer able to work.'
'I worked outside the home. I was lonesome when I retired.
I missed the cows and being out in the fresh air... if I was able to work in the morning it's back to that I would go again.'

Need for Information on Entitlements

The need for information on entitlements arose in relation to several areas discussed in the course of the interviews. As indicated previously, several of the elderly interviewed were unaware of services available to them - services such as home-help, meals-on-wheels, day centres. Likewise, many were unaware that sheltered housing existed. Lack of information on entitlements is also illustrated in the case of the woman who had lost her free travel pass and had not reapplyed because she did not know whom she should contact. Lack of information is vividly illustrated in the following quote:

'I'd like a bit more in the pension... but I manage alright... like there is free fuel... I don't know whether I'll be entitled to that or not... there are a lot of things like that I don't know about.'

SUMMARY

The interviews conducted with the ten elderly people have highlighted many areas of unmet need across different aspects of their lives. In two cases - social contact and transport - there is almost complete unanimity among those interviewed that the need highlighted is currently unmet. With regard to other identified needs, there are some who considered that these are being met by current services while others experience them as being unmet. Finally, there are areas of unmet need which are not directly identified as such by the interviewees but which are evident from the experiences and perceptions they describe. The following summarises the key areas of unmet need brought to light through the interviews.
Most Frequently Mentioned Unmet Needs

- social contact
- adequate transport system

Additional Perceived Unmet Needs

- adequate financial support
- help to remain in own home
- suitable housing to facilitate independence
- choice of housing options
- affordable nursing homes
- safety
- adequate hospital service for acute illness
- domiciliary support services
  - public health nurse service
  - home-help service
  - meals-on-wheels
  - physiotherapy
- day care centres
- information on keeping fit and healthy

Inferred Unmet Needs

- advice on planning for future needs
- understanding from others of the needs of the elderly
- need for advice on active retirement
- information on entitlements
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CHAPTER FIVE

THE UNMET NEEDS OF CAREERS OF
PEOPLE WHO ARE PHYSICALLY HANDICAPPED

Introduction
The primary objective underpinning the development of policies in Ireland in relation to people who have a physical disability is to enable them to develop to their full potential and to participate to the greatest possible extent in the life of the community. While services for people with a physical handicap have been the subject of a number of reviews and investigations, little research has been carried out on the needs of those who care for them at home and thus enable them to remain in the community. Carers provide an invaluable social service which not only represents a large saving of State expenditure but also has a very great influence on the well-being and quality of life of the person with the disability. It is impossible to calculate the benefit to persons suffering a physical disability of avoiding institutionalisation and being able to remain at home where they have their social networks and are in familiar surroundings. Caring, however, often involves personal sacrifice and can result in strain in different areas of the carer's life. In order to enable the carers to continue caring without adversely affecting the quality of their own lives it is necessary that their needs too are acknowledged and addressed. Research shows, however, that carers tend to focus exclusively on the needs of those for whom they care and frequently neglect, or fail to look at, their own needs. The interviews described in this chapter provide an opportunity for carers of persons with a physical disability to focus on their own lives and to identify the needs and concerns which they themselves experience.
CONTEXT

This section provides a context within which the needs of the carers may be assessed and understood. The section outlines policies which have relevance to the life of the carer and describes the benefits and supports currently available to them.

Numbers Involved
While up-to-date information exists on the numbers who provide home-care in Ireland for elderly people who cannot look after themselves\(^1\), no data are available with regard to carers of disabled people generally. Apart from their carers, the lack of accurate statistical information on the numbers of persons with a disability in the country, has frequently been noted\(^2\). It has been pointed out that data on the number, distribution, forms and extent of disability are a necessary prerequisite for assessing need and comprise the only sound basis on which to plan relevant services and policies\(^3\). The same point on the necessity of data for planning and policy-making may be made in relation to the carers of persons with a disability. In response to the sparsity of data, a physical handicap record system was initiated in 1980/81 which was to be compiled within Community Care areas, in each of the eight Health Boards. The record system is not designed to provide a census of disabled persons but rather comprises a listing of people who, because of their physical disability, are either in receipt of a service or deemed to be in need of one. It has been noted that only a minimum of preliminary statistics are so far available through the second system\(^4\). In the **Green Paper on Services for Disabled People - Towards a Full Life** - it was considered that: \(\text{the record system, when complete, will supply the basic information necessary for an accurate assessment of needs and for planning of services to meet those needs}\)^5. However, it has been agreed both by the Union of Voluntary Organisations for the Handicapped (UVOH) and the Irish Wheelchair Association (IWA) that the physical handicap record does not include the kind of detailed assessment of needs,
economic position, housing situation and employment potential which is needed to adequately inform planning and service provision for disabled persons. It might also be added that the assessment should include information on the needs and circumstances of those who care for the disabled persons and thus enable them to remain in their own homes.

The Policy Framework

Consideration of the needs of the carers and the extent to which these are addressed has to be set in the context of the policy approach which affects the lives of those for whom they care. A major benchmark in the development of policy and services for the disabled is the Green Paper on Services for Disabled People - Towards a Full Life - published in 1984. This Green Paper had been preceded by two influential reports; the first produced in 1975 by the Working Party on Training and Employing the Handicapped, and the second produced by NESC in 1980 and entitled Major Issues in Planning Services for Mentally and Physically Handicapped Persons. In all three reports the major emphasis is placed on integration of disabled persons into the community. In the Green Paper the ultimate policy objective is defined as follows:

'...to equip disabled people to realise their full potential and to participate to the greatest extent possible in the life of the community'.

A second theme strongly emphasised in the Green Paper is the importance of developing a systematic and co-ordinated approach towards meeting the needs of disabled persons.

The integrationist philosophy underlying official policy has received widespread support and is reiterated in the consultative document Health: The Wider Dimensions, produced by the Department of Health in 1986. Commitment to integration is also evident in Ireland's continuing participation since 1981 in the EC HELIOS programme which is designed to develop 'vocational training
and rehabilitation, economic integration, social integration and an independent way of life for disabled people. It is noted in the Green Paper that to put into practice the objective of integration requires good-will and effort on the part both of disabled and non-disabled persons: 'the achievement of social integration of disabled persons is of necessity a two-way process. It requires a willingness on the part of disabled people to reach out into the community; equally, it demands that the public is made aware of the problems faced by disabled people and is encouraged to play its part in reaching an acceptable solution'.

In the present context 'reaching an acceptable solution' clearly involves not just awareness of the problems of the disabled but also awareness of the needs of their carers and the support they require to enable them continue with the very significant role they play in integrating the disabled into the community.

Income Support System for Carers

Adequate financial support has a very significant role to play in putting into practice the objective of community living and avoidance of institutionalisation. While the focus of this section is specifically on income maintenance policy with regard to carers, it is clear that in this area the interests of the carers and those for whom they care coincide. Accordingly, while the main emphasis of this section is on the supports provided to carers, reference is also made to those provided for disabled persons since these also affect the lives of the carers.

With regard to disabled persons, it has frequently been noted that financial deprivation is a key factor contributing to the disadvantage and isolation which many experience. Since 1970, a number of income maintenance payments have been introduced designed to promote integration into the community. Among these is the invalidity pension, payable through the Department of Social Welfare, to insured persons who are judged permanently incapable of work after completing a year on Disability Benefit. A feature of the invalidity pension which has particular relevance
for the carer is that a Prescribed Relative Allowance may be payable with it. The Prescribed Relative Allowance, first introduced in 1968, is payable to blind and invalidity pensioners and any elderly person who is getting any pension or allowance from the Department of Social Welfare and who is in receipt of full-time care. The allowance may be seen as some acknowledgement of the role of carers in putting into practice the objective of integration. During the period since 1970 significant changes were also made to the Disabled Persons Maintenance Allowances in respect of adult and child dependents of recipients. The UVDH is currently campaigning for the New Carer's Allowance to be made payable to the carers of persons in receipt of the DPMA. Since October 1990, DPMA recipients who are unable to fully use their free travel pass without the help of another person may bring that person free of charge. Disabled persons in receipt of the DPMA can, since 1977, avail of a number of schemes including the travel on public transport, free electricity allowance and a free telephone rental allowance. In 1979 a Mobility Allowance was initiated which is payable, subject to a means test and strict medical conditions of eligibility, to persons aged between 16 and 66 years who cannot walk and also would benefit from occasional trips away from home.

Despite these improvements, there is widespread agreement that the existing system of income supports for disabled persons is seriously inadequate and falls far short of that required to achieve the goal of integration\textsuperscript{14}. It is noted that the plethora of benefits and allowances which has emerged has not served to provide a comprehensive income support system but rather has developed into a 'highly confusing, fragmented and wasteful set of schemes which require urgent rationalisation'\textsuperscript{15}.

With regard to income support for the carers there are but three schemes which are of relevance. As indicated previously, a Prescribed Relative Allowance may be payable in certain circumstances. However, there are strict conditions of
eligibility whereby the prescribed relative must be living with the pensioner, must not work outside the home, must not be a married person dependent on her/his spouse and must not be eligible for any social welfare benefit unless that benefit is less than the amount of the Prescribed Relative Allowance. In 1973 a Handicapped Child Allowance was introduced. This allowance is paid through the Health Boards and is intended to offset some of the costs involved in maintaining a severely physically or mentally handicapped child at home. The child must be aged between 2 and 16 years and the disability must be so severe that s/he needs constant care and supervision. A new Carer's Allowance was introduced in October 1990. This means-tested allowance is payable to a person who is living with and providing full-time care to a pensioner who is receiving a Blind or Invalidity pension or who is 66 years or more and receiving any social welfare payment. The allowance is payable in some cases to a person in receipt of the DVA. With this new allowance, married people will not be debarred from income support provided they meet the other conditions laid down.

Domiciliary Support

A second area of policy in which the interests of the carer and of the disabled person are very much interlinked is the provision of domiciliary support services. It is clear that any practical assistance provided to the disabled person influences the level of strain and burden experienced by the carer. Despite the strong emphasis on integration and community care, the level of development of domiciliary support services for persons with a physical disability has been very limited. There are few services specifically for disabled people who, instead, are covered by general services with wide-ranging applicability where they have tended to be regarded as a low-priority group.

