

# The Quality of Life of Older People With a Disability in Ireland



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Report No. 99

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and Older People

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As Chairperson of the National Council on Ageing and Older People (NCAOP), it gives me great pleasure to present this study, *The Quality of Life of Older People With a Disability in Ireland*, which is the first such research to be undertaken in this country.

Current data on ageing and disability reflect the timeliness of this study. For example, while 8 per cent of Irish people experience disability, this figure rises to 32 per cent for those aged 65 years or over (CSO, 2002). We also know that the incidence of disability rises with age, and that more and more people with a lifelong disability are living to older age. It is in this context that the NCAOP has been working with the National Disability Authority (NDA), with a view to identifying policy and service issues at the interface between ageing and disability.

Previous Council research has shown that public policy and service planning for older people can be improved by a quality of life focus (Murphy *et al.*, 2006). The findings of this study serve to complement this work by broadening our understanding of the experience of living with a disability in older age and identifying concepts which, it is hoped, will inform and underscore public policy, service planning and service delivery for older people with a disability including person-centred care, meaningful consultation, flexibility, advocacy, equity and age awareness. The importance of age-proofing policies and services that affect the older population is also highlighted. In addition, the research findings demonstrate that a needs assessment process for older people with a disability would benefit from adopting a quality of life focus, which would collect information that extends beyond the traditional parameters of health. Finally, this study represents an important exercise in advocacy for older people with a disability and its wealth of findings are evidence of the value of advocacy work with older people.

On behalf of the Council, I would like to thank Dr Kathy Murphy, Dr Dympna Casey and Ms Adeline Cooney from the Centre for Nursing Studies, NUI Galway, and Prof. Eamon O'Shea, Irish Centre for Social Gerontology, NUI Galway, for their commitment and dedication to this study. I would also like to thank Mr Pat O'Toole who chaired the Consultative Committee that assisted the progress of the research and oversaw the preparation of the report. Thanks are also due to members of the committee: Mary Desmond, Cope Foundation; John Grant, West of Ireland Alzheimer Foundation; Shari McDaid, NDA; Dr Ruth Loane, Consultant Psychiatrist in Psychiatry of Old Age; Prof. Desmond O'Neill, Trinity Centre for Health Sciences; Maria Fox, Disability Federation of Ireland; Dr Paul Finucane, Medical School Development Centre; and Mary Nally, Summerhill Active Retirement Association.

Finally, the Council would like to thank its Director, Bob Carroll, and Research Officer, Liza Costello, who steered the project on the Council's behalf. Special thanks are also due to Gabrielle Jacob who prepared the report for publication and to the Council's administrative staff for their assistance throughout the course of the project.



A handwritten signature in black ink, reading "Ciarán F. Donegan". The signature is written in a cursive style. To the left of the signature is a solid red circle.

**Dr Ciarán F. Donegan**  
Chairperson


## Authors' Acknowledgements

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# Council Comments and Recommendations



# Council Comments and Recommendations

## 1. Background

For many years the National Council on Ageing and Older People (NCAOP) has advocated the importance of meaningful consultation with older people in order to inform public policy and facilitate the development of services to meet their needs. This research study was commissioned to present a picture of quality of life in older age for people with a disability in Ireland and was grounded in consultation with them. It is the first such study to be undertaken here.

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As interpretation of one's quality of life is subjective and concepts of disability are steadily evolving (Minkler and Fadem, 2002), a qualitative approach was considered most appropriate for this research study. This approach is concerned, not with 'uncovering a pre-existing truth, but with uncovering meaning: how people make sense of their lives, their experiences, and their worlds' (O'Day and Killeen, 2002).

The richness of the research findings is testimony to the value of this approach. The study paints a complex picture of individual experience and highlights the heterogeneity and diversity of this group of older people. Against this background, many age-specific aspects of the experience of disability in older age are identified. Some are positive, such as the ability to contextualise impairment within the narrative of life. Others are negative and act as barriers to quality of life including experiences of ageism, loss of family and friends, and diminishing social networks. The study further identified five domains of quality of life across all types of disability: the health of the individual; their environment; sense of self; social connectedness; and income.

The personal strengths of many of those interviewed – their tenacity, positivity, humour and religious faith – demonstrated an inner resourcefulness and highlighted its value in maintaining quality of life in older age. This is an important lesson for those who stereotype older people and equate old age with passivity and dependence (McGlone and Fitzgerald, 2005). These findings also point to the role of self-efficacy in improving and extending quality of life. As Walker (2005) commented, 'policy prescriptions aimed at extending quality of life ... must contain a mixture of those aimed, on the one hand, at reducing

disadvantages and inequalities that constrain action and, on the other, at promoting self-efficacy and self-realisation and the maintenance of health and capacity’.

For the first time in an Irish setting, older people living in the community expressed in their own words their experiences and perceptions of living with a disability. This study is, therefore, an important exercise in advocacy for older people with a disability.

## 2. Public Policy

### A Framework for Person-Centred Care

This research study demonstrates that it is impossible to generalise the experiences and needs of older people living with a disability: concepts of dependence and independence have different meanings for each subject, hence quality of life can be affected by a range of factors including type of disability, time of onset, social support structures, life history and experiences, socio-economic factors, and an individual’s level of psychological resilience.

The research findings reinforce the importance of a person-centred model of health and social care. The Council has consistently advocated a person-centred approach in public policy relating to older people (NCAOP, 2005) and it reiterates this here in light of the research findings. The Council welcomes the adoption of the life-cycle approach in *Towards 2016* (Government of Ireland, 2006a), which facilitates the provision of person-centred health and social care services. **In order to ensure that the life-cycle approach translates into service planning and delivery, the Council reiterates its recommendation (Delaney *et al.*, 2001) that a care management approach to service coordination and planning and a case management approach to the delivery of health and social care services to vulnerable older people be adopted by those planning and providing services for older people, including those with a disability. It further recommends that care managers be appointed to coordinate the delivery of services for older people with a disability. Care managers should be enabled to access the appropriate services from the relevant care group programme, whether older people, mental health or disability.**

### The Ageing and Disability Interface

The evidence presented in this study provides some support for greater integration of public policy for ageing and disability services. This would ensure that older people are not excluded from disability services on the basis of their age and would also facilitate the development of person-centred care.



*Towards 2016* (Government of Ireland, 2006a) identifies the National Disability Strategy (NDS) as the key focus of disability policy. Many aspects of the NDS have the potential to improve the current situation of older people with a disability. The Council particularly welcomes the departmental sectoral plans and looks forward to all individuals benefiting equally from their implementation, regardless of their age. **In order to ensure that people of all ages benefit equally from the NDS, the Council recommends that implementation of each aspect of the NDS be age-proofed and it welcomes the commitment in *Towards 2016* to monitor progress ‘for the revision of goals and targets in the light of experience’ (Government of Ireland, 2006a).**

### Preventing Dependency

This study demonstrates that disability impacts negatively on an individual’s ability to undertake activities of daily living and their ability to maintain the home environment. This can affect quality of life negatively. **In this regard, the Council recommends that the Department of Health and Children (DoHC) should adopt and support the implementation of the National Strategy to Prevent Falls and Fractures in an Ageing Population that is currently being developed by a national steering committee established by the NCAOP, in partnership with the HSE and the DoHC’s Health Promotion Unit (HPU).**

It further recommends that the DoHC should adopt a life-course perspective in the development of future national health promotion strategies.

In addition, the Council welcomes and reiterates the principle set out in the policy document, *A Vision for Change*, that ‘regardless of their mental health history, they [older people] should have access to the services most appropriate to their needs’ (DoHC, 2006). **Acknowledging the deficits in information on the mental health of older people, the Council commits itself to exploring with the Mental Health Commission and others what information is required to plan and provide appropriate and effective mental health services for older people. It will then endeavour to address the deficits identified in liaison with the appropriate authorities.**

## 3. Service Planning and Delivery

### Achieving High Standards and Equitable Service Delivery

One of the most alarming conclusions of this study is that the community care system has failed many older people with a disability for a range of reasons, including inadequate

standards of service, poor coordination and unacceptably long waiting periods. Inequity is an inevitable outcome of this. The failure of the community care service to meet the needs of this population of older people places those who are dependent upon the State in a very vulnerable position. For example, while this study identified the home and local environment as a critical domain of quality of life, many of the older people interviewed reported difficulties in accessing grants to make necessary modifications to their homes within an acceptable timeframe.

The Council recommends that new standards for community care services should be developed by the Health and Information Quality Authority (HIQA). These should be guided by the following principles:

- person-centred care – the older person as equal partner in the assessment, identification and delivery of care
- flexibility – services meeting need rather than need meeting services
- holistic services – services responding to the broad determinants of health, such as income, education and the environment
- accessibility – awareness among older people of eligibility and entitlements; disability friendly provision of services
- quality – evaluation of services, identification of good practice, commitment to delivery of highest quality in service provision
- equity – national binding standards for all community care services for older people.

The Council welcomes the planned development of a national housing strategy for people with a disability. **In order to ensure that the strategy meets the housing needs of all people with a disability, the Council recommends that the Department of the Environment, Heritage and Local Government (DoEHLG) consult older people and their advocates in its preparation.**

The Council also welcomes the Government's commitment to a 'more seamless set of responses to the housing needs of older people and people with disabilities', including reform of the Disabled Persons and Essential Repairs Grant Schemes in order to improve equity and targeting (Government of Ireland, 2006b). With regard to the Disabled Persons Grant, the findings of this report highlight the need for ease of access, equitable availability and efficiency in the administration of grants. **The Council, therefore, welcomes the commitment made in *Towards 2016* (Government of Ireland, 2006a) to reform grant schemes for older people in private housing with the aim of making them more**

accessible. In this regard, the Council reiterates its recommendation that the DoEHLG should ensure that all local authorities assess for and administer the Grant in a consistent and transparent manner (NCAOP, 2003). The Council also recommends that the DoEHLG should develop a client-centred approach in the reform of the Grant, in order to provide seamless and efficient delivery.