A flexible home nursing service is generally regarded as an essential element of a comprehensive and effective community care service for disabled people. However, it has been found that
home nursing for disabled persons is not adequately developed. It emerges from a study of the work of Public Health Nurses in the Mid-Western area that part of the problem in this regard is the increased demand for home nursing imposed by other groups, particularly the elderly. A second factor in the inadequacy of the service is the fact that home nursing is generally unavailable outside normal working-day hours.

Apart from home nursing, the home help service is a second major component of domiciliary support. Under the 1970 Health Act, the Health Boards were empowered, but not required, to provide a home help service for a number of different groups including sick or infirm persons and persons who but for such a service would have to be institutionalised. While persons with a physical disability are seen as legitimate clients for home help, in practice the extent to which the service has been made available to them is very limited. At present, the service is almost exclusively confined to elderly people. In addition, a 1987 NESC report on community care draws attention to the fact that there is considerable reluctance to provide a home help service to people living with relatives.

A third potentially important element in domiciliary support for persons with a disability is the home care attendance service. This however, is a relatively new scheme which was first introduced in 1983, and, at present, its availability is very limited. The service was initiated by the INA who were concerned about the gaps in the home nursing and home help services and the resultant strain on families caring for people with severe physical disabilities. Home care attendance is intended to be available at unsocial hours and at short notice where necessary and is meant to 'act as a substitute for the relative to enable them to do whatever they want to do, or need to do'. An initial report on the service highlighted its potential usefulness in supporting families who care for disabled people. Later the Green Paper on Services for Disabled People acknowledged that a
home care attendance service had a potentially significant role to play in enabling disabled people remain in the community rather than being institutionalised. However despite these reports, it appears that no commitment of resources has been made for the development of this service.

Respite Care Facilities
From the perspective of the carers, respite care facilities may be seen as foremost in enabling the goals of integration and independent living to be put into practice. Respite care facilities are intended to provide relief to carers, to alleviate the burden of caring responsibilities and consequently, to reduce the level of stress which they and their families may experience. Respite care may be provided in different ways; through, for example, places in centres, through placement with host families and through places in hospitals and other institutions on an emergency basis. A 1990 report of the National Rehabilitation Board (NRB) indicates that currently there are around 190 respite care places available throughout the country, most of which (155) cater for carers of persons with a mental handicap with just 2 places designated for cares of persons with a physical disability. The distribution of such respite places is quite unequal around the country with the Eastern Health Board being the only one in the country with facilities specifically for people with physical handicap. With regard to respite through host families the NRB report indicates that there are currently 260 families involved in the scheme; 30 of whom are in the Mid-Western area. However, to date this kind of respite care has been provided only for children with mental handicap. In addition to the respite care places and host family scheme, respite care is provided in situations of crisis by a number of hospitals and voluntary organisations. However, it emerges that due to high demand and scarcity of resources to meet the demand, the agencies involved do not publicise the fact that they provide such a service.
Day centres also play an important role in providing respite to carers. There are currently 169 centres throughout the country, most of which, however, cater for those with mental illness (69) and mental handicap (59) with just 16 catering specifically for those with a physical disability\textsuperscript{26}. The distribution of such centres is also uneven around the country with the Mid-Western area having one centre for those with physical handicap.

**LITERATURE REVIEW**

Although families play a key role in enabling the state to fulfil its objectives of independent living among disabled persons and their integration into the community, very little attention has been focused on the particular needs of carers. This section presents an overview of the small amount of literature to date on the experiences and concerns of those who look after persons in need of care and attention in their own homes.

**The Caring Process**

Recent research on carers of the elderly in Ireland reveals that caring may be best understood as a process comprising the following stages\textsuperscript{27}:

- decision to become a carer
- becoming a carer
- daily caring
- review of caring process
- termination of caring role

Different needs arise at these different stages and the kind of support most important to the carer may vary from stage to stage. At the initial stage, for example, advice and information on the nature and kind of care required are essential in enabling a decision to be made in a considered fashion, based on a review of the different possible care choices and alternatives available. At the final stage of the caring process, where the carer’s role has been terminated, through death or institutionalisation of the
person being cared for, the most important support required may be
counselling in dealing with feelings of loss, loneliness or guilt.

A comprehensive support system for carers requires recognition of
the different stages of caring and awareness of the different
needs which arise during these stages.

Costs of Caring

Research on carers of the elderly shows that caring can extract a
cost in many aspects of the carer's life including financial
circumstances, social life, personal relationships and physical
and emotional well-being. Financial circumstances may be
adversely affected both through loss of employment opportunities
and through extra expenses incurred through caring such as home
adaptations and special caring aids. Carers may be confined to
the home for long periods during the day and often find it
difficult to find a substitute carer which would enable them to go
out at night. Consequently, the social life of the carer is
frequently very restricted with few involved with evening classes,
cinema or theatre or with visiting friends. Even when carers do
get involved in social activities, they often find it difficult to
let go of their caring responsibilities. Very few carers manage
to have a holiday. Caring has consequences also for the carer's
personal relationships. It has been found that children are most
adversely affected through having an incapacitated elderly person
in the home but marital relationships can also suffer negative
effects. The demands and stresses of caring can often take a
toll on the carer's physical health. Research on carers of the
elderly shows that almost one-third believe their health has
suffered because of the demands of caring. Likewise, emotional
well-being is affected with 33 per cent of carers indicating that
they experience very high or high levels of strain.

Needs of Carers

In the context of care of the elderly, research shows that the
primary needs of the carers revolve around:

1. practical help in caregiving
. respite care
. financial support
. psychosocial support
. advice and information

In the context of care of persons suffering from schizophrenia, similar concerns have been identified. Addressing the primary needs of carers of this group is seen to involve the following:\textsuperscript{35}:

. A care plan for every person being looked-after; including medical care, financial support, living accommodation and employment and vocational development
. professional 'friend' for each caring family with skills in, for example, counselling and stress management, who would call weekly and who would have first-hand knowledge of the family's circumstances and particular needs
. drop-in centre in every neighbourhood which would act as a kind of social club
. respite for the carer through the provision of twice yearly, structured and predictable holidays
. financial support
. community education which provides families and those being cared for with the information they need and which enables others in the community to respond with awareness and sensitivity
. crisis intervention facility capable of an immediate and effective response to a call for help from the carer

While at least some of the services which would meet the needs of carers are already in existence - services such as public health nurses, home helps, respite care - as indicated previously these services have either been inadequately developed or are not reaching carers who look after people who are physically disabled. Apart from factors such as inadequate public funding and lack of effective management structures, it has been suggested that an important element in failure to provide adequately for carers is the absence of a framework which would allow their participation
in the planning and delivery of community care services\textsuperscript{36}:

**Charter for Carers**

It has been proposed that the primary role of the carer in the delivery of community care should be recognised and acknowledged through the establishment of a Carer's Charter. The carer's charter outlined in the study of carers of the elderly sets out the following elements as essential in providing the support required to enable the carer to provide care in a way that ensures a high quality of life for both parties concerned\textsuperscript{37}:

- need for recognition of central role of carers in community care
- need for practical help
- need for back-up services
- need for financial support
- need for involvement of all family members
- need for emotional and moral support
- need for information, advice and training
- need for counselling
- need for planning
- need for assessment
- need for integration and co-ordination of services
- need for liaison between formal, informal and voluntary sources of assistance
- need for awareness of services and easy access to information.

**METHODOLOGY**

This section outlines the procedures employed to explore unmet needs among carers of those with a physical disability. It describes the general characteristics of those interviewed and lists the themes around which the interviews were structured.
Profile of Carers Interviewed
Ten people were interviewed in the carers group – nine women and one man. The interviews, which were exploratory in nature, took place with carers ranging in age from those in their mid-fouries to 70 years of age, their ages being dependent on whether they are caring for spouses, siblings or children. Two of the carers are looking after their spouses, and one other is looking after her sister. The remaining seven are all caring for children. Of the ten interviewees, three are caring for a member of the family with Multiple Sclerosis, five are caring for children with Spina Bifida and the remaining two are caring for children who are confined to wheelchairs – one as a result of an accident and one due to a debilitating bone disease. Urban and rural areas are equally represented – five are from Limerick City, and five from rural County Limerick and Clare areas. Among the group interviewed, all but one are involved in caring full-time.

Means of Contact
The carers interviewed were contacted through community welfare officers in the Limerick City area and through social workers employed by the Spina Bifida and Multiple Sclerosis Associations in the Clare and Limerick areas. The persons involved were informed of the study and were told that staff from the SRC would contact them to invite them to take part. Interviewees were advised that the study was being carried out by an independent agency and that their participation was voluntary. Following their agreement to take part, the interviewees were called upon by SRC fieldworkers.

In all, 15 contacts were made from which 10 were eventually chosen. In the case of 5 of the contact names obtained, although the person being cared for did have some degree of physical handicap, little or no caring responsibilities were involved and so were considered unsuitable for the study.
Location and Duration of Interview

All of the carers were interviewed in their own homes. This was necessary as most of them were unable to leave their houses during the day. In all cases nobody else was present but the carer and interviewer. However, in two instances the interviewees had to get up several times during the interview to check on the disabled person. These carers' inability to sit down for an hour without being disturbed is indicative of their absorption into the caring role.

Interviews ranged in duration from one hour to two hours. Most of the carers interviewed expressed pleasure at being given the opportunity to express their opinions. One interviewee indicated that the interview had in a sense been therapeutic for her because she rarely got to talk to people outside her home.

Themes Covered in the Interview

The emphasis of the interview was in allowing carers of the physically disabled the opportunity to relate their experiences and to give their perceptions of their needs as carers. They were also asked to relate how adequately they felt their needs are currently being met. The exploration of their needs covered the following themes:

- general needs
- family circumstances
- diagnosis/extent of disability
- finance
- housing
- practical help
- day centres/training
- transport/mobility
- social contact
- support networks
- health
FINDING: MOST FREQUENTLY MENTIONED UNMET NEEDS

An important finding from the interviews with the carers is that they apparently find it difficult to consider what their own needs are as distinct from the needs of those for whom they care. Most of those interviewed tended to articulate needs in terms of what was required to make life easier for the person with the handicap and constantly had to be refocused on their own needs as carers.