This study highlights the role that transport plays in the accessibility of health and social care services, and in the experience of social connectedness for older people with a disability. The Council welcomes the recent removal of the restriction of the Free Travel Scheme service during peak hours. It also welcomes the recent commitments made to the roll out of the Rural Transport Initiative (RTI) for wider target groups on a nationwide basis and the undertaking of a qualitative research study in 2007 with a view to identifying the effectiveness of RTI projects (Government of Ireland, 2006a). **The Council recommends that this research process should pay particular attention to the experiences and needs of older people with a disability in relation to the RTI. It further recommends that the DoEHLG pilot an urban-based transport initiative to improve the accessibility of health and social services, as well as the social connectedness of older people. In addition, the Council recommends that the current travel pass provided to people 66 years and over be extended to include provision of taxi fares for those living in areas where there is an inadequate level of public transport.**

### Information Framework

In 2005, the Council called for the development of a national framework of information about the older population for policy and service planning purposes (NCAOP, 2005). The evidence presented in this study of *ad hoc* and fragmented delivery of services for older people with a disability again highlights the importance of comprehensive and integrated data on disability in the older population. **There is an urgent need for information systems to capture and analyse such data and the Council reiterates its call for the development of a national framework for the collection of information about the older population and vulnerable subgroups of that population.**

The Council welcomes and endorses the recommendation in the policy report, *A Vision for Change*, that mental health information systems should be developed locally and should provide the national minimum mental health dataset to a central mental health information system (DoHC, 2006). **With regard to existing databases, the Council recommends that:**

- the age limit of 65 years for the National Physical and Sensory Disability Database (NPSDD) is removed as a matter of priority

- subject to safeguarding privacy, mechanisms are developed to ensure that disability databases such as the NPSDD and the National Intellectual Disability Database (NIDD), facilitate the inclusion and tracking of those with multiple disabilities.

## Needs Assessment

The Council welcomes the provision made for an assessment of need of all individuals with a disability in the NDS. **In this regard, it recommends that the assessment of needs under the NDS should encompass both late and early onset disability.**

The Council also welcomes the national care needs assessment tool for older people being developed by the HSE. **It advocates that the NDS assessment of needs and the national care needs assessment tool should be compatible, in order to ensure that information on assessed needs and the services provided is transferable between information systems.**

In addition, this research has found that a range of factors impact on the quality of life of a person with a disability, other than the impairment experienced. One factor that emerged strongly was social connectedness. This is not the first time it has emerged as a key indicator of quality of life (Murphy *et al.*, 2006) and it is clear that any attempt to measure the effectiveness of public policy that impacts on the well-being of older people must take this into account. This report concludes that the impact of policies can only be tracked by the development of connectedness indicators and the Council recommends that the care needs assessment tool should include a section on social connectedness indicators. Such indicators could include, *inter alia*, the proximity of family and friends, whether or not the individual lives alone, involvement in local clubs/organisations, and connectedness to their local community.

Finally, the study findings demonstrate that maintaining one's sense of independence and identity is a determinant of quality of life when ageing with a disability. The planning and allocation of care for older people should, therefore, facilitate meaningful involvement of the older person in any decision-making. The Council recommends that in all needs assessment processes and care delivery, the older person is facilitated to be centrally involved in determining care goals or targets.

## Rehabilitation Services

One finding that is to be welcomed is the very positive perception among interviewees of rehabilitation services provided for older people recovering from stroke. The Council is concerned, however, by the lack of flexibility regarding the length of time this service is provided and the negative outcomes this has for service users. **The Council recommends that all rehabilitation services should allow for greater flexibility in terms of the number of rehabilitation sessions available to the service user, and that these should be determined using a person-centred care approach.**

## 4. Advocacy

One of the most important findings of this study is that 'ageism exacerbates the potential for exclusion that disability creates'. It presents a strong case for the need for advocacy groups that represent the specific needs of older people with a disability. **In this regard, the Council welcomes the piloting of the Dementia Rights Advocacy Service in North Dublin as a model of best practice and proposes that this model should be emulated elsewhere in Ireland, as appropriate.**

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The Council also welcomes the personal advocacy service, to be established under the Citizens Information Act 2007. However, it is concerned that the onus remains on the individual to access this service. Consideration must be given to how this service can reach the more vulnerable, such as those who are older and living alone with a disability. **The Council recommends that wide-ranging information dissemination exercises about the service be undertaken at national and local levels, and that assistance in accessing this service is provided under the case management structure recommended above, where necessary.**

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# Executive Summary





# Executive Summary

## Introduction

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This report explores the interface between ageing, disability and quality of life in Ireland. It examines the various meanings that older people attach to independence and dependence in their lives. Independence and dependence are not simply objective features of life but have subjective interpretations, which are personal to individuals and families. The purpose of this research is to shed light on some of these interpretations.

The report provides contextual data and policy analysis on older people with disability in Ireland and draws on both ageing and disability literature to explore the various meanings associated with independence, dependence and quality of life in older age. The research takes a life-course perspective to disability and seeks to integrate both medical and social understandings of independence and dependence. The lived experiences of older people with a disability, both contemporary and historical, and their subjective accounts of well-being also inform our understanding of quality of life. The qualitative approach taken in the study is, therefore, particularly relevant to the subject of disability, the meaning of which has often been described as complex and evolving. A qualitative approach allows for a deeper and more sophisticated analysis of participants' experiences of ageing and disability.

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## Rationale and Objectives

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The key rationale for the study is that it provides information on the lived experiences of disability among older people in Ireland. This is the first time in an Irish context that older people have been asked to explain and interpret the experience of disability in their own words. Hearing the voice of older people is a powerful motivation for the work. This approach allows us to identify common factors that contribute to quality of life for older people with a disability, as well as differences that occur across categories due to time of onset, type of disability or illness and living arrangements. The report also fulfils an advocacy role in that the direct experiences of older people are recorded and presented, where appropriate, without translation or mediation. The findings of the study

will, therefore, address a significant knowledge gap and inform policymakers and service providers in the planning and provision of services for older people with a disability.

The objectives of the study were:

- to illuminate the experience of ageing with a disability in Ireland
- to explore participants' own perception of their disability
- to explore participants' perception of the role and interplay of other factors, such as cultural attitudes, physical environments, institutional arrangements and adequacy of service provision, in their experience of disability
- to identify common factors that contribute to quality of life for people with disability
- to develop indicators of quality of life
- to identify barriers to reaching a good quality of life for people with a disability
- to explore meanings and significance attributed to concepts of dependence, independence and interdependence
- to inform public policy for people with a disability.

## Ageing and Disability Interface

People with an early onset disability are said to age with disability while those with later-life onset are said to have disability with ageing. These groups will likely have different experiences with disability related to the length of time spent living with a disability. They will have different expectations, coping mechanisms and adaptation strategies for dealing with disability. An analysis of the life-course will reveal many influences and experiences that serve to separate rather than unite the two groups. Yet, these two groups are also likely to share many attributes. The issues of needs assessment and person-centred care are central to both groups. So too, are the issues of social rights and citizenship for all people with a disability. Yet in contemporary debates about social care for older people, ageing and disability tend to remain separate in discussions of both policy and practice. In social services, disability programmes and ageing programmes have been distinct for many decades. Moreover, analytical and theoretical research in the field of ageing with physical and intellectual disabilities is just beginning.

The gains made by the disability movement in the development of a social model of disability also contain many lessons for groups and organisations representing older

people. Currently, the service models of care used in disability and ageing programmes are different. Disability programmes typically incorporate concepts of independence, autonomy, self-direction and empowerment. In contrast, ageing programmes tend to follow the medical model more closely, with health and social care professionals having a much more direct input into the decision-making process. As more people age with disability, the medical model of ageing will become under increasing scrutiny from people demanding a social model of care provision. The trend in the future will be towards the integration of the medical and the social models through the adoption of a biopsychosocial approach to ageing and disability.

## Quality of Life and Disability

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For an individual with a disability, the most important domains of quality of life, as identified in the literature are: physical health, psychological well-being, family and social support, physical environment and care environment. Physical health is important to the quality of life of older people with a disability, irrespective of the disability. Psychological well-being is also important as it impacts on how people deal with fact of disability. Families provide not only practical support but emotional support also, which may be essential in helping the individual cope with their disability. Opportunities to connect socially with families and friends remain central to the lives of older people with disability. The physical environment is also important for quality of life for people with a disability. A poor environment can reduce mobility and independence and create dependency where none should exist. The care environment also matters. Older people with a disability must be empowered, provided with choice, and given autonomy over their lives in both community and residential care settings.

## Methodology

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As outlined above, the purpose of this study is to improve our understanding of older people's experiences of living with a disability, including how the latter impacts on quality of life. A grounded theory approach was used to guide this study because of its suitability to the research question. Grounded theory emerges from the data, allowing the views of older people to be clearly represented in the research.

The sample was comprised of six groups of older people with the following disabilities: dementia; depression; intellectual disability; rheumatoid arthritis; sensory disability; and stroke. A comparative group of older people without a diagnosed disability was also interviewed. The study sample comprised of 143 older people. The majority of participants were female and aged between 51 to 91 years. Quantitative data on participants' self-esteem, independence/dependence and quality of life health measures was also collected. The SF-36v2 survey was used to measure health-related quality of life. Self-esteem was assessed using Rosenberg's Self-Esteem Scale. The Katz Index of Independence in Activities of Daily Living was used to determine the independence/dependence of participants. This data provides a context for the qualitative findings which emerged from face-to-face interviews with participants.

## Quantitative Findings

The purpose of the quantitative findings was to contextualise the qualitative data. The numbers in each disability group were too small for any worthwhile generalisations to be made, so the findings relate solely to the various groups under observation. People with dementia had the highest self-esteem score across all groups. One possible reason for this is that some participants were not hindered in their perception of their self-worth by negative past experiences as they could no longer recall such experiences, so each day or moment is, as it were, a new beginning. In such instances they may be able to judge their self-worth more positively. The self-esteem of people with an intellectual disability was also relatively high. Participants in this group were happy and very satisfied with their work achievements, which may account for the overall higher self-esteem score. Participants suffering from depression recorded the lowest self-esteem score across all groups. Given the nature of depressive illness it is not surprising that self-esteem scores were on the whole low. Whether low self-esteem triggers depression or depression results in lower self-esteem is not known.

Of the sample, 133 participants completed the SF-36v2 survey. The stroke group recorded the lowest value for physical functioning, indicating that this group experienced the greatest physical impairment. As some of this group were living in residential care and needed help with all activities of daily living this finding is not surprising. The rheumatoid arthritis group also recorded low scores for physical functioning, as well as the poorest scores for bodily pain. The depression group had the lowest score of all groups on mental health. Scores for vitality, physical function and general health in the depression group were also low in comparison to most other groups. The sensory disability group recorded high levels of physical functioning and physical roles. However, they had the lowest score

on social functioning, indicating that this group had most difficulty with engagement in social activities. The intellectual disability group had the highest vitality of all groups and the least bodily pain. The score for general health among the intellectual disability group was the highest of any group. As this group were younger than all other groups this finding is not surprising.

All participants were asked to complete the Katz Index of Independence in Activities of Daily Living. The overall results for the disability groups indicated that all participants recorded high levels of independence in relation to transferring (92 per cent), toileting (90 per cent), dressing (84 per cent), continence (86 per cent) and feeding (97 per cent). The main area of dependence where participants required assistance from others was with bathing (73 per cent). The stroke group had the highest levels of dependence overall in relation to activities of daily living. People with a disability in this study considered themselves largely independent in respect of a range of activities of daily living, suggesting that care needs to be taken when undertaking objective instrument-based assessments of disability among older people. Older people may not view their disability in the same way as health professionals.

## Living With Disability: Issues of Independence and Dependence

The experience of living with a disability is unique to each individual. To understand how older people live with disability, one must talk to people themselves. There is no generic experience. Personality and life-course experience combine with socioeconomic structures to provide the key to understanding in this field. Participants' accounts suggest that living with a disability is a balancing act involving a trade-off between taking risks and having to be sensible. Some participants showed enormous tenacity in continuing to live life on their terms. These participants viewed their disability as a challenge and concentrated on rising to the challenge. Others were stoical, resigning themselves to a radically altered existence. Participants' response to disability was largely determined by the severity of their symptoms. Some participants had no option but to live very restricted lives. Participants mourned the loss of function/ability and feared further loss, such as an exacerbation of their condition. In this context, retaining autonomy and independence, no matter how little, was important. Participants drew strength from several sources including their spouse or family, pets and religion. Several factors impacted on participants' experiences of living with their disability: the severity of their symptoms; whether the onset of the disability was gradual or traumatic; their general attitude to life; and whether they had good support from family or carers.

Participants defined independence as being able to do things themselves and not having to rely on others for help and support. They found it difficult to distinguish between these concepts and tended to define one as the opposite of the other. Their definitions divided into two main categories: those that centred on avoidance of dependence, such as 'being able to look after myself'; and those that centred on autonomy, capacity for self-direction and being able to make choices. Those who were self-caring tended to cite the former definition. Those who were dependent on others for help with activities of daily living tended to cite the latter. Participants' personal definition of their independence or dependence shifted relative to others and/or improvement or worsening of their capacity to self-care. People feared increasing dependence, particularly in relation to needing help with personal intimate care. In the transition from independence to dependence, having to accept help, beyond that given by family, was a significant milestone for participants. Acknowledging that they needed help outside of the family was a tacit admission of increasing dependency and, as such, threatened self-esteem and personhood. It was not a decision they took lightly. That is why some people preferred to struggle on, even when they obviously need help.

## Ageing and Disability

One of the important aspects of the research was the issue of whether there are particular age-related aspects to the understanding and interpretation of disability among older people. The life-course experience of older people participating in this study may have helped them rationalise their disability in more positive terms than younger people with disability. Participants demonstrated an ability to contextualise the disability within the narrative of their own life, with reference to all the ups and downs that life had brought them. Some accepted disability as a natural consequence of the ageing process in the knowledge that most of their life was disability-free.

Conversely, age may also confer disadvantages. Ageism is a pervasive fact for older people with disability who participated in the study. It leads to prejudice and discrimination and ultimately a different experience of disability between younger and older people with disability. Ageism exacerbates the potential for exclusion that disability presents. There is evidence of rationing by age for participants through delaying care and provision rather than through overt denial of services. The data in this study suggests that one of the key features of being old with a disability in Ireland is waiting. People wait for services and appointments that sometimes never come.

Older people are also very conscious of the losses that accompany age. They lose family and friends. Their life is characterised by diminishing social networks, sometimes leading to isolation and loneliness. In some cases, people are dealing with the onset of disability at the same time as mourning the loss of a loved one. They can be fearful of a future without the support of family and friends. They are acutely aware of the various thresholds associated with their disability and are conscious of the impact that changes in their own condition, or their social networks, can have on their ability to cope and continue to live independently. Changes to the local neighbourhood can exacerbate the isolation sometimes felt by an older person with a disability. New people may move in, leading to new relationships having to be formed, which may be difficult for older people if disability reduces the opportunities for social contact. Communication may diminish and potential solidarity relationships may never develop. Social connectedness declines, as does quality of life.

## Quality of Life and Disability

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The analysis of data revealed five key domains of quality of life for people with a disability: health, environment, sense of self, connectedness and income. All participants were conscious of their health and described the impact this had on their day-to-day activities. Some people had very poor health and their impairment was so severe that they could not wash, dress or feed themselves; other participants were healthy and independent in all activities of living. Participants' accounts revealed that health mattered for quality of life and that disability impacted on health, but it was also evident that perceptions of health changed with increasing physical disability. People feared ill-health and what that might mean for their independence in the future. The impact of ill-health on disability could be catastrophic for people, transforming independence to dependence within a short period. On the other hand, some people remained optimistic even with significant ill-health, invariably putting their own situation into some comparative context. People compared themselves to others who were worse off.

Some participants had very poor physical health and were unable to undertake some or all of the activities of living. These people were totally dependent on others for help in all activities of living, which they found frustrating and depressing. People with ill-health often felt powerless and unable to help themselves. For some participants this was due to serious decline in physical functioning, for others it was a lack of motivation. Participants who were depressed found it particularly difficult to stay motivated. Sometimes people lacked essential information on basic services that that might improve their health situation. For others, support from health professionals was absent or difficult to access.

There was evidence of significant waiting among the people interviewed for health and social care services that, were they available sooner, might have improved their situation leading to enhanced quality of life. Keeping people with a disability healthy should be a key objective of health policy. This requires a proactive primary care system and reductions in waiting times for key services, such as physiotherapy, occupational therapy, day hospital, out-patients and screening programmes.

Living environment is very important to a person with a disability because it can facilitate independence or compound dependence on others. Many people in the study had adapted their own home in order to maximise their independence. This was easier for people living in their homes than it was for those living in rented accommodation. Adjustments included stair rails, reorganisation of the kitchen, improving wheelchair accessibility, colour marking steps, and installing showers, ramps and raised toilet seats. The experience of home adaptation varied considerably across the country. Some participants were able to access support via the Disabled Grants Scheme; others were not. Some participants found that the wait to have their homes modified was so unacceptable that they had the modifications done themselves. In these circumstances, participants often reported that it was their family who paid for and organised them.

For many participants, the place in which they live is very important to their quality of life. They described their connection to the area, identified it as where they were from and many had a profound sense of place. Some participants, while living most of their adult lives away from their home place returned in late adulthood, drawn by a sense of place and belonging. If place was important for quality of life, so too was access to shops, recreational facilities and local amenities. The capacity to physically access local amenities and networks depended on where a participant lived, the extent of disability, having access to a car and the availability of public transport. Participants with the poorest health living in isolated rural communities without public transport had most problems in this regard. Transport was a significant issue for older people living in rural areas. In these areas, shops, churches, banks and recreational facilities were often far from the participant's home. While most participants had a free travel pass, few were able to use it. Public transport was too far away, too infrequent, too inflexible or inaccessible to participants who needed special aids or ramps to board the vehicle. The absence of suitable and flexible public transport for older people reduces quality of life; where rural transport schemes exist quality of life is higher.

Participants identified a good social environment and social networks as important to quality of life. Disability made it more difficult for some participants to remain active in their communities but social connectedness remained important in their lives. Some participants socialised with neighbours, and were supported and helped by them. Participants described how the families in their neighbourhood had aged together, and how they had



supported, helped and befriended each other. Others reported that contact with neighbours and friends had declined as communities changed and people became more insular. They perceived that the community had fundamentally changed and that most people living in the locality were now strangers to each other. Many participants, particularly those living in rural areas, lamented what they perceived to be changing social practices. They described how 'visiting', which was a feature of their childhood, does not take place anymore. They believed that people were too busy now to be bothered with 'visiting' but missed the companionship and fun that was part of this practice. In all of the interviews, the desire for social relationships was strong and connection with others was seen as central to quality of life. For people with a severe disability, the most important connection was with their family carer. Without the support of their family carer, many of these people would not be able to continue living at home.

There was great diversity in the extent to which participants engaged in social or recreational activities. Some participants had very active social lives while others did very little. Disability however made it more difficult to engage in recreational activities because of limited physical capacity, sensory problems, transportation issues and motivation. Some people found they were unable to pursue the recreational activities they had enjoyed when they were younger, but had developed new interests in the home. Many people reported positive experiences from membership of active retirement associations (ARAs). Others attended day centres and found the recreational activities on offer generally enjoyable. Some people with a sensory disability avoided group activities because they found them very difficult. Participants who had hearing impairments found it extremely difficult and embarrassing when they could not follow conversations. People with depression also found some group activities difficult, although people did value the social outlet associated with day care attendance. However, people with depression could only attend psychiatric day centres if they were receiving treatment for depression; once they started to feel better they were discharged, often leaving them with no social outlet.