The interviews reveal four major areas of unmet need among those who care for people who are physically handicapped. Foremost among these is the need for respite from caring. A second major unmet need, and one which is closely related to the need for respite, is the provision of practical help and back-up support. A further unmet need is the provision of an adequate advice and information service. Finally, transport emerges as a significant area of unmet need which adds to the difficulty and strains of caring. These frequently noted areas of unmet need are described in detail below.

Need for Respite from Caring
In speaking of their everyday lives and what it means to care for a person who is physically handicapped, all of those interviewed describe how caring is a 24-hour job. The daily grind involved in caring is clearly indicated in the following quote from a wife looking after a victim of Multiple Sclerosis:

'It's nearly the same everyday. I get up in the morning. Sometimes he's not awake when I get up so I leave him to sleep - as long as he wants because he mightn't have had any sleep. Mind you I wouldn't have any sleep either but he has a walking stick and he knocks on the wall if he needs me so I go in and try and lift him up in the bed as best as I can because he's a dead weight and it's very hard to get him up. I give him his breakfast, then give him his tablets and empty his water bag and then he might go back to sleep again. Then I shave him, tidy his bed and do the room. Then I start on
lunch. In the meantime you've a lot of other jobs to do - you've the kids to look after... you've to do the shopping, washing, do the ironing. Things don't always go right... but I mean you have to cope all the same... it's a 24 hour job, seven days a week - I'll put it to you like that'.

The restriction imposed by caring on freedom to do the most ordinary and simple tasks is described by one woman as follows:
'I suppose it's just having to be there... I can't really go out. If I really want to go and get my hair done I have to see if Mary's okay first before I go... if she wants to go to the toilet or needs a drink. And I have to rush back then. It's a burden really to have to be there, you're not free at all'.

The continuous round of caring without respite means that social life is very restricted. One woman describes how she has not got any time for meeting friends because 'I get up at seven o'clock and go on 'till eleven at night and then I'm so tired that I just fall into bed'.

Just two of the carers interviewed had had a holiday in the previous year. Those who had been away had been enabled to do so only because a family member had been willing to take over the caring role:
'My sister-in-law looked after her... I couldn't get anyone else to look after her... If I didn't have her I wouldn't have been able to get away'.

Given the day-to-day circumstances of caring, it is not surprising that most of the carers interviewed see the provision of respite from caring as their most significant unmet need. Many are pessimistic about the possibility of somebody else taking over the
caring role in order to provide a break. As one woman expressed it:

'No there isn't anyone available - there's nobody, nothing to help - you're caught really'.

Even an occasional break is seen as providing relief:

'Well they should give people a little more help - take them away on a holiday or something - if it's only a week for a break'.

Some find that voluntary organisations such as the Irish Wheelchair Association do alleviate the pressure to a degree but it is felt that sometimes their outings do not adequately meet the carer's need for a break:

'I do find them a help. But it's only once a month - the outings - and once a month isn't enough'.

The importance of respite is highlighted by the fact that all of those interviewed see caring as having taken a toll on their physical health and well-being. Some complain of what may be regarded as stress-related symptoms such as agoraphobia, high blood pressure and weight loss. Others complain of back-ache due to the strain of lifting the handicapped person. The over-riding infirmity, however, of all the interviewees is chronic fatigue. As one woman commented in relation to her health:

'It is affected. I seem to get tired more easily. I'd be snoring every night... and I get depressed just thinking there's no way out'.

Another woman describes her condition as follows:

'I have bad days... and I'm so tired, I find it hard to do anything, especially when it's all the time - it's very tiring... it's a long day'.
Need for Practical Help

Closely allied to the need for respite is the need for practical help in the day-to-day tasks of caring - a need which the carers of the present study indicate is currently unmet. One woman describes her need as follows:

'I think more could be done for the carer in the line of someone coming in... not just in the morning... you'd want someone to come in in the day-time and maybe take the person out for a walk, or if they want to get out of the wheelchair during the day... if someone did come in they could do that'.

The majority of the carers interviewed carry the sole responsibility for providing care. Where help is available from family members or persons outside the home, this help is restricted to household chores or 'keeping an eye on' the disabled person.

It might be expected that the home-help service would provide the kind of practical support which the carers require. However, the feedback obtained from the carers reveals that such a service is not always the solution to their problems. Some express their concern about preserving their privacy:

'I suppose I just don't fancy someone coming into the kitchen - well you like to have privacy don't you?'

Others feel that having a home-help would disrupt their own particular way of managing home-care:

'I have my own way of doing things. I can do my own thing. If I want to leave the dishes from the night before I can leave them but if I have a home-help coming I'd have to wash them, so what's the point in that - you're defeating the issue there. I think I'd not bother at all'.

In some cases the home-help is of little value because the time-schedule of the service is inappropriate to their needs. For some, the need for practical help could be most usefully met
by providing adequate financial assistance which would enable
carers to choose the particular kind of help which best suits
their circumstances.

Need for Practical Aids to Caring
The provision of aids such as wheelchairs, incontinence sheets and
pads and bed hoists are important in the practical support of the
carers. However, most of those interviewed experience difficulty
in getting some of these aids:

'It's impossible to get these aids - this wheelchair, he has
it two years. It's gone so small he's squashed up into it.
We applied for one six, no nine months ago - they told him if
someone died he'd get one... someone did die, but if they
hadn't he'd still be scrunched up in the wheelchair and his
back is bad. You get nowhere with the authorities'.

Delay in getting practical aids is frequently experienced.
According to some this is so as a result of reductions in the
health services:

'Well the only thing she needs is the callipers and crutches
and wheelchair... We might be waiting a while but eventually
we get it. But now they have cut back... in the line of
crutches and wheelchairs... Now they only give a grant
towards the wheelchairs and I have a new wheelchair needed so
I don't know what will happen'.

Voluntary bodies are seen to be of most help in the provision of
practical aids:

'Well she got a walking frame from the Multiple Sclerosis
Society and she also got a wheelchair on loan from them'.

Up to date equipment, however, is only available to those who can
afford it. This is seen as a major injustice:

'They had a lovely bed on the Late Late Show one night - it
does everything'. It costs £800. I was inquiring of the
nurse whether they have them in the Health Board. She said she didn't think so. But where are you going to get £800 - that's okay for people that do have money'.

Need for Domiciliary Support

The Public Health Nurse is recognised as a central figure in the Primary Health Care team. As such it is expected that the Public Health Nurse would provide nursing care for the physically disabled and back-up support for the carers. However, mixed feelings are expressed in the present study in relation to the service provided by the Public Health Nurse - perhaps an indication of a lack of uniformity in delivery of this service. In rural areas, in particular, the service offered by the Public Health Nurse is not seen to be of benefit to either the carer or the disabled person:

'No, they don't help. They should give a little help at times. They come in and say everything's all right - they don't visit at all now'.

On the other hand, one carer who lives in a built-up area had the following to say about her Public Health Nurse:

'Fantastic, I couldn't say any more. Any time I can't get down she comes up. Yvonne gets pressure sores and she treats them. She comes at a time that suits me - if I say Yvonne won't be here until four o'clock she'll wait 'til she's here. I feel I can chat to her too and tell her all my problems'.

Need for Information and Advice

Several of the carers spoke of their unmet need for information and advice that would enable them to provide the best possible care. In particular, information and advice at the time of diagnosis of the handicapped person's problem is seen to be almost non-existent. One man, for instance, describes his efforts to track down information of Multiple Sclerosis so that he might be better able to help and support his wife in coming to terms with
her illness. The mother of a child with Spina Bifida describes her need as follows:

'Well you'd want to have the information you want really and doctors who would talk to you - give you support - talk to you at your own level'.

This kind of support is seen as essential in the early stages of caring where the carers are unsure of what is involved:

'I think in the early stages, the first few years to have someone who understands, someone you can go back to if you need something... information and back-up support is vital... a lot of parents don’t know how to go about things'.

Need for Empathy and Sensitivity
The needs of carers who look after a family-member from birth differ greatly from those who care for someone with a disability that starts later in life. In relation to being told a doctor's diagnosis after the birth of a child, some carers feel that more sympathetic methods could be used. One woman relates her experiences following the birth of her baby daughter who had Spina Bifida and hydrocephalus as follows:

'I knew by the sister in the hospital. I had a difficult birth but I never thought anything would be wrong... she was very gruff about it'.

A similar experience was related by another woman concerning the diagnosis of her sister's condition:

'The doctor at the Regional told me about it. The doctor just said there was no cure for her disease and that her nerves were dead - a bit crude... Well it was just thrown at us, at her and she was seventeen'.

Need for Adequate Transport Service
Transport is seen as a major problem for the carers. Firstly, for those attending school, public transport is not always available.
One woman describes her situation as follows:

'Well we had to get two cars because Dad needed a car to go to work and I had to get a car and take her up and down to school - there was public transport but they wouldn’t take her in it'.

Some school buses cannot take wheelchairs on board causing problems for families. Another need expressed by one woman in relation to transport is that while disabled people are entitled to exemptions from road tax, their spouses are not:

'Because Noel didn’t drive, I thought I’d get the tax thing on the disabled but they wouldn’t give it because he wasn’t driving. The man couldn’t drive the car but they wouldn’t pay the tax to have him driven around - I’d like to see that provided'.

For those who do not have their own transport, alternatives are either expensive or unwieldy or both:

'I don’t have my own transport but I think it would be great for Jill. When she needs to go to physiotherapy we have to get a taxi and I have to take the time off work to help her out and in. I’d love a car'.

ADDITIONAL PERCEIVED UNMET NEEDS

Need for Financial Remuneration for Caring
When asked whether they perceive that carers get a fair deal, some of those interviewed indicate that they do not because they are not financially recompensed for the work they do. One woman, whose son was paralysed in a car accident, explained her position as follows:

'He gets his Disability Allowance all right but I never got a Carer’s Allowance... people need something to help them out - some allowance for yourself, I mean'.

Another woman referred to the inequity of the system whereby the spouse of the disabled person is not entitled to a carer's allowance:

'To tell you the truth, I don't get Carer's Allowance or anything like that. Now if I was anyone else they would get Carer's Allowance, but the wife doesn't and I think that's a disgrace, I really do'.

The point was raised by many of the carers that they get no financial recognition for the work they do despite the fact that if the disabled person had to be maintained in hospital the cost to the State would be very much greater:

'I mean the fact that hospitals are so expensive now, that the fact that you're looking after them at home, you're saving the State and you should be entitled to some help'.

The interviews reveal that there are many costs incurred in providing care for a disabled person. As one mother reports:

'Well there's creams and powders needed and she's a devil for tearing tracksuits - I've loads of tops but the bottoms are ripped'.

Others point out the expense involved in purchasing items such as incontinence pads, sheets and nappies; for which, as one carer emphasises, they receive no recompense. There are also other expenses which those not involved in caring frequently do not understand. The mother of a child with Spina Bifida points out that:

'You have to buy soft shoes costing a lot more and they wear out clothes quicker'.

Some find it hard to get by, particularly in the situation where the disabled person had previously been the breadwinner of the family. As one woman expresses it:

'You just get by - I'll put it to you that way. What you get you can just live on it. If there's anything extra you just don't have it'.

This shortage of money, not surprisingly, is perceived as adding to the emotional strain of caring:

'I don't think there's anything else needed at the moment besides money. It's an added worry'.

Need for Emotional Support

It emerges from the interviews that those carers with little or no contact with friends or family express greater strain in caring. Family members are the most usual confidants of the carers and are seen as providing the most support because they understand the situation better than others. Carers without family support speak of 'strain' and 'tension' in caring and indicate an unmet need for someone to whom they could talk openly:

'I think there should be a social worker there. Just someone to chat to - when a person is feeling low... to give a sympathetic ear'.

Some carers report that voluntary groups, such as the Multiple Sclerosis Society, are very helpful in that 'you meet people in the same position as yourself'. However, most carers, although having contact with the relevant voluntary organisation, feel that support for the carer per se is not an obvious objective of these agencies. One woman who was involved with the Spina Bifida Association, commented as follows:

'I would love somebody to come to me... someone in my situation, not even that but something similar, to come along and talk to me and tell me how they feel and how they get through it'.
Similarly, another woman would like to see more support for carers but recognises the difficulties in getting people to attend:

'I think there should be groups like that... the only way you meet people is by going to the Multiple Sclerosis meetings. Mostly it's for the people themselves so you don't get involved - we used to go... but then a lot of people don't have the time when they're looking after people... if it was on, something might happen that you couldn't go'.

Need for Social Contact
For all of the carers, social life is affected to some degree by their caring role. One woman, looking after her husband, explains how she no longer goes out socially because 'it used to agitate him... it used to cause too much hassle'. Some find that they are simply too tired at the end of the day or they have not got the time for any kind of social life. Others find that getting out for an evening does not really help because they worry about leaving the handicapped person in the care of another:

'Social life is gone by the way side. I would like to get out but I don't relax when I'm out at all - maybe it's me - I think the fear of something happening... I'm frightened that the kids will say something to her'.

Lack of money also restricts the social life of the carers:

'Well financially we couldn't have a social life 'cos Orla would suffer - she wouldn't have anything - we just had to do without social life - we just can't go on holidays or anything'.

The result of constriction of social life and lack of contact is that some carers experience loneliness and feelings of isolation.

Need for Greater Access to Educational Services
Most of the individuals being cared for by the carers of the present study are of school-going age. As indicated previously, transport generally can be a major problem for carers and disabled
people. Lack of appropriate transport also hinders access to educational services. A further difficulty related to schooling arises from unwillingness to accept children with disabilities into mainstream schooling. One woman described her experiences as follows:

'There were problems when she started first - they didn’t want to take her to a normal school and I kept on fighting and I was fighting for 12 months until she got into the school and eventually I went into the doctor one day and he said "Molly did you get her into school" and I said 'no' and he said 'why?' and I said something to do with the Sisters not wanting to take her'.

Need for Long-Term Care Facilities
In a few cases, the carers indicate that they have discussed long-term care with the disabled person. Where the person being cared for was willing to go to hospital should the need arise, the carer no longer worried. However, for some carers the issue of long-term care is a serious concern. One woman who is caring for her sister described her worry as follows:

'On the long-term I just wonder where she’ll finish up. If I weren’t there I know Mary would not be at home - she’d be in a home which she wouldn’t really like'.

INFERRED UNMET NEEDS

Need for Recognition of Differences Among Carers
The interviews reveal that carers differ greatly according to their life circumstances and the nature of the care which they provide and, accordingly, their needs vary. The provision of services on the basis that carers form a homogeneous group results in a mismatch between the individual needs of carers and the help given to them. In addition, service-provision needs to take account of the particular stage of the caring process which the carer is experiencing since different needs come to the forefront
at different stages. The present interviews reveal, for example, the importance of advice and information at the initial stages of caring whereas options for long-term care assume more significance at a later stage.

Need for Focus on Carers' Own Needs
All of the carers of the study experienced difficulty in responding to questions related to their own needs as individuals apart from their caring role. Needs, for the most part, are articulated by them in terms of what is required to look after the disabled person. It is clear from their responses that carers need to be encouraged to focus also on their own lives and to acknowledge and respect their own needs. It is important that carers re-focus on their own needs not only for their own sakes but also so that they may continue to be in a position to provide the quality of care which they currently give.

Need for Monitoring of the Carer's Health
The finding from the interviews that many of the carers suffer from back-strain, chronic fatigue and a variety of stress-related symptoms clearly implies the need for monitoring of the carer's own health. Where health-workers do call to the carer's home the focus is on the health of the disabled person. It is clear that if the carers are to continue to provide care on a long-term basis, their own health also needs to become a focus of attention. An important aspect of looking after the carer's health would seem to be the provision of counselling to enable the carer deal with the tensions and emotions arising from caring. The development of stress-management skills would also appear to be of significant value.

SUMMARY

The interviews reveal the dedication and commitment which the carers of the study bring to their caring role. Their descriptions of their everyday lives indicate how arduous and
time-consuming this role can be. The feedback obtained from the carers highlights how the difficulties of caring are exacerbated through failure to meet many of their needs. Foremost among these unmet needs is the provision of practical back-up support. Failure to meet this need not only increases the difficulties of caring but also rebounds on the carers' health and restricts their social lives. This and other needs identified by the carers as being currently unmet are summarised below.

Most Frequently Mentioned Unmet Needs
- need for respite from caring
- practical help in caring/back-up support
- practical aids to caring
- regular contact with Public Health Nurse (rural areas)
- easily accessible information and advice
- empathy and sensitivity in conveying diagnosis
- appropriate transport

Additional Perceived Unmet Needs
- payment for caring/better financial support
- emotional support
- social contact
- long-term care alternatives
- greater access to available educational services for the disabled person

Inferred Unmet Needs
- recognition that carers are not a homogeneous group
- acknowledgement and respect for their own needs among the carers themselves
- monitoring of carer's own health
- counselling; stress-management Skills
References:


5. Green Paper on Services for Disabled People, 1984, op cit, p. 28.


References:

13. Ibid.


22. Ibid.


25. Ibid.

26. NRB, Day Care and Day Activity Centres for People
References:

(Ref No. 26 continued from previous page)


28. Ibid.

29. Ibid.

30. Ibid.


33. Ibid.

34. Ibid.


36. Ibid.

CHAPTER SIX

THE UNMET NEEDS OF ADULTS WITH LITERACY PROBLEMS

Introduction
The purpose of this chapter is to describe the unmet needs of adults who experience problems in relation to literacy. For the purposes of the study, adults with literacy problems are defined in terms of attendance at a literacy scheme and unmet needs in relation to literacy are explored through the experiences and perceptions of people who attend such schemes. There are, however, many in the community who are experiencing literacy problems but who remain unidentified because they have not sought help. Because of the nature of their problem and the perceived social stigma attached to it, adults with literacy difficulties are frequently concerned not to attract publicity to themselves. Accordingly, it is particularly important that people with such problems are given the opportunity to present, in a confidential forum, their views on their needs and the extent to which these needs are currently being met.

CONTEXT

This section presents the context within which the needs of those with literacy problems may be viewed. The section begins with a discussion of definitions of literacy followed by an outline of the kind of information society within which people with literacy problems have to live. The section also describes current literacy provision in Ireland.

Definitions of Literacy
The literature reveals that there is no one accepted definition of literacy and different definitions can lead to greatly differing estimates of the numbers with difficulties in the area. It is generally agreed, however, that the conventional view of literacy
which equates it simply with ability to read and write is probably inadequate. A distinction may be made between the technical skills involved in literacy and comprehension skills\(^1\). Technical skills comprise knowledge of the letters of the alphabet, associating each letter with its sound and combining letters into words, phrases, sentences and whole texts. The comprehension aspect of literacy is sometimes referred to as 'cultural literacy' and requires knowledge of vocabulary as well as background information that enables written messages to be placed in context and that makes them intelligible\(^2\). In the conventional sense, or in terms simply of technical skills, illiteracy nowadays may not be very widespread.

Three widely used approaches to definition of literacy may be identified\(^3\):

1. definition in quantifiable terms such as reading age on standardised reading tests
2. definition in terms of socio-linguistic structures which takes account of social expectations and values and the relationship between spoken and written language
3. definition in terms of the literacy skills required by an adult to function competently in his/her own society.

The use of reading age on a reading test as a criterion for the assessment of adult literacy has been criticised on a number of grounds. Such tests are standardised on children's performance and may have little practical relevance to adults. However, a more serious concern, implicit in relating adult problems to those of children, is that adults with literacy difficulties come to be equated with children and are treated as such\(^4\). The administration of such tests to an adult who has presented for help may have the added negative effect of damaging self-confidence and acting as a reminder of previous educational failures\(^5\).
Definitions of literacy in terms of socio-linguistic structures have led to explorations of the role of language deprivation and language ability in reading failure. While such an approach may be useful in exploring the nature of the reading process it may be seen as of little practical value in identifying people with literacy problems.