A sense of self is key to a person's well-being; it relates to a person's identity and sense of who they are. A sense of self develops over the life-cycle and can be shaped and reshaped by life-altering events. Personal identity is derived from an individual's unique set of attributes and is expressed in many different ways that are unique to that individual. Disability has the potential to threaten a person's sense of self because it may lead to a role change, dependency on others, isolation and lack of opportunity to express the things that are important to the individual. Personal attributes may also be questioned. Retaining a sense of self when faced with disability is, therefore, the key personal challenge for older people with a disability.

Disability had forced some people to retire as they could no longer manage the day-to-day demands of their work. These people often experienced great difficulty in adjusting;

the loss of role was compounded by the physical loss suffered as a result of the onset of disability. Others felt cheated out of normal retirement because they could no longer do the things in retirement that they had been looking forward to. For many participants, their role within the family was central to their identity. They took great satisfaction in the achievements of their children and grandchildren, and in the contribution they had made within the home. Even when participants were dependent on others, they looked for opportunities to engage in reciprocal activities. They wanted to give something back to others, even when their disability made it difficult for them to do so. Participation in social groups and activities also impacted on their own identity. Many participants had been active members of social groups and some had lead roles within these groups. Some people found that group activities were too difficult for them following the onset of disability and withdrew from social life, often with negative consequences for their own self-image. Others went to great lengths to continue their involvement in social activities because they realised the importance of maintaining participation for their own identity.

Income matters for the quality of life of people with a disability. Some participants with a longstanding disability reported that their working life had been curtailed because of the nature of their disability, with adverse long-term effects on their income and living standards. On the other hand, some people with a disability were financially secure and had good pensions which provided maximum choice in later life. For people needing care and therapeutic services, having money enabled them to purchase appropriate care as required. Services, such as home help, physiotherapy, cooked meals and nursing care could be bought by participants who had the financial resources to do so, but these were beyond the means of many participants. People with financial resources did not have to wait for services. Conversely, people without financial resources were dependent on the State for all services and usually had to wait long periods for these to be provided. One participant reported that as he could not afford to buy a hearing aid, he would have to wait for 18 months until he qualified for a medical card to get the hearing aid he needed. In the absence of public transport, people often had to pay for taxis out of their own resources. These out-of-pocket payments could be considerable for people living in rural areas, far away from amenities and health and social care facilities.

## Conclusions

Our results show that independence and dependence are subjective concepts. Disability is experienced personally by older people, which means that care responses must be person-centred and tailored to meet the specific needs of older people. Need assessment is a critical component of person-centred care. So is the provision of greater choice to older

people with respect to the form, timing and location of health and social care services. Consideration must also be given to the social dimensions of incapacity because, in many cases, dependency is created and sustained by weak social relationships, impoverished social conditions and disabling social structures. This means greater investment in barrier-free housing and the provision of flexible public transport for older people with a disability. It is not disability that creates dependency; rather it is the failure of public policy to facilitate autonomy and independence among people with a disability through a rights-based approach to legislation. The latter is necessary to allow older people to participate equally in society.

Disability tends to have a negative influence on quality of life. Sometimes, however, the effect of disability on quality of life can be mediated by forces outside the disability. The psychological nature of the individual may enable them to cope well with their disability. Ageing policy must support and nurture the psychological resilience of older people with a disability and their desire for greater autonomy and independence. Environmental and social support may also lessen the impact of any disability on quality of life. Unfortunately, the importance and potential of both physical and social environments has never been fully realised within a social care system dominated by a functional approach to health and well-being. Overall, the disability sector has been much more successful than the ageing sector in empowering and protecting people with a disability. There are huge gains to be realised for older people through greater convergence between the two sectors in Ireland.



# Chapter One

## Introduction



# Chapter One

## Introduction

### 1.1 Introduction to the Study

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This report explores the interface between ageing, disability and quality of life in Ireland. Older people with a disability in Ireland include people with a disability acquired at a younger age and those who acquire a disability later in life. Disability may be physical or cognitive and can be exacerbated by social forces and social structures. Older people with a disability are at risk of double discrimination. People with a disability generally, both young and old, are presented with numerous social, structural and economic barriers that deny them full citizenship and equal opportunities. Discrimination may also arise from ageist attitudes within society that exacerbate the already marginalised position of the older person with a disability. Therefore public policy needs to provide for older people with a disability and ensure that can full participate fully within society.

This report provides contextual data and policy analysis on older people with disability in Ireland. It draws on both ageing and disability literature to explore the various meanings associated with independence, dependence and quality of life in older age. Quality of life is explored for six disabilities: dementia; depression; intellectual disabilities; sensory disabilities; rheumatoid arthritis; and stroke. The rationale for selecting these categories lies in the Disability Act 2005, which refers to physical, sensory, learning and mental health, or emotional impairment as the main components of disability. Interviews were carried out with approximately twenty people in each of these disability groups. The lived experiences of older people with a disability, both contemporary and historical, and their subjective accounts of well-being inform our understanding of quality of life in this research. The subjective experience of people with a disability, as well as their interpretation and experience of wider contextual factors, are also critical to this understanding. The qualitative approach to data collection used in this study allows both the lived experiences of older people with a disability and the social context within which they live their lives to be articulated and valued.

If public policy is to be effective and efficient, it must target the domains of quality of life most important to older people with a disability. These domains are similar to other

groups in society and broadly include: physical and social environment; connectedness to family, friends and place; independence and autonomy; health; and material circumstances. Personality, coping mechanisms, and physical and social infrastructure can mediate the effect of any disability on quality of life. Each person is likely to have a unique perspective on their own situation which may be different to the objective assessment of the 'expert' or 'professional' view (Janse *et al.*, 2004). Older people with a disability must not, therefore, be treated as a homogeneous group or 'batch-processed', rather, they need to be centrally involved in giving meaning and interpretation to their own disability and how that disability impacts on quality of life.

Disability matters for individuals, families and society; that fact is the starting point for this study. Our task is to give a voice to older people with a disability in Ireland. In that respect, the research fulfils an important advocacy function. We examine the meanings that people with a disability attach to independence, dependence and interdependence within a quality of life framework. Sometimes the dependence that is associated with disability is innate, it arises from the fact of the disability; other times that dependence is socially constructed arising out of the way disability is defined, articulated and understood by society. We bear witness to the lived experiences of people with disability and make recommendations for practice and policy now and in the future.

## 1.2 Defining Disability

Disability is not easy to define. It is a multidimensional concept with both objective and subjective characteristics. Traditionally, disability has been equated with physical, sensory and/or intellectual impairment. When interpreted as an illness or impairment, disability is seen as located in an individual's body or mind; disability is intrinsic to the individual. This interpretation underpins the medical model approach to disability, which sees it as an individual problem, directly caused by disease, trauma or other health conditions. Not surprisingly, treatment for disability under this approach is conceived of in terms of medical care.

In a broader context, disability does not reside solely within individuals who have impairments and physical limitations, but also in the social, physical, economic and political environments within which people live. When interpreted as a social construct, disability can be examined in terms of the socio-economic, cultural and political disadvantages resulting from the exclusion of individuals from the normal activities and experiences of life. For example, the National Disability Authority Act, 1999, defines disability as 'a substantial restriction in the capacity of a person to participate in economic, social

or cultural life on account of an enduring physical, sensory, learning, mental health or emotional impairment'. The social model (of which there are many variations) distinguishes impairment, which is a condition of the body and/or mind, from disability, which is a situation of social exclusion caused by the organisation of society.

A 'post-social' model of disability that incorporates elements of both the social model and the medical model underpins our understanding throughout this report. We regard disability in older age as a dynamic phenomenon that relates to individual physiological and psychological conditions, as well as to social position, cultural norms and environmental contexts (BURDIS, 2004). Impairment in all its forms, physical, cognitive and emotional, is an intrinsic part of disability but it does not define it. Extrinsic conditions determine the extent to which individual impairment leads to disability and the exclusion of individuals from participation in economic, social and civic life. Our approach is, therefore, in keeping with the World Health Organisation (WHO), which posits a biopsychosocial model based on an integration of medical and social understandings (WHO, 2002). Disability incorporates individual impairment, activity limitations and participation restrictions, all of which are influenced by the physical and social environment.

### 1.3 The Interface Between Ageing and Disability

Population ageing has intensified the relationship between ageing and disability. For some, population ageing has a linear association with increasing disability as the incidence of disability in the population increases with ageing. Others point to accumulating evidence of morbidity compression in older age which is likely to make the relationship between ageing and disability much more ambiguous. The USA has witnessed a decrease in the prevalence of disability among older people (Cutler, 2001). There, a decline in mortality rates, reduced numbers of nursing home residents and lower dependency ratios all point to a reduction in the prevalence of disability. These changes are due to several overlapping factors including changes in technology, behaviour, diet, economic circumstances and education. However, it is unlikely that the current position is a long-run equilibrium and it is conceivable that disability in older age may increase again in the future due to current poor consumption and exercise patterns in younger and middle-age populations. Bhattacharya *et al.*, (2004) predict that while per capita Medicare costs in the USA will decline for the next 15 to 20 years, per capita costs will rise and continue at an accelerating rate after 2020 as disability in older age begins to increase again.

The interface between ageing and disability is barely recognised in Ireland, either in terms of service provision or policy. Historically, health and social care services have

been organised around distinct client groups, with very little integration of services across groups. Distinct client groups exist for older people, people with a disability and people with mental illness. Responsibility for the organisation and delivery of services for these groups is assigned to Care Group Managers who control the budget for their particular client group only, making it impossible to engage in joint planning across the three care groups. Not surprisingly, this has led to fragmentation in provision, thereby undermining any attempt to provide person-centred, holistic care for people, irrespective of age or circumstance. Responsibility for ageing and disability is also separated within the Department of Health and Children (DoHC) leading to separate policy channels for each, resulting in an even greater dichotomy. The two main advisory agencies on ageing and disability, the National Council on Ageing and Older People (NCAOP) and the National Disability Authority (NDA), have also tended to focus specifically on one or the other; the NCAOP on ageing and the NDA on disability. This is now changing, with the two agencies engaged in exploring the interface between ageing and disability in Ireland.