The most commonly adopted approach to literacy problems among adults involves the concept of functional literacy. This approach focuses on literacy in terms of tasks requiring literacy skills and aims to develop the person's ability to function comfortably in his/her own society. The functional view of literacy relates it directly to specific problems experienced by the adult in his/her community and allows the development of tests to establish at what level the adult is functioning in his/her specific environment.

Functional Literacy

It has been suggested that the degree of literacy the person's lifestyle demands is the most appropriate criterion for deciding whether or not the person has a literacy problem. According to this view, literacy may be defined in functional terms as follows: 'The possession of skills perceived as necessary by particular persons and groups to fulfil their own self-determined objectives as family and community members, citizens, consumers, job-holders, and members of social, religious, or other associations of their choosing. This includes the ability to obtain information they want and to use that information for their own and others' well-being; the ability to read and write adequately to satisfy the requirements they set for themselves as being important for their own lives; and the ability to solve the problems they face in their daily lives.'

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This definition of functional literacy highlights the importance in determining literacy needs of finding out what the individuals themselves see as their objectives and what their circumstances and lifestyles require. The importance of taking account of the person's situation is underscored by research which shows that both adults and children are unlikely to be successful in learning and retaining literacy skills unless their environment demands literacy and rewards its acquisition\(^\text{10}\).

This definition also highlights the impossibility of having set criteria of literacy since there can be no set criteria with regard to how much people ought to know or should be able to read, in order to function adequately in society. As society becomes more complex, the level of literacy required also increases. Conceptualised in this way literacy becomes a variable requirement determined by the level of complexity of the society in which the individual finds him/herself. Accordingly, definitions of literacy need to have in-built flexibility to allow for changes in society leading to increased demands on literacy skills. Recognition in Ireland of the importance of the concept of functional literacy is evident from the following statement taken from a 1983 edition of the newsletter of the National Adult Literacy Agency\(^\text{11}\):

'... it is far too minimalistic to use the words 'adult literacy'. The term adult basic education or training is far more comprehensive, integrative and relevant. Adult basic education includes those programmes (learning activities) designed to provide adults with skills in learning, reading, writing, spelling, listening, speaking and computation, together with the coping and interpersonal skills which will assist adults to deal adequately with real life situations'.

The Information Society
The definition of functional literacy described above implies that the level of social, economic and personal disadvantage experienced by a person with literacy problems is contingent on
the standard of literacy demanded by his/her society. In this context, it is important to note the changing nature of Irish society. Since the beginning of the 1960's, Ireland has undergone considerable economic, social and cultural change. There has, for example, been a shift from agriculture to industrial employment and a shift also from blue-collar to white-collar jobs. Ireland is also now experiencing the worldwide movement from jobs in industry to jobs in services. The advent of the microprocessor has brought radical change in a wide variety of activities. Information technology is replacing muscle power, knowledge is becoming the key industry and the key product and there is an increasing demand for knowledge workers.\textsuperscript{12} In an increasingly sophisticated and complex society, characterised by rapid change, literacy becomes an essential skill being both a tool and a facilitator of change. It has been pointed out that the standard of literacy generally required to function in today’s society has risen to unprecedented levels of complexity and severe disadvantage is experienced by those who have not managed to reach these levels.\textsuperscript{13} In a previous era, being able to read a little and to sign one’s name could have been regarded as a sufficient, minimum level of attainment. Such a minimum level is, however, clearly inadequate to cope with today’s information-based society.

### Estimates of Adult Literacy Problems in Ireland

The development of an effective and co-ordinated national literacy campaign clearly requires accurate assessment of the extent of literacy difficulties within the country as a whole. However, leaflets published by the National Adult Literacy Agency (NALA), for the 1990 International Literacy Year, point out that it is very difficult to establish a precise figure for the number of adults in the Republic of Ireland with reading and writing difficulties. The European Bureau of Adult Education estimates that between five and 10 per cent of the population of the Member States possess literacy skills so inadequate that they are prevented from participating effectively in social and community life or finding employment in a modern and changing economy.\textsuperscript{14} On
the basis of such figures and available Irish statistics, NALA estimate that currently in Ireland there are at least 100,000 adults who are experiencing significant difficulties with reading and writing and are in serious need of help. In addition there are many other people who require help in improving their reading and writing to enable them participate more fully in a society which requires increasingly complex literacy skills.

A 1984 report on identifying adults with literacy needs points out that assessments of the scale of the problem in Ireland are typically made on an inferential basis being derived mainly from school-based or school-related research. However, the interpretation of adult literacy problems in terms of those literacy related skills required to function effectively in the community requires a very different approach to assessment. Assessment of functional literacy needs to be based on the individual's level of mastery of the practical literacy tasks of his/her society. A national survey of literacy difficulties based on functional criteria has not been carried out, to date, in this country.

Adult Literacy Provision in Ireland

Provision in Ireland for adults with literacy problems began in the mid-1970s with the establishment of literacy schemes in Dublin and Cork. While the 1970 National Adult Education Survey had pinpointed 'functional illiterates' as a priority group in the development of a new national adult education programme, there was, however, little official recognition of the extent of literacy problems. Over the later years of the 1970s a number of local literacy schemes were established around the country by voluntary groups and by some Vocational Educational Committees (V.E.C's). Many of these schemes were, however, abandoned due to lack of governmental support and finance. In 1980 the National Adult Literacy Agency (NALA) was established to act as a co-ordinating and campaigning body for all those involved in adult
literacy work in Ireland. Since 1985, NALA has received a grant-in-aid from the Department of Education.

A second commission on adult education was set up in 1981 and the Report of this commission which was published in 1983 - *Lifelong Learning* - recommended that adult literacy provision should be free and that adult literacy organisers should be paid. Since 1985 some funding has been available through the Department of Education for local adult literacy schemes through the Community Educational and Literacy Budget. The budget is allocated on a yearly basis and is administered through ad hoc Adult Education Boards of the VEC's. The Community Education and Literacy budget for 1989 for the entire country, amounted to £500,000; only part of which is allocated to local literacy schemes which currently number around 80. As shown below, funding for literacy classes comes from different sources:

- prison service funded by Department of Justice and VEC
- Psychiatric hospitals and day centres funded by Health Boards and VEC
- Centres for the unemployed funded by FÁS, ICTU, VEC, SES
- Rehabilitation Institution Training Programmes funded by ReHab
- Youthreach Programme funded by FÁS
- Travellers' centres funded by FÁS and VEC
- Community training workshops funded by FÁS and VEC

A survey carried out in 1989 by NALA among 159 centres involved in literacy provision - excluding institutional settings not accessible to the general public - found that around 4,113 adults are currently receiving help with literacy in the 96 centres which took part in the study. The survey highlights that the number of adults receiving literacy help is only a very small percentage of the estimated total of 100,000 in need. Despite the recommendations made in the *Lifelong Learning* report, the survey found that approximately 95 per cent of tutors in local literacy schemes are unpaid. The survey also highlights the fact that most
literacy scheme participants can expect only two hours tuition per week amounting to a fortnight's full-time tuition per year; a level which is clearly insufficient to meet their needs.\textsuperscript{20}

The NAIA has drawn up 'A Charter of Rights for People with Literacy Difficulties' in which a number of reforms necessary for a comprehensive and accessible literacy service are spelled out. These reforms include the following:

1. Recognition by the State, Education Organisations and society at large that a significant proportion of our population does not benefit from the school system.
2. It must be understood that such a deep-rooted educational and human crisis can only be properly tackled by the provision of adequate resources and funds. These funds must be made available in a flexible manner to meet the needs of the learners at local level.
3. Paid staff, especially organisers and tutors, are an essential ingredient for any system of provision.
4. The adult literacy service must be based on sound principles of adult learning. In particular the learner must be seen as an equal partner in the operation and delivery of the service.
5. Proper facilities must be made available for tuition. It is important that these facilities have an adult ethos and are available at different times and different locations.
6. It is essential that bodies such as the National Adult Literacy Agency are adequately funded to deal with research, training, promotion, development of materials, etc.

LITERATURE REVIEW

To date, little research has been carried out in the Irish context in relation to literacy difficulties and the effectiveness of literacy schemes established to remedy such difficulties. This section highlights key issues identified in the available literature related to:
. publicising literacy schemes
. basic ingredients of adequate literacy provision
. confidentiality
. perceived causes of literacy problems
. effects on people's lives of literacy problems

Publicising Literacy Schemes

According to the authors of a study on the experiences and perceptions of the participants in the Co. Offaly Reading and Writing Scheme, one of the most outstanding findings of their research 'is that most of the students experienced considerable difficulty in finding out about and making contact with the literacy scheme'\(^{21}\). Participants who had made the decision to seek help found information hard to obtain with most spending several years thinking about classes and making tentative enquiries before taking the first step. Most participants eventually found out about the Reading and Writing Scheme through a friend or relative\(^ {22} \). Publicity is also recognised as an important issue by other literacy schemes such as the Co. Clare Reading and Writing Scheme\(^ {23} \). The findings highlight the need to address the issue of disseminating information particularly among those who may not have the support and assistance of friends or family in finding out about schemes. Support and encouragement are very important in maintaining motivation and, clearly, potential literacy scheme participants need to be facilitated in every way possible in taking their first step to seek help.

Two elements in relation to publicity may be distinguished. The first element involves making information available to potential literacy scheme participants while the second element involves publicity aimed at raising community awareness of literacy difficulties. With regard to publicising literacy schemes among potential participants, the students involved in the Co. Offaly research project made a number of suggestions as follows\(^ {24} \):

- television is very important;
- radio should be used, both local and national networks;
there should be clear and frequent church announcements (e.g. every two months); also local clergy should be well informed about the issue and about local provision;
- advertisements in local newspapers are useful and should always include a phone number;
- leaflets should be distributed, giving full information and a section to fill in name and address and send off to the scheme;
- clear signs may be helpful;
- there should be places locally (e.g. in villages) where people could call in for advice and information at specific times advertised locally;
- posters are needed in prominent places, including churches, shops, FAS offices, welfare clinics;
- social workers should all have information;
- literacy students should be encouraged to tell others who have difficulties and help them come along;
- it should be made clear in publicity that confidentiality is respected.

The experiences of scheme participants highlight the importance of including a phone number or contact address in any publicity material.