There are numerous examples of the difficulties caused by the separation of ageing and disability provision for older people. For example, people with early onset dementia cannot always access dementia care services because they are too young. In particular, people aged less than 65 years with intellectual disabilities who develop dementia have no clear pathways to care under the current system. There are also gaps in services for younger stroke patients, due to the service being geared primarily towards older people. Conversely, disability services may be the most appropriate placement for some people aged over 65 who acquire a disability later in life, but they cannot receive such services because they are too old. This failure to direct older people to the most appropriate care provider or care setting is often due to ageism masquerading as rational resource allocation. Older people are denied proper care simply because of their age. On the other hand, people are sometimes forced to move from one service to another upon reaching the age of 65, irrespective of the trauma and dislocation involved. This is particularly true for people with mental illness living in institutional care who are sometimes forced to move to long-stay facilities, often to settings unapproved for mental health care, away from familiar surroundings and familiar faces.

There have been legislative developments that have sought to address the interface between ageing and disability. The Equal Status Acts 2000-2004 and the Employment Equality Acts 1998 and 2004 offer protection against discrimination on the basis of age and disability. The Equality Authority has also produced a key policy document, *Implementing Equality for Older People* (The Equality Authority, 2002), which addresses the topic of ageing and disability. The National Disability Act 2005 is, however, likely to carry most significance for the development of closer relationships between ageing and disability in Ireland. The Act is a key element of the National Disability Strategy agreed by the Government to underpin the equal participation of people with a disability in society.



The Act covers a wide range of issues including: needs assessment; individual service statements; rights; redress; advocacy; and accessibility; and provision for integrating sectoral plans by Government Departments could also potentially facilitate a much closer integration between ageing and disability services than has existed up to now. Certainly the language used in terms of independence, empowerment, rights and citizenship is one that is increasingly common to both ageing and disability sectors.

## 1.4 Data on Disability in Ireland

According to Census 2002 (CSO, 2002), there were 323,707 people with a disability in Ireland, accounting for 8 per cent of the total population. Of these, 135,696 or 42 per cent were 65 years old and over, accounting for 31% of the older Irish population. The incidence of disability increases exponentially with age; a 65-year-old person is nine times more likely to develop a disability than a person aged 15-24 years (Gannon and Nolan, 2005). Some older people have more than one type of disability. Of people with a disability aged 65 years and over, about two thirds experience multiple disabilities. The number of older people with disability is classified by disability type in Table 1.1. More than two thirds of older people with a disability experience restrictions in physical activity. Older people also have a high rate of sensory impairment, with 30 per cent experiencing blindness, deafness, or a severe vision or hearing impairment. A similar proportion has difficulty in learning, remembering or concentrating.

**Table 1.1: Disability among older people in Ireland**

Type of disability	People aged 65 years and over
Total persons with a disability	135,696
Blindness, deafness, or a severe vision or hearing impairment	41,415 (36%)
A condition that substantially limits one or more basic physical activities	90,985 (24%)
Difficulty in learning, remembering or concentrating	41,528 (11%)
Difficulty in dressing, bathing or getting around inside the home	52,985 (14%)
Difficulty in going outside the home alone	73,556 (19%)
Difficulty in working at a job or business	77,795 (21%)
<b>Total disabilities</b>	<b>378,264 (100%)</b>

Source: CSO, 2002

More specific and person-centred data on the interface between ageing and disability is harder to source. Older people tend to be absent from existing disability databases. For example, the National Physical and Sensory Disability Database excludes persons whose disability arises from the age of 66 onwards. There is no database covering people who develop cognitive impairment after the age of 65. Nor is there a comprehensive information set on older people with mental health difficulties. Steps are being taken to improve the data available on disability in Ireland; the first National Disability Survey is currently being undertaken as a follow up survey to Census 2006 (CSO, 2006). Joint initiatives between relevant agencies are also being explored to improve the level and volume of knowledge available on disability and ageing in Ireland.

While these signs are encouraging, we still encountered problems when establishing baseline populations for each of the disability categories being examined in this report. The data currently available for each of these categories is fragmented and the estimates provided should be regarded in that light.

### 1.4.1 Dementia

Studies on the prevalence of dementia, which seek to estimate the number of people with dementia at a given point in time, show a sharp rise in the prevalence of dementia with age. Prevalence increases almost exponentially with age, nearly doubling every five years, but the increase is much more rapid for females for whom prevalence of dementia is much greater in the oldest age categories (OECD, 2004). Prevalence rates for the Irish population have mostly been derived from EURODEM (Hoffman *et al.*, 1991), which provides a statistical integration of age-based rates from a number of different prevalence studies. The application of EURODEM rates to the most recently available published population Census data for Ireland suggests that there were just over 34,000 people with dementia in the country in 2002, made up of 20,000 females and 14,000 males (Table 1.2). The projections suggest that there are currently 38,000 people with dementia in Ireland. In line with the ageing of the population, the major increase in the number of people with dementia is likely to occur after 2021, with the numbers projected to increase to over 100,000 by 2036.

Even in such a small country as Ireland there are clear regional differences in prevalence rates for dementia, reflecting imbalanced age distributions across the country, underlining the importance of age structure for prevalence estimates. Western counties tend to have the highest share of the population with dementia, with Leitrim having the highest share at 1.4 per cent of the total population. Eastern counties tend to have the lowest share of the

population with dementia, with Kildare having the lowest share at 0.5 per cent of the total population.

**Table 1.2: Estimated number of people with dementia in Ireland, Census 2002 by EURODEM prevalence rates**

Age category	Males with dementia	Females with dementia	Persons with dementia	Percentage
30-59 years	1,547	772	2,319	0.1%
60-64 years	1,241	383	1,624	1.0%
65-69 years	1,436	750	2,186	1.6%
70-74 years	2,379	2,356	4,735	4.2%
75-79 years	1,869	3,513	5,382	6.0%
80-84 years	2,696	4,937	7,633	13.0%
85-89 years	1,747	4,602	6,349	21.4%
90+ years	970	3,088	4,058	33.5%
<b>Total</b>	<b>13,885</b>	<b>20,401</b>	<b>34,286</b>	

### 1.4.2 Depression

No comprehensive statistics exist for older people with depression. Usage of acute services by all individuals with mental health problems is reported under the National Psychiatric In-Patient Reporting System (NPIRS). Approximately 12 per cent of all admissions to psychiatric hospitals are of people aged 65 years and over. Overall, just over two fifths of all admissions of those aged 65 and over are for depressive disorders. The NPIRS does not provide detailed analysis of outpatient psychiatric services disaggregated by age. Nor is there an equivalent national database that provides primary and community-based coverage of older people with mental health difficulties, including people with depression.

### 1.4.3 Intellectual Disability

The National Intellectual Disability Database (NIDD) gathers demographic information about people with an intellectual disability, although it does not include those people who have never been attached to services, some of whom may be very vulnerable (McCarron, 2006). The Database informs regional and national planning in relation to need and specialist services for people with an intellectual disability. In 2005, there were 24,917 registered individuals who had an intellectual disability, of whom 2,611 or 10 per cent were aged 55 years and over (Barron and Mulvany, 2005). There has been a steady increase in the proportion of people with an intellectual disability aged 35 years and over, from 29 per

cent in 1974 to 47 per cent in 2005. There is no information on how many people with an intellectual disability are aged 65 years and over, reflecting the lack of convergence between ageing and disability in respect of data collection and analysis. The changing age structure of people with an intellectual disability will have major implications for service planning in the years ahead, as more people with intellectual disabilities survive into older age.

#### 1.4.4 Rheumatoid Arthritis

There have been no prevalence studies of rheumatoid arthritis in Ireland. A report by Fitzgerald *et al.* (2002) for the Irish Society for Rheumatology (ISR), estimates that approximately 1 per cent of the Irish population suffers from rheumatoid arthritis. Although no breakdown of the age distribution of rheumatoid arthritis sufferers is available for Ireland, Urwin *et al.* (1998) suggest that there is a higher incidence of disability due to musculoskeletal conditions such as rheumatoid arthritis in older age groups than in younger age groups. Women are significantly more likely to be affected than men. Leaving rheumatoid arthritis untreated can lead to significant functional disability in older populations (Fitzgerald *et al.*, 2002).

#### 1.4.5 Sensory Disability

The National Physical and Sensory Disability Database monitors the service needs of people with a physical or sensory disability. In 2005, there were 22,429 people registered aged 65 years or less (Doyle *et al.*, 2005). However, data is only collected on service users who have been identified before the age of 66 years. Data is not collected on people who develop a physical or sensory disability after the age of 65, even though we know that the risk of developing visual impairment rises with age. For example, estimates provided by Munier *et al.* (1998) suggest that over half of all blind people in Ireland are aged 65 years and over, with one third aged 80 years and over. Using UK prevalence rates, the NDA estimates that some 153,000 people have hearing impairments in Ireland (NDA, 2005). International research shows that, similar to visual impairments, the risk of developing a hearing impairment increases with age (Quaranta *et al.*, 1996).

#### 1.4.6 Stroke

We do not know the number of older people with stroke in Ireland. However, according to the Irish Heart Foundation, the majority of strokes occur in those aged 65 and over, as the likelihood of having a stroke doubles for every decade one lives after the age of 55 years. An extrapolation of data produced by the American Heart Association suggests that there are an estimated 30,000 people in Ireland with a residual disability resulting from a stroke. These disabilities are likely to include hemiparesis (48 per cent), help needed with daily living (24-53 per cent), cognitive impairment (33 per cent), depression (32 per cent) and inability to walk (22 per cent) (Helgason and Wolf, 1997).

## 1.5 Structure of the Report

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Following on from the Introduction, Chapter Two explores ageing and disability literature in an attempt to find relationships, commonalities and interfaces between the two strands. Chapter Three provides an overview of the most important domains of quality of life of older people, both generally and for older people with a disability. The methodology used in the study is outlined in Chapter Four. Chapter Five details the empirical analysis of the six disability groups. Chapter Six provides a direct account of the experience of disability by the various groups; concepts of independence and dependence are also explored in this chapter. Chapters Seven and Eight report on quality of life for participants in the study, and policy issues are taken up in Chapter Nine.



# Chapter Two

## Ageing and Disability



# Chapter Two

## Ageing and Disability

### 2.1 Introduction

Some people acquire disabilities early in life and age with disability, while others may not acquire disabilities until later in life. These groups will likely have different experiences related to the length of time spent living with a disability. They will have different expectations, coping mechanisms and adaptation strategies. An analysis of the life course will reveal many influences and experiences that serve to separate rather than unite the two groups. Yet, these two groups are also likely to share many attributes. The issues of needs assessment and person-centred care are central to both groups. So too are issues of social rights and citizenship. Yet in contemporary debates about social care for older people, ageing and disability tend to remain apart in discussions of both policy and practice. In social services, disability programmes and ageing programmes have been distinct for many decades. Moreover, analytical and theoretical research in the field of ageing with physical and intellectual disabilities is just beginning.

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The gains made by the disability movement in the development of a social model of disability also contain many lessons for groups and organisations representing older people. Currently, the service models of care that are available in disability and ageing programmes in Ireland are different. Disability programmes typically incorporate concepts of independence, autonomy, self-direction and empowerment for participants. In contrast, ageing programmes tend to follow the medical model more closely, with health and social care professionals having control of the decision-making process; the structure of social care provision does not allow older people much choice or autonomy in respect of the type of services received or the timing of these services. As more people age with disability, the medical model of ageing will come under increasing scrutiny from people demanding a social model of care provision; one that emphasises empowerment for older people.

This chapter focuses on the interface between ageing and disability, and explores the common ground between the two in relation to both theory and practice. To begin with, we examine the concepts of dependence and independence and the relationship between the two. The main theories of ageing and disability are then set out, mindful of Putnam's

(2002) conclusion with respect to the former that 'most theories of ageing do not consider the cumulative experience of disability'. The importance of the social model for the disability sector is highlighted, as is their rejection of the dependency model. The chapter also includes a brief examination of discrimination on the margins between ageing and disability. The implications for policy of extending the social model of disability into the ageing sector are considered, as is the possibility of developing a biopsychosocial focus in policy formulation and implementation.

## 2.2 Dependence and Independence

There are no commonly accepted definitions of dependence or independence in the literature. This has led to a lack of conceptual clarity and difficulty in comparing research findings. Some authors assume that the concepts are fully understood and do not define these terms (Secker *et al.*, 2003). Researchers who do define these concepts take one of two main approaches: the functional approach or the capacity approach.

Researchers who take a functional approach define the concept of dependence or independence by identifying what a person can or cannot do by themselves. This approach is evident in the work of Goodwin *et al.* (2003) and Covinsky *et al.* (2003) who define dependence in terms of the extent to which a person is reliant on others for care and define independence as the ability to self-care or a lack of reliance on others. The functional approach has been shaped by a medical model of care which is principally concerned with physical function and disease. As a result, this approach has been criticised by many researchers as it fails to appreciate the broader, more holistic and subjective nature of these concepts (Falter *et al.*, 2003).

Researchers who take a capacity approach stress the complexity and subjective nature of independence and dependence (Falter *et al.*, 2003). They argue that these terms cannot be seen in absolute terms and should focus on a range of dimensions including physical functioning, emotional functioning, and economic circumstances (Bowers, 2001). Physical capacity, therefore, is only one dimension of independence (Cohen, 1992; Bowers, 2001; Falter *et al.*, 2003; Secker *et al.*, 2003). These researchers also make a crucial distinction between executional and decisional independence. While the former focuses on the actual physical capacity to undertake activities of living, the latter relates to the extent to which a person can exercise control and autonomy, and make decisions over what they do. Falter *et al.* (2003) investigated older people's perceptions of independence and dependence, and found that perceptions of independence cannot be explained by disability alone. These researchers found that some older people who were perceived as highly dependent



categorized themselves as highly independent. Dependency, therefore, was not just about the ability to do but also the capacity for autonomous decision-making.

The relationship between dependence and independence is also far from clear. While some may present the relationship as inversely correlated, in that any increase in dependence results in a consequent decrease of independence, Secker *et al.* (2003) found that this is not necessarily the case. Their research revealed that a person may be highly dependent on others for care but could perceive themselves to be highly independent. People may be reliant on others, but may see this as part of an essential reciprocity that characterises human existence. Independence and dependence are more likely to be distinct notions rather than opposites (Gignac and Cott, 1998). Relationships are likely to be complex and individually determined. French (1993), for example, believes that the notion of independence can be taken too far, restricting the lives of people with a disability rather than enriching them as independence can give rise to inefficiency, stress and isolation.

Notions of disability, independence and dependence are also likely to be culturally determined. Some communities and cultures place a high value on intergenerational reciprocity, with strong social norms in respect of family ties and obligations. This affects how people think about independence and assistance. Finch and Mason's (1992) major empirical work on family obligations highlighted the common-place nature of care freely given and received within families. These relationships were seen as a characteristic part of family life, symbolising neither independence nor dependence. Verbrugge *et al.* (2006) point to differences in the interpretation and understanding of independence and dependence between older people in the USA and in Singapore. Older Singaporeans live in a culture of interdependence, whereas older Americans live in a culture of individual independence. Not surprisingly, in their self-ratings of dependence, no older person in Singapore said that he or she was 'totally independent' or 'totally dependent'. In contrast, almost one quarter of Americans said that they were 'totally independent' despite having disability and assistance. These cultural explanations are heavily influenced by behavioural and psychological content (Baltes and Baltes, 1990), suggesting that people's subjective perceptions of dependence and independence are more important than any objective indicators. These findings encourage us to examine, rather than assume, what notions of independence and dependence mean to older people with disability in Ireland.

## 2.3 Theories of Ageing and Disability

There are no theories on ageing with a disability, but rather separate theories on ageing and on disability (Putnam, 2002). This divergence impacts on our ability to conceptualise

important relationships between ageing and disability. It is worthwhile, therefore, to examine the ageing literature and disability literature separately for insight into the potential interface between the two. We begin with a brief overview of theories of ageing and the evolution towards more social frameworks for analysing age and disability.

The main influences on theories of ageing can be divided into biological, psychological and sociological categories. Biological theories of ageing examine ageing at cellular, organism and molecular levels (Johnson, 2005). Medical indicators, such as functional capacity (which evaluates the ability to carry out daily tasks and is measured by activities of daily living), are also included in biological age (Aiken, 2001). Psychological theories of ageing are concerned with feelings, attitudes and an individual's overall approach to life. A positive approach to growing older takes into account the advantages of older age, such as less responsibility, more leisure time and less preoccupation with what people think (Aiken, 2001). Sociological theories of ageing, or social gerontology, is the least developed of the three areas, with theoretical progress in this field more challenging than with biological and psychological theories of ageing. Sociological theories of ageing are primarily concerned with how social roles and activities change with age, as well as the effects of social relationships and institutional structures on age (Phillipson, 1998).

Three major theories of individual ageing are disengagement theory, activity theory and continuity theory (Putnam, 2002). The difficulty with all of these theories, particularly the first two, is that they were developed to explain so called 'normal ageing'; that is ageing without physical or mental impairment. Disengagement refers to the gradual withdrawal of individuals from earlier life roles, such as paid work, in older age (Cumming and Henry, 1961). Activity theory, in contrast, focuses on participation and the maintenance of activity as central to well-being in older age (Lemming *et al.*, 1972). Continuity theory incorporates role adaptation in the maintenance of internal psychological structure, both of which are influenced by external structure in the social and physical environment (Atchley, 1989). However, none of these theories deals directly with the social forces that impact on individual ageing.

Theories that incorporate the relationship between the ageing individual and society contain the promise of a more nuanced understanding of the relationship between ageing and disability. Social exchange theory posits an accounting relationship between the ageing individual and society, one that is positive in favour of individuals during their working life but which moves into deficit as one enters old age (Dowd, 1975). Disability or ill-health can exacerbate the deficit experienced by the older person, causing them to lean more on the personal and social reserves generated earlier in life, but it is not central to the theory. Modernisation theory puts forward an industrial explanation of the role and position of older people in society that links their worth and well-being to their continued involvement in the technological workplace (Burgess, 1960). Disability only matters when it interferes with the

ability of the older person to participate in the labour force, or undermines the capacity of the older worker to re-train or re-skill. Age stratification theory explores social roles over the life-cycle (Riley *et al.*, 1972). Its basic premise is that age matters for social roles, and roles change as people age and cohorts mature. Once again, however, neither ageing with disability or disability in older age are specifically addressed within this framework, even though disability does impact on social role and function.

The ecological model of ageing recognises the relationship between an individual's capability and functioning, and their environment (Lawton and Nahemow, 1973). The physical environment may sanction disability through its failure to provide suitable opportunities for mobility and communication across spaces and places. Indeed, even the perception of environmental impediments to movement and communication may have a causal effect on behaviour that may be independent of the physical attributes of the environment. Alternatively, the physical environment may prove to be liberating and accommodating through suitable design and physical layout so that independence is promoted instead of dependence. There is harmony between individual capabilities and the demands of the physical environment (Kahans, 1982).

Critical theories of ageing and disability attempt to provide an understanding of the relationship between ageing and social forces, albeit mediated through power relationships rather than directly. For example, the political economy of ageing approach emphasises the social construction of age and examines the influences of social structures and processes on public policy for older people (Townsend, 1981). Power relations matter in developing shared understandings of age and ageing, and in establishing rights, responsibilities and obligations within society. Power differentials translate into structural influences that determine resource allocation and public policy for older people, thereby affecting how ageing is interpreted and experienced.

Feminist theorists have drawn attention to the dominance of the male understanding of ageing in official thinking (Arbor and McGinn, 1991). This criticism could also be applied to the significance attached to social class divisions within prevailing critical theories of ageing and dependency. So far, the experiences of older people with a disability have not received adequate consideration in this field. Instead, the dependency that arises in older age is seen as socially constructed, having its origins in unequal social relations and social class divisions rather than in disability.