The finding that most participants learn about the literacy scheme through friends or family underscores the importance of raising awareness among the general public both of the existence of literacy difficulties and the schemes available for those in need of help. In this regard, it has been noted that in providing general information it is important to distinguish adult literacy schemes from traditional school education. It has been suggested that a useful means of disseminating information is to target key people in the community who may be the first point of contact for people seeking help. While each local scheme needs to identify who are the key people in their own particular area, the following have been suggested as useful targets:
teachers
librarians
public health nurses
job search personnel

Tutors in the Co. Clare Reading and Writing Scheme have also found a multi-pronged approach to disseminating information to be the most useful and employ the following variety of strategies:

- Christmas cards to firms, organisations, tutors and participants
- Clare Radio - advertisements and interviews
- Posters
- Local paper and parish newsletters - advertisements and information
- School visits
- Liaison with agencies such as FÁS, Social Services, Psychiatric Hospitals
- Brochures distributed through libraries and display stand at Shopping Centres

In recognition of the role which libraries can play in increasing public awareness of literacy problems, Dublin Public Libraries have initiated a number of schemes including the establishment of Adult Literacy Resource Centres, the provision of information on audio and video tapes suitable for people with literacy problems, organisation of lecture programmes and workshops and provision of meeting places for tutors and students.

Adequate Literacy Provision
A number of issues arise in considering the provision of an adequate literacy scheme. These issues include:

- frequency of tuition
- type of tuition
- setting of tuition
- selection and training of tutors.
As indicated previously, adults with literacy problems in Ireland can expect to receive about two hours tuition per week. The findings from the Co. Offaly research project indicate that this level of tuition is perceived by literacy scheme participants as being 'just not enough'. While some would be unable to attend classes more than once a week many participants would like more frequent tuition.

With regard to the type of tuition, teaching may be provided on a one-to-one basis or in a group setting. The former type of tuition has frequently been promoted on the basis that it preserves confidentiality. However, two-thirds of the participants in the Co. Offaly project indicated either that they would prefer a group at some stage or else that they had no objection to group tuition. It is interesting to note that among those who had reservations about group tuition, their primary concern was with the pressure of competition rather than with the issue of confidentiality. It has been found that participants in group tuition experience greater self-confidence and higher self-esteem and find that working with other students is the best way to share and expand their literacy skills. The need to address the competitive aspect of group tuition has also been raised in other schemes. According to the organisers of the Clare Reading and Writing Scheme, one-to-one tuition on a continuing basis has the drawback that students become dependent on tutors and feelings of isolation are reinforced. In their experience lack of confidence arising from negative school experiences and inability to 'keep up' is at the basis of concern about group tuition. The Co. Clare scheme has had a long and successful history of tuition with 'natural' groups either where a number of family members present together for tuition or where a particular institution has organised a group.

Existing research shows that a further factor in adequate literacy provision is the setting in which tuition takes place. In some rural schemes, participants may live from 20 to 50 miles distance
from the base of scheme organisers\textsuperscript{36}. Such distances can lead to difficulties in monitoring progress and in keeping contact with scheme participants. What is required is the establishment of locally based resource centres which allow privacy and space for both individual and group tuition.

A further issue in adequate provision which is highlighted by research is related to scheme tutors and the support and training they receive. Typically, volunteer tutors play an important role in literacy schemes. However, research shows that there is a high turnover among volunteers and that they require a large amount of training and support\textsuperscript{37}. It has been proposed that a more cost-effective and efficient approach to tutoring would be to appoint a number of paid tutors who would give a number of hours of tuition each week both on an individual and on a group basis\textsuperscript{38}. These paid tutors would be the key workers in the scheme and would receive back-up support from volunteers. It is considered that such a scheme would provide for greater continuity among tutors.

Confidentiality
Because of the stigma attached to literacy problems and the embarrassment which those who suffer such problems may experience, the importance of confidentiality in literacy provision has frequently been emphasised. Confidentiality is regarded as being of particular importance in the rural context where communities tend to be close-knit and where people inter-marry and are well-known to each other\textsuperscript{39}. However, the Co. Offaly research project clearly showed that while confidentiality may be important in initial publicity of the literacy scheme, many participants, at a later stage, are not concerned with this issue and are very willing to participate in group tuition\textsuperscript{40}. Later research in another rural setting found that confidentiality was essential in the initial stages of literacy tuition and participants indicated that they would not approach a scheme unless confidentiality was assured\textsuperscript{41}. The issue of confidentiality may be of less significance in an urban context. According to organisers of one
urban scheme while confidentiality is always respected, 'it is not an issue which is foremost in the scheme's list of priorities and it is rarely mentioned in local publicity campaigns'. There is evidence that the need for confidentiality is linked with lack of confidence and that with improved literacy skills confidentiality becomes less important.

It appears that rather than over-emphasising confidentiality which may in the long term lead to isolation, the focus should be placed on developing self-confidence so that scheme participants may be enabled to overcome isolation and social stigma.

**Perceived Causes of Literacy Difficulties**

With regard to perceived causes of literacy difficulties, research in the Irish context shows that school-related issues are the most frequently identified by scheme participants. Participants in one rural scheme noted, for example, that physical punishment, the experience of 'being ignored' and 'being made to look small' were major contributory factors in their literacy difficulties. Likewise, participants in an urban literacy scheme perceived that factors such as large numbers in classes, corporal punishment and an over-emphasis on less practical subjects - such as Catechism - contributed to their failure to acquire adequate literacy skills. Further, less frequently noted, factors in literacy difficulties include family problems, illness and physical problems such as poor eyesight. The 1986 discussion document on adult literacy lists a number of factors which are generally accepted as contributing to problems with literacy. These factors include: physical problems; home background; school; special problems; and intelligence and social background. The findings obtained in the Irish context match closely those obtained in other countries. For example, in a survey conducted in Britain, teachers and students were asked to classify the causes of reading failure under the headings of 'intellectual', 'emotional', 'sensory', and 'circumstantial'. Among the students, factors were ranked as circumstantial, sensory and intellectual with 'poor teaching'
being perceived as by far the greatest contributory factor. According to the teachers in the study, contributory factors may be ranked as intellectual, sensory and circumstantial.

Effects of Literacy Difficulties

Research from Great Britain and the U.S. highlights the economic, social and personal costs experienced by adults with literacy difficulties. It has been found, for example, that comparatively, many adults with literacy difficulties are unemployed and are dependent on Social Welfare. The employment profile of the adult illiterate in the US has been drawn as follows:

- he is less likely to be a member of the labour force
- if he is, he is less likely to be employed
- if he is employed, he is less likely to have a full-time job
- if he is employed, his income is likely to be less that that of a literate person.

A checklist of the social, economic and personal disadvantages consequent on literacy problems drawn up by American researchers includes the following:

- has a devastated concept of his/her own self-worth
- is usually the last to be hired and the first to be fired
- is a target for replacement by automation
- has difficulty complying with society's regulations
- is likely to be on welfare
- leads a survival-based life - live for today syndrome
- generally does not see value in returning to school - which was a bad experience for the few years he did attend
- tends to perpetuate illiteracy through example and attitude to his/her children
- is fearful of new experiences
- is unaware of the changing environment because his/her own world seems unchanged
- is an inefficient consumer
- is likely to have health problems.
Similar findings have been found within the Irish context. Almost half of the participants in the Co. Offaly research project noted that their job or work opportunities had been affected in different ways: through limitations on the work available to them; by creating tensions in the job; by restricting opportunities for promotion or change. Many participants in this project also felt that their everyday activities and social contact were restricted by their literacy difficulties, while some felt that their relationships with families—especially children—had been adversely affected.

METHODOLOGY

This section outlines the procedures used to explore unmet needs in relation to literacy. It presents a profile of the group interviewed and describes the themes around which the interview was structured.

Profile of Literacy Interviewees
Ten people with literacy problems were interviewed; four of these being female and six male. The ages of those interviewed varied greatly from 16 to 50 years indicating the lack of homogeneity among people with literacy problems. The youngest interviewee represented a category of early school leavers who had not acquired even the basic literacy and numeracy skills. Interviewees were drawn equally from urban and rural areas with five being from Limerick City and outlying areas and the remainder coming from parts of County Clare.

Although all of the interviewees had low levels of educational achievement, this was not always related to socio-economic circumstances since those interviewed were drawn from a variety of backgrounds. The only common feature among interviewees was that they were all participants in Literacy Schemes organised by their local V.E.C. Participants in Literacy Schemes were chosen for interview both because of ease of identification and also because
it was felt that people with recognised literacy difficulties who were not attending schemes might not adequately perceive their problem with literacy and consequently might be unable to articulate their needs as individuals with literacy problems.

Means of Contact
Contact was made with those interviewed through the organisers of Literacy Schemes in Counties Limerick and Clare. Interviewees were informed of the purpose and nature of the study and invited to take part. It was necessary that contact with the SRC should take place through scheme organisers because of the issue of confidentiality guaranteed to those who get involved in Literacy Schemes. It was emphasised that the study was being carried out by an independent agency and that participation was voluntary.

Ten respondents were contacted, all of whom agreed to take part in the study. All interviews took place at times assigned by the scheme organisers.

Location and Duration of Interview
Because of the importance of the issue of confidentiality, interviewees could not be interviewed in their own homes. Instead, they were interviewed in the locations they normally attend for classes. All interviews were conducted with just the respondent and the interviewer present. During one interview, held in a community centre while a literacy class was in progress, children from the area continuously knocked at the windows and doors, jeering participants of the scheme. This highlights the necessity for sensitivity in dealing with the organisation of schemes and again raises the need for confidentiality. Interviews ranged from 1 to 1½ hours in length. None of those interviewed indicated any problem with the recording of the interview.
Themes Covered in the Interview
The interview was intended to facilitate people with literacy problems in presenting their own views on their needs and concerns and in assessing to what extent they felt their needs are currently being met. Within this exploratory framework, the following themes were covered:

- general needs
- family circumstances
- education
- becoming aware of literacy problem
- occupation/economic circumstances
- problems caused by literacy difficulties
- overcoming literacy problems
- literacy schemes
- using public services
- participation in the community
- personal relationships

FINDINGS: MOST FREQUENTLY MENTIONED UNMET NEEDS

Need for Confidence Building
One of the most outstanding impressions arising from the interviews is the devastating effect on self-confidence which literacy difficulties can have and the very great need for recognition of this and the need to build confidence and self-esteem among people who suffer such difficulties. The importance of confidence is illustrated vividly in the following quote:

'The most important thing to do is to make people feel at ease and comfortable and then if they learn a little bit each day... a person needs confidence, and they need to be shown how to cope with it because there are lots of things you cannot cope with when you cannot read or write... and you are holding it in and you are afraid all the time. Fear is the one thing to try and get out of the way... a lot of it was fear for me.'
While most of those interviewed indicate that their confidence has increased greatly since becoming involved in the literacy scheme, there are others who suggest that more needs to be done in this area. In one woman's opinion there should be specific classes related to confidence-building:

'I think all the people who are lacking in confidence should get together for a simple session or group... where you would have to stand up in the room by yourself. I think that it is a great way to build your confidence. At the same time I think people with reading and writing problems need to be on their own before they go into a group'.