Nagi's (1965) functional limitation model is seminal to the development of the social model of disability. He classified disability as a limitation in performance of socially defined roles and tasks within a specific socio-cultural and physical environment. That being so, disability pathways could be identified as having specific risk factors including physical and social environmental factors, behaviour and lifestyle (Verbrugge and Jette, 1994). Disability

results from the interaction of an individual and their environment, rather than from the fact of impairment. Further work focused on the development of an enabling-disabling process model, which linked dependency to the absence of alignment between the capabilities of the impaired individual and their physical, social and environmental world (Brandt and Pope, 1997). It was not long before the enabling-disabling process model became politicised through the development of political models, such as Hahn's (1993) minority group model of disability. In the latter, social attitudes were identified as the main source of the problems confronting people with a disability.

## 2.4 Towards a Social Model of Disability

The medical model of disability equates disability with loss and dependency through enduring physical, sensory and/or intellectual impairment: the focus is on the individual; the loss is internalised; and the problem is endogenous. Treatment is considered in terms of medical care provided by doctors or other healthcare professionals. In contrast, social models of disability focus on events and circumstances external to the individual: disability is not inherently part of the person, but rather a function of the interaction between the person and their social world (Nagi, 1965; Begum, 1992; Hahn, 1993; Brandt and Pope, 1997). Impairment may exist but it need not and should not always lead to dependence.

As outlined in Section 2.3, the social model of disability can be traced to a number of theoretical developments with origins in both ageing and disability literature (Putnam, 2002). Theoretical developments on their own, however, were unlikely to lead to equality for people with a disability; a political input from those who experienced the disadvantages and discrimination associated with disability was needed. One of the principal catalysts of the disability movement was the civil rights movement in the USA (Oliver and Barnes, 1993). Disability rights groups began lobbying for equal rights and in 1972, the first Centre for Independent Living was founded in California. The independent living movement propounded that people with a disability know best how to provide for the needs of others with a disability and, in order to develop a full and vibrant community, everyone must be included. Organisations for people with a disability began to look for equal status and equal rights for people with a disability and campaigned for an end to what they considered the social oppression of people with a disability. In 1976, the Union of Physically Impaired Against Segregation (UPIAS) defined disability as 'the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression'.

This marked the first steps towards a social model of disability (Oliver and Barnes, 1993). The introduction, after much lobbying, of the Americans with Disabilities Act 1990 put pressure on the British Government to enact similar legislation. In 1995, the British Government introduced the Discrimination Disability Act followed by the establishment of a Disability Rights Commission (Smith, 2005). The United Nations Standard Rules on the Equalization of Opportunities for People with a Disability (United UN, 1992) emphasised certain rights for older people, such as equal participation and the right to remain within their own local communities. Accessible environments and integrative structures were necessary prerequisites for the promotion of independence and autonomy among people with a disability.

In Ireland, the National Disability Strategy (NDS) is of pivotal significance to the development of a social model of disability. The NDS is comprised of the Disability Act 2005, the Comhairle (Amendment) Bill 2004, a multi-annual investment programme for disability services and departmental sectoral plans aimed at ensuring comprehensive and holistic delivery of services for people with a disability. It has taken time for the social model of disability to reach Ireland, but the NDS recognises the distinction between impairment and social exclusion, and offers the potential for a social conceptualisation of independence and dependence.

There remains dissatisfaction that the legislation does not adhere strictly to a rights-based model (NAMHI, 2004). For example, while the Act recognises the right to an individual assessment of health and educational needs, services do not automatically follow. Rather a service statement is produced outlining the services that can be provided to the individual subject to five criteria: the assessment report; eligibility criteria for services; relevant standards and Codes of Practice; the practicability of providing the service; and the financial resources available. An individual is informed of the services that will be available to them, rather than the services to which they are entitled by right. For some, this represents a victory of economics over rights; for others, it represents a pragmatic compromise. Some sections of the Disability Act are rights-based, such as those relating to public services. For example, significant progress has been made in the area of access to public transport for people with a disability through the Rural Transport Initiative (RTI).

## 2.5 Integrating Ageing and Disability

In general, the success of the social model in disability and the gains made by the disability movement have been slow to cross over into the age sector. The arguments in favour of a closer alliance between the disability and ageing sectors relate to the adoption of the

social model of disability and its potential to empower older people in relation to the health and social care system. Choice is currently denied older people in respect of social care services, which are determined mainly through an administrative model designed to meet the needs of providers rather than clients. Ageism and age discrimination can exacerbate access and utilisation issues for older people (Heywood *et al.*, 2002), with chronological age sometimes being used as a mechanism to allocate scarce resources (McGlone and Fitzgerald, 2005). For example, in Ireland breast cancer checks are only available for women up to the age of 65. While younger people with a disability can also be subjected to social care practices and policies that lead to rationing, disempowerment and social dependency, they are less likely to suffer discrimination than older people with a disability. This makes the resistance among older people and their organisations to identify with disability cultures and identities hard to understand (Priestley, 2002).

One reason for this resistance and the consequent absence of commonality between the two sectors is that a majority of older people do not experience disability. Therefore, a generic campaigning attitude to disability in older age could potentially create problems where none exists. Moreover, even when disability exists in later life it is seen by many, including older people themselves, as part of the natural process of growing old. Older people do not want to politicise a process that they see as, in some way, natural. An additional complication may be that the social model is not individual enough for older people with a disability. Older people may want their problems when they occur to be medicalised not socialised, particularly where pain and distress accompany the disability (Morris, 1991).

Another potential explanation for the absence of commonality is that the disability movement itself continues to emphasise the needs of younger adults rather than older people (Walker and Maltby, 1997; Priestley, 2000), and older people have largely been absent from the disability movement (Priestley and Rabiee, 2002). The independent living movement has, for example, mostly focused on younger people with a disability and, in its early days, mostly on younger males. Political forces in the disability movement mobilised around the areas of work, unemployment and education; all of which are outside the sphere of older people interests. Moreover, it was easier for younger people with a disability to mobilise around these issues given that they shared a common discrimination. The circumstances, needs and aspirations of older people with a disability can vary significantly from those of younger people with a disability (Vincent, 1999). This can largely be attributed to the fact that the majority of older people with a disability have a late onset condition, such as dementia or rheumatoid arthritis (Verbrugge and Yang, 2002). People with a late onset disability are likely to experience a profound sense of personal loss. Issues of dependence and interdependence may be more relevant to them than that of independence (Kennedy, 2002). Despite these differences, discrimination remains at the interface of ageing and disability.

## 2.6 Discrimination at the Interface

Older people and people with a disability continue to suffer discrimination. Older people with a disability are in danger of being doubly discriminated against on the basis of both age and disability. Older people are subject to ageism within health and social services in Ireland (McGlone and Fitzgerald, 2005) and society generally (NCAOP, 2005). Older people are treated as 'the other' and this gives rise to inequality (Oldman, 2002). In the UK, for example, the general perception is one of considerable age discrimination: local authorities spend less on the provision of services for older people with a disability than for younger people with a disability (Priestly and Rabiee, 2002). Older people with a disability complain about the inadequate, less empowered services they receive when they transfer from Disabled Services to Services for Older People (Oldman, 2002). In the USA, Liebig and Sheets (1998) found that the lingering effects of ageism and structural lag in ageing and disability policies and programmes limit the access of older adults with a disability to environmental interventions. They studied the provision of assistive technologies and home modifications, and found that policies did not adequately meet the environmental intervention needs of older disabled adults.

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Similar levels and forms of discrimination exist in Ireland and have been well documented elsewhere (NCAOP, 2005). Confusion remains with respect to entitlements for older people, and this is often used to conceal inertia in respect of adequate resource allocation to the sector. For example, confusion remains with respect to entitlements for older medical card holders (The Equality Authority, 2002). In addition, resources are rationed on the basis of age, particularly within acute care settings. An example of routine discrimination is the conditions of entitlement to the Mobility Allowance, under which those who develop a disability after the age of 66 are treated differently to those under 66 years of age. The regulations state that it 'is a means-tested monthly payment payable by Health Service Executive (HSE) Areas in Ireland to people aged between 17 and 66 who have a disability and are unable to walk or use public transport and who would benefit from a change in surroundings (for example, by financing the occasional taxi journey). If an allowance is awarded, it will be continued beyond the age of 66 but you may not apply for the allowance if you are aged 66 or over'.

## 2.7 Policy at the Interface

In Ireland, there are separate policies for the ageing and disability sectors. This is similar to the approach in many other countries where disability programmes and ageing

programmes are distinct (Torres-Gil and Putnam, 1999; McCarron and Lawlor, 2003). Disability programmes tend to concentrate on work, education, training and residential services for younger persons while ageing programmes concentrate on placement and disease management programmes for older people. Advocacy for younger people with a disability has been stronger than for older people with a disability. This is likely to change in the future, particularly with increasing numbers of younger people with a disability now living to older ages (Kennedy and Minkler, 1998). The term 'common ground' is now used regularly by those seeking to merge the traditional separatist thinking about disability and ageing (Verbrugge and Yang, 2002).







# Chapter Three

## Quality of Life and Older People



# Chapter Three

## Quality of Life and Older People

### 3.1 Introduction

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The term 'quality of life' has become very popular and is used in all walks of life – from marketing to medical care, from ecology to economics. There is substantial literature on quality of life with contributions from many diverse disciplines, but there is no consensus on the meaning of the term. Contemporary discussion on quality of life has focused on the importance of both objective and subjective assessment and interpretation of the concept. This chapter aims to give a broad outline of the concept of quality of life, its theoretical underpinnings, its measurement and its application to the lives of older people, including older people with a disability.

### 3.2 Conceptual Approaches

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Defining quality of life has proven to be a difficult task. As the study of quality of life has been undertaken in many disciplines, these respective approaches and perceptions have resulted in differing definitions. It is not that all these disciplines are in disagreement, but rather that their emphasis is on different conceptual components. This section aims to divide the study of the concept of quality of life into the different disciplines concerned: environmental; healthcare; sociology; economics and psychology.