A similar need is expressed in the following statement:

'I think we get to have low opinions of ourselves... we have no confidence. People need to bring their problem out in the open more but they need to have courses to build up their confidence. You need somebody to tell you that there is help out there for you'.

It is also suggested that confidence could be built up through participation in evening classes, provided that publicity material makes clear that there is no writing involved:

'There should be more... especially these evening classes now... thousands of women and men would like to do carpentry or needlework or flower arrangement... but they have such a fear of going in there and having to write something. When they are advertising they should say that there will be no exams or no writing involved. You would be surprised how many people would come forward if the fear that there was written work was removed. There should be more courses for these people... very few people are going to go into a teacher and say 'I'm dyslexic'. I'd love to be taught how to address people... courses like these - they all help to build self-confidence'.
The adverse consequences to which lack of confidence can lead are illustrated in relation to work in the following quote:

'The only jobs I have been in for have been on the buildings. The last job that I was in before I had to leave work was in a kitchen. I was offered a bit of a promotion but I was too embarrassed so I let the job go to somebody else'.

Need for More Adequate Literacy Provision

Without exception, all of those interviewed reiterate the need for literacy classes on a more frequent basis than is currently offered. The greatest complaint in relation to present literacy provision is that services are too few and too infrequent. The urgency with which this need is felt is expressed in the following quote:

'I find the course is great, but there is not enough nights of the week of it... it's only one night a week. I feel it should be nearly four nights a week... on a constant basis. I go on a Monday night and by the following Monday night you have nearly forgotten what you did the week before so you have to keep looking up your book. You try to cram everything into that hour... it's not enough time. I feel that everything should happen overnight... I want it to happen so fast but I feel it is not enough. I feel I need a couple of nights a week at least'.

Another aspect of provision noted by some as being currently unmet is the need for early intervention:

'I'd like to see more of these classes and I'd like to see them for teenagers as well because I know a lot of them myself who very much lack confidence... I'd love to see something for 15 and 16 year olds'.

One woman, who is herself dyslexic and has two children with the same problem, sees the provision of special schools for dyslexic children as an unmet need:

'I would like to see schools set up for dyslexic children
because it's unfair for them to be left in the classroom to be humiliated... teachers haven't got time... there are too many children in the classroom. They are still sending these children to 'Bawmore' - for slow children... when some dyslexic children have an IQ of 110 or so. There are no schools for these children which there should be. I think the Government should do something to help these children... otherwise they turn out frustrated (like myself)... and there is nothing much you can do in life because everything is geared to reading and writing. The Adult Literacy Scheme is a brilliant scheme. It is fine for my age group. But children coming out of school, now'.

Need for Information
The comments of those interviewed make it quite clear that the marketing of the literacy schemes is an issue which needs to be addressed. Many of the interviewees highlight the fact that accessible and appropriate information is still an unmet need. As one man points out:

'I don't think people are aware of the services. I don't think they are made aware of these services... it should be put into the papers - advertised - I'm sure there is money for it because it's an important area'.

The need to publicise the services available is emphasised several times as in the following comment:

'If possible I'd like to make it known that the service is available... and to have it in more centres, you know, so that it is more accessible to people. I think it should be advertised on a regular on-going basis and to give a contact name that people can get in touch with'.

Some point out that current means of publicising schemes are often inappropriate. It is noted, for example, that posters or notices are of limited value since those to whom they are aimed cannot
read them. Advertising the schemes on the radio is the most frequent suggestion for useful publicity:

'I think it should be advertised more on the radio instead of on the paper'.

Another suggestion put forward is to make announcements on the literacy schemes on a regular basis at Sunday Mass.

In addition to publicising schemes, some of the interviewees point to another aspect of information which involves raising awareness of literacy difficulties among the general public. This view is illustrated in the following comment:

'I think the person should be helped to accept that they have a problem, and then to find out that there is help there. I think it should be really publicised and brought out into the open'.

Similarly, one of the women interviewed spoke of the need for public education on the problem of dyslexia so that the kind of problems experienced by her dyslexic son might be avoided:

'In school my son's friends call him stupid... Christy Brown... Things like that. Okay, they are young, they don't know any better but the teacher should stand up in the classroom and explain about dyslexia and educate the children. I think school should get people to speak about dyslexia... but I think people only speak freely outside their own area'.

Need for Attention and Understanding at School

Negative experiences in school were recounted by all but one of those interviewed. The following quote exemplifies the kind of perceptions expressed:

'I hated school... and I hate school today and I would never go back to school. I hated the nuns, I hated the way they treated me, they used to kill me'.
Some felt that their problems started in school where classes were large and 'slow' children got left behind:

'School was awful... I hated it... that's where my problem started... there were so many in the school that if you fell back you were left behind... there was no such thing as trying to bring a child up... only the children who were getting on were brought up and the children who weren't were left behind'.

The experience of being left behind in a large class is noted by several of the interviewees:

'I was just left... there were three classes in the one room... it was a country school... then I went to the Tech and I lost the drift of things there as well... I was just going through the motions. I think smaller classes would have been better for me and I think good teachers are needed too'.

The lack of attention experienced in school is highlighted in several comments such as the following:

'I often ducked school because they were so strict and they had no time for me - do you understand me... they had no time for me at all'.

The significance of the need for attention and the positive consequences which such attention can bring about are very clear in the following comments from one of the men interviewed:

'There was a lot of difference made with the people who were rich and the ones who were poor. Mrs ....... was the best because she didn't care where you came from... I felt great when I was in her class... she would make you do your work in school... She wouldn't tell you to go home and do it like the rest of them did... you felt good because you knew you had something done that day. If I had stayed with Mrs ....... I wouldn't have needed to come here because she was great... she was nice about it too... she wouldn't push you. When I
went into her I was the lowest and she knew it. She started paying me attention and when I started coming on she had excellent time for me. If I stayed with her I wouldn't have a problem'.

The failure of teachers to provide the understanding needed of the problems being experienced is shown in comments such as the following:

'Is it would have been better if the teachers helped instead of roaring at me. If they only helped when I couldn't do things... instead of hammering me all the time... If they listened'.

Several comments indicate that the interviewee's need for help from teachers with school work frequently went unmet:

'I just sat at the back of the classroom and everybody called me stupid. The teacher would just say: 'Go and sit down... I haven't got time'... and all I needed was a bit of help'.

Likewise, help at home was often not forthcoming:

'If one of my brothers or sisters just kept me inside in the room at night and said... Come on, you have to do it now... and just stayed with me and taught me from the beginning with reading and writing... I think that would have helped a lot'.

Need for Remedial Service
In the view of some, what is most lacking is the provision of an appropriate remedial service. One woman points out that had such a service been available to her, her current problems might never have arisen:

'I think there are not enough remedial teachers. I know parents where their children went to these remedial classes because they were weak at a subject and it really helped them. If that had been there for me years back (I was weak at my spelling) I mightn't be attending Literacy today. What
I needed then was that extra bit of attention that I didn’t get, and I fell behind and I was left sitting there, and the further it went on the harder it got. I was lost.

Another woman claims that an appropriate remedial service is still not available today. Her son attends a remedial class but finds it difficult to understand what is going on in his own class when he returns to it:

‘When you go to a remedial teacher for two hours and then you go back into the classroom again, you have lost two hours of your class. You are doing one thing and they are doing another thing... they know you are going to remedial class. If there was a classroom with a full-time remedial teacher, and all the slow children went to that class until they started to come on, then they could go back into their own classroom again’.

Need for Respect as Equals and Removal of Stigma

Issues related to stigma and prejudice arose at several different points in the course of the interviews. For example, when asked about their greatest need, one woman commented as follows:

‘I’d like teachers, universities and the Professors and all those people who are supposed to be so well educated to teach the ordinary people that there is nothing wrong with people who have a literacy problem. They are normal... it’s just that they have a disability’.

Likewise, when asked to comment on whether people with literacy problems get a ‘fair deal’, one woman expressed the view that they were unfairly treated because of the continued existence of stigma attached to illiteracy:

‘I don’t think these people get a fair deal because first of all people make a fool out of you. They think you are stupid and in general walk all over you. The more times you try to be nice the more horrible people are to you. I think people
are basically equal and should be treated that way... if you cannot read or write you're not. There is a lot of stigma attached to it'.

In speaking of difficulties related to access to services, many of the responses illustrate that the real problem concerns the attitude of public service personnel to people with literacy problems. The problem is clear in the following quote:
'I had a bit of trouble with the forms alright when I was signing on. I could sign my name alright, but when I was applying first I had to write other details. The girl in the office was not a bit helpful - she was really sarcastic... that really made me worse'.

Similarly, another man recounts unhelpful experiences with Social Welfare staff:
'When I went to claim my stamps... the man, he was a very cheeky man. He would come along and throw you out a form and he would want you to fill it out in two seconds... "Hurry on, hurry on. He asked me over and over, why did you leave your job?" after me telling him once why'.

According to one interviewee 'you need to know what you are doing' and if you do not you are unlikely to get help:
'You need to know what you are doing... Like the fellas in the Fás Scheme... they are inclined to be down on top of you. They don't even care about you at all. Then the problem is, if you are filling out a form you might write something you didn't mean to'.

Failure of others to treat people with literacy problems with respect is again illustrated in the following quote:
'I had my children's allowance signed in block letters... the man gave out to me and refused to give me my children's allowance until I joined it up. I turned to him and said 'If
I couldn't write at all you would have to accept an X. He said 'Join it up or you will get none at all'. I should have reported him. He had no authority to refuse me.

Problems related to prejudice again arise in relation to employment opportunities. As one man explains:
'I have tried for work several times... but every time they just told me they were full... they weren't even interested in what education I had... they just seemed to have made up their minds'.

Some feel that while they are capable of work, they are not given credit for this:
'I'd like to have a load of letters after my name. I'm not boasting or anything but I'd do a lot better job than a lot of them do'.

Need for Confidentiality
Confidentiality in relation to receiving literacy tuition is most important to some of those interviewed. One woman explains the reason for this as follows:
'I think it has to be confidential because people won't turn up otherwise'.

The importance of confidentiality is expressed in the following quote:
'I think myself that there should be strict rules that whatever goes on inside the classes shouldn't be heard of outside. There should be absolute secrecy... if people cannot keep their mouths shut then they should not be tutors'.

Similarly another man comments:
'It's good for it to be confidential because you are not being embarrassed by anyone... there is nobody to say that you are completely illiterate... you don't want anybody
talking about you like that... it could be your next door neighbour. They would all be talking about you behind your back... I wouldn’t agree with that at all.

ADDITIONAL PERCEIVED UNMET NEEDS

While the needs described above are those most frequently identified as being currently unmet among people with literacy difficulties, the interviews also highlight a number of additional areas of need which warrant attention. These additional, perceived unmet needs are described below.

Need for Encouragement and Support
Among almost all of the interviewees, there appears to be quite a lapse between the time that they first recognised their literacy problem and the stage where they sought help. Many decided to seek help only when their children began to need assistance with homework. As one woman commented:

'It took me three years to do anything about it. I talked about doing something but I got lazy. The TV was a great excuse. When the children asked questions and I couldn’t answer them... that’s when I really felt stupid altogether... When I thought about it I decided I had to go'.

One of the men interviewed makes a similar comment:

'Anytime I helped them I would come up against this word and I would have to stop and look at it... 3rd class level... I felt awful'.

Some point out that they were able to seek literacy tuition only because they had been given the necessary encouragement by others. The importance of encouragement is illustrated in the following comment:

'It was on a newspaper... it was, my father who saw it... he just said to me “there is a chart there on the paper about
education and it would be very good for you, it would help you out an awful lot'. He told me where to go and I said I would go - I went straight there that afternoon.

One of the women interviewed illustrates the problems which can arise when a partner is not encouraging or supportive of attempts to improve literacy:

'It caused terrible rows in the beginning.... he was so against me going... it wasn't because of it he used to say, but I know it was, because his father is so well known in the area. I went to a public meeting where I had to read out a piece about myself in front of a big crowd. I was terrified but I did it. There I was doing all these things and how was it going to be kept a secret anymore... it nearly caused a separation'.

Choice of Tuition

The need for choice with regard to the type of tuition received is evident from the finding that while some of those interviewed like group tuition, others prefer tuition in a one-to-one context. One woman describes her preference for one-to-one tuition as follows:

'I came to ....... and she got me a tutor... a lovely person... and he has a degree himself. He helped me on a one-to-one basis and spoke to me as an intelligent person. He explained things to me and I found I learned a lot from him. It took a while, but he helped me so much in the way he didn't speak down to me'.

On the other hand group tuition is seen as useful because:

'In the group you can ask each other different questions... something would always come up in the group that you mightn't know about and you can discuss it and somebody else would give their opinion. I find that very good because there is more information'.
However, it is felt that groups are not always structured in the most appropriate manner as is evident in the following quote:

'As you are advancing I think you are better off in a group..... I think as a beginner you would be better with one-to-one. When you are advancing a group is a good idea, but you must select the groups properly..... we had a bit of a problem with the group I was in... the lady was after being in a one-to-one situation... as well there were some people better than me in the group... I was not as good as some of the rest of them... I found it hard... I told .......... who explained it to that tutor but the same tutor didn't like the explanation. You see, the teacher didn't understand that in a group everybody must be basically on the same level'.

It appears that choice of tuition is not always available. According to one man:

'It's a group scheme I go to and the one-to-one would be a better idea for a person who is slow like myself'.

Choice of tutor also emerges as an important issue. As one man points out:

'you need to have a nice person teaching you... not a person who has a bad attitude against you... patience is also really important and another important thing is for the tutor to have no favourites... that nobody gets a better chance for that reason. It wouldn't turn me off though because I was used to that going to school... but everyone is not the same, it might turn a lot of people off'.

It appears, however, that the tutor provided does not always meet the needs of those interviewed. One woman expressed her dissatisfaction as follows:

'I used to find it hard myself because she used to move very fast and I was afraid to say something. She was a good
teacher but she was impatient. I think you need a lot of patience for this kind of teaching because it is harder to teach adults than children.

Similarly, another woman commented:
'I went to a group first of all but I found that the teacher was very 'Major-like'. Within a group you get this kind of complex... so I couldn't face this learning from a child's book. I knew I was above that... you know. I went a couple of times and she was saying - I'll find out which ones are higher and which are lower... I didn't like that at all'.

Certification for Literacy Scheme Attendance
A further issue in relation to literacy provision raised by one of those interviewed is the lack of certification on completion of a literacy course.
'The course itself is okay... but it's like all these schemes... you do the scheme but it does nothing for you... what should be done in my opinion is that everybody who comes to any of these classes should have the paper to prove that they have done it... so that no matter where they go they can say they did it'.

The award of a certificate is linked with the need for encouragement and support and could increase motivation to attend literacy schemes.

Need for Simplification of Official Forms
Several of those interviewed relate difficulties with such tasks as claiming social welfare or completing a bank transaction because of the forms which need to be completed. The problem is illustrated in the following quote:
'I have problems with forms. When letters come my wife mainly looks after them. I wouldn't be able to answer a lot of the questions. Sometimes there might be some things my wife isn't able to answer herself. Then I bring them down to
my father because he knows more about the Government than ourselves'.

Similarly, another interviewee illustrates the difficulty experienced with Social Welfare forms:
'I think something should be done with Social Welfare forms... they ask you to give details about all sorts of things... I mean if you are sick, you are sick... but they ask for all sorts of details of your past. They ask you to go back years. I think it's stupid because once your number is there all your records should be there already. I think forms should be simpler'.

Those interviewed suggest that not only should official forms be simplified but special help should be available in these situations for people with literacy problems. It is suggested that part of the help that might be given would be to ensure privacy 'so that they can explain things at their own pace'. Privacy is seen as important because:
'the feeling of being watched makes you so nervous that you cannot think of anything. If you are in a line you are just going to be afraid of people behind you and what they would think'.

**INFERRRED UNM T NEEDS**

Apart from those needs specifically identified as being unmet by the interviewees, the experiences recounted point to further areas in need of attention. In the context of literacy, one such area which emerges is education of public attitudes.

**Education of Public Attitudes**

Some of the most striking experiences recounted in the interviews relate to the embarrassment and indignity frequently suffered by people with literacy problems. One woman, for example, speaks of the fear she experiences when required to fill in a form or write
a note - an activity which others take for granted:

'My biggest problem is spellings ... I am very bad at spellings and I get very nervous if I have to fill in forms or write a note to the school if the children have been cut sick or something. I suppose people take it for granted that you can do these things - it's only when you cannot that you realise that it's an awful drawback ..... If I went in somewhere and I was asked to fill in a form I would nearly get sick - I'd say something like 'I haven't my glasses with me... I'll have to bring it home'. More often that not I can fill it in but I get so nervous at the thought that I mightn't be able to fill it in'.

The embarrassment that can be experienced is illustrated in the following quote:

'It stopped me going for other jobs as well. I went down to ... for a job a few times... I didn't know anybody so nobody helped me fill out the forms... that's a big problem you know, going for jobs, and as well if there is writing involved on the job unless you have a person with you who is a friend and will help you, you won't manage'.

Experiences such as those recounted above highlight the need for public education so that people may be made aware of the difficulties encountered by those with inadequate literacy skills. Without such understanding, people with literacy difficulties will not receive the encouragement and support which they indicate is so important to them. In addition, the kind of stigma and prejudice referred to by the interviewees is likely to continue until attempts are made to educate the public on the existence and nature of literacy difficulties.
The experiences and perceptions described in the previous sections highlight a number of areas of unmet need with regard to people with literacy difficulties. These unmet needs are summarised below.

Most Frequently Mentioned Unmet Needs

- confidence building
- more adequate literacy provision
- information on services: accessible and appropriate
- attention, help and understanding while at school
- respect as equals and removal of stigma and prejudice
- confidentiality

Additional Perceived Unmet Needs

- encouragement and support in attending literacy classes
- choice in tuition: group/one-to-one
- certification on completing literacy course
- simplification of official forms

Inferred Unmet Needs

- education of public attitudes
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INTRODUCTION

Travellers have always occupied a marginalised position in Irish society. Attempts to ‘integrate’ them into community living have frequently met with stolid opposition. Authorities dealing with the problem previously envisaged that housing of all travelling people would resolve existing conflict and generally improve the situation. However, recent research has revealed that settlement of travellers does not take their attitudes and wishes into account and does little to improve their acceptance by the settled community. To date, little information is available on travellers’ needs. Their marginalised position has meant that travelling people are not given the opportunity to express openly what would help them to live their lives more fully and satisfactorily. This chapter explores travellers’ perceptions of their needs and how they feel about the services available to them.

CONTEXT

Demography

Demographic information on the travelling people is relatively scarce. The 1981 Census enumerated an estimated 14,821 persons comprising 2,551 families. A later count recorded a 9.3 per cent increase on this figure indicating that the population of travellers is growing rapidly. The 1981 Census of the travelling population noted that the number of travellers in Ireland has more than doubled in size over the past two decades. This growth in numbers poses a challenge to social policy in tackling the needs of travellers.

The age structure of traveller families differs greatly from that of the general population in that there is a predominance of