#### 3.2.1 Environmental Approach

The environmental approach to quality of life is concerned with the physical and social quality of an individual's environment, as well as the interaction of individuals with their environment. It suggests that, even if the surrounding environment is not ideal, quality of life is more likely to be determined by how the individual relates to their environment. This

would suggest that individuals are flexible and can adapt to different environments. One's environment may refer to one's own home at the micro level, and the local community or the global environment at the macro level (Uzzell and Moser, 2006).

### 3.2.2 Healthcare Approach

The two main reasons for the development of a concept of health-related quality of life (HRQL) are to assess the impact of a treatment on a patient's life and to compare outcomes of alternative health interventions (Moons, 2004). HRQL may be disease-specific or generic; the latter allowing for greater comparative analysis. HRQL includes elements, such as mobility and self-care (which measure physical function), and anxiety, depression and well-being (which measure emotional function) (Guyatt *et al.*, 1993). The incorporation of quality of life into health outcomes indicates an increasing appreciation that the patient's feelings and sense of satisfaction with their treatment are extremely important (Carr and Higginson, 2001).

The field of HRQL is broad and well developed, yet, similarly to the global concept of quality of life, a concrete definition of HRQL has yet to be agreed (Carr and Higginson, 2001; Bowling, 2003). HRQL measurement instruments traditionally focused on impediment and disabilities, but now evaluates quality of life both in negative and positive terms (Bowling, 2003; Moons *et al.*, 2004). Other issues involved in measuring HRQL are the respective roles played by expectations and experience in an individual's quality of life. For example, individuals may compare their current health state with their concept of an ideal state (Carr *et al.*, 2003; Carr and Higginson, 2001). People may also use adaptive strategies as they age in order to maintain a strong sense of subjective well-being, by changing goals, changing social comparators or developing alternative selves. Individuals may, for example, compare their health and well-being to others who are, in their view, worse off than themselves (Murphy *et al.*, 2006). This is also evident in the testimonies of older people in later chapters of this report.

### 3.2.3 Sociological Approach

The sociological approach examines quality of life from an individual and societal perspective. Does the individual achieve satisfaction by their own means, or does society have a role to play in quality of life (Schuessler and Fisher, 1985)? This approach emphasises the various connections that individuals have to families, friends and communities. The nature and form of these social relationships play a critical role in determining the quality of life of individuals. Individuals also make social comparisons as part of a process to develop and maintain their 'sense of self' (Atchley, 1991). If an individual compares themselves to someone who is equivalent, this may result in feelings of belonging and kinship.

### 3.2.4 Economic Approach

Economic theories on quality of life are concerned with income, wealth and rational resource allocation at both micro and macro levels. This approach takes the satisfaction of preferences as the starting point for discussions on quality of life. Individuals aim to optimise their quality of life rationally subject to the constraints of limited resources and their own budget constraints (Diener and Suh, 1997). At a macro level, broad economic aggregates, such as GDP per capita are used as objective indicators of quality of life.

### 3.2.5 Psychological Approach

The psychological approach is concerned with fulfilling needs beyond those of a material nature. An individual experiences feelings of satisfaction and well-being when their needs have been met. Sirgy (1986) defined quality of life in terms of Maslow's theory, as 'the hierarchical need satisfaction level of most of the members of a given society'. The hierarchy ranges from biological need satisfaction at the bottom to self-actualisation needs at the top. Browne *et al.* (1997) theorised that there are two main approaches to quality of life: the standard needs approach and the psychological processes approach. The former identifies a predetermined set of needs and it examines to what extent these needs are fulfilled for the individual. It is an objective analysis of an individual's quality of life. The latter is more subjective in its orientation; as individuals interpret life circumstances differently, the individuals themselves should define and measure their own quality of life. This approach sees the individual as the best judge of their own quality of life (Browne *et al.*, 1997) and has gained increasing credibility in the field, which is reflected in the shift of quality of life measures from global to individual.

Psychological processes may also help to explain the disability satisfaction paradox which refers to the fact that many people with severe and chronic disabilities describe their quality of life as good or even excellent (Bowling and Gabriel, 2004). Older people often value their quality of life higher than objective assessments might suggest. Consciously or unconsciously, people may accommodate or adjust to deteriorating circumstances, whether in relation to health, socioeconomic status or other factors, because they want to feel good about themselves. O'Boyle (1997) suggests that an individual's ability to cope and adapt to a disability can contribute to successful ageing. Put simply, individuals, even in difficult circumstances, may choose to 'look on the bright side' of things (Lawton, 1983).

## 3.3 Quality of Life and Older People

The quality of life of older people is a complex and multidimensional issue. There is no single definition of quality of life for older people, so this section aims to break down quality of life of older people into the domains that are most important to them, as identified in the literature. As there is substantial research output in this field, this section does not attempt to review all of the studies that are available, rather it is a cross-sectional review of the conceptual, qualitative and quantitative work in this area. Only the main domains are reported as follows: health; psychological well-being; social relationships; activities; home and neighbourhood; financial circumstances; and spirituality and religion.

### 3.3.1 Health

Bowling (2005) emphasises that theories on ageing have moved away from the traditional negative models to more positive ones. Health status is treated by gerontologists and other academics as an important influence on quality of life (Bond and Corner, 2004). As ill-health may result in physical and/or psychological dependency, older people frequently nominate health as an important element of quality of life. Indeed, Bowling *et al.* (2003) concluded that ill-health is the most negative influence on quality of life; 44 per cent of respondents in their study cited the importance of good health for quality of life. Those who were healthy and who had little or no difficulty in physical functioning and carrying out activities of daily living were more likely to mention good health as a contributor to quality of life. Other individuals compared their health to those who were not in good health and also spoke of coping mechanisms when one becomes ill. Half of the respondents mentioned ill-health as a negative influence on quality of life.

The vast majority of healthy older people surveyed by Browne *et al.* (1994) also nominated health as an important domain of quality of life. There was no difference in the weights assigned to health by the older and younger age groups interviewed. This implies that the domain of health is important at all ages. Borglin *et al.* (2006) found that 48 per cent of those who reported a high quality of life also had 'excellent' or 'good' self-rated health. They also had higher scores in psychosomatic health than those in the moderate and poor quality of life groups. Being healthy allows respondents to participate in activities, thus contributing to feelings of enjoyment and having a role in life (Grewal *et al.*, 2006).

### 3.3.2 Psychological Well-Being

Psychological well-being is important for quality of life. Indeed, psychological well-being and quality of life are sometimes interpreted as meaning the same thing (Meeberg, 1993; Anderson and Burckhardt, 1999; Hass, 1999). In Grewal *et al.* (2006), 38 per cent of respondents spoke of psychological outlook and well-being as contributing to quality of life.

A positive outlook on life was believed to contribute to quality of life. Respondents referred to being optimistic, satisfied, believing that one had a role in life and also having happy memories of the past. Those who spoke of the negative effect of a poor psychological outlook were more likely to be suffering from anxiety or depression (or other psychiatric morbidities). Farquhar (1995), although not including a domain of psychological well-being, reported that 12 per cent of respondents said that feelings of misery and unhappiness detracted from their quality of life. Borglin *et al.* (2006) found that those groups with the highest self-rated quality of life in their study had significantly higher total scores in the area of mental stability than those of the moderate and poor self-rated quality of life groups.

There is conflicting evidence from the literature in relation to disability and self-esteem. On the one hand the literature indicates that self-esteem is negatively associated with the severity of disability and disease progression (Earle *et al.*, 1979; Cornwell and Schmitt, 1999; Nosek *et al.*, 2003). Alternatively it is suggested that satisfactory psychological adjustment is possible despite the extent of disability or seriousness of disease progression (Brooks and Matson, 1982; Fuhrer *et al.*, 1992; Barnwell and Kavanagh, 1997). While others propose that it is the contextual, social, physical and emotional aspects of having a disability that influence self-esteem rather than the disability itself (Brooks and Mastson, 1982; Walsh and Walsh, 1989; Craig *et al.*, 1994; Barnwell and Kavanagh, 1997).

With regard to the older person and self-esteem, the literature is also ambiguous, with some research indicating that self-esteem reduces in old age (Ranzijn *et al.*, 1998) and others indicating an increase or no change (Erdwins *et al.*, 1981; Gove *et al.*, 1989). Self-concept is related to self-esteem in that 'people who have good self-esteem have a clearly differentiated self-concept' (Franken, 1994). In relation to intellectual disabilities the literature indicates that this group are more at risk for low self-concept (Dunn, 1968; Covington, 1987; Evans, 1998; Elbaum and Vaughan, 2003) and, hence, low self-esteem.

### 3.3.3 Social Relationships

According to Bond and Corner (2004), 'the importance of family and kinship to quality of life has been generally recognised in social gerontological studies'. Social interaction with people, including connectedness to family and friends, is usually beneficial and a positive influence on quality of life. People who are not connected to others often experience loneliness, which detracts from quality of life. That said, loneliness is not always mentioned by respondents in response to quality of life surveys, but this may be due to the stigma attached to being lonely and/or the inadequacy of survey designs. However, older people sometimes mention being afraid of feeling lonely as a result of a decline in social networks due to illness and death among friends.

Bowling *et al.* (2003) reported on a national survey of those aged 65 years and over living at home in Britain. They concluded that good social relationships were critical to quality of life, with good social relationships being mentioned by 81 per cent of respondents. Individuals emphasised the emotional and practical support provided by children and grandchildren. This support was often through face-to-face contact or by telephone. They felt they were able to play a reciprocal role by taking care of and helping their grandchildren. Respondents also spoke of their pets, who were as important as family to some respondents.

Aspects of social relationships that detracted from quality of life included difficulties maintaining contact, family disputes or family members not having enough time to visit. Similar evidence of the importance of social relationships for quality of life is found in a survey by Farquhar (1995) in which older people were asked to describe their quality of life and the aspects of life which contributed to their quality of life. Family was the most important influence on social relationships. Reduced social contacts and feelings of loneliness were cited most frequently as a problem which detracted from quality of life.

The importance of family and social relationships is also highlighted in other studies. Browne *et al.* (1994), used the SEI quality of life method to determine the quality of life of healthy older people in an urban Dublin area: 89 per cent of the respondents nominated family as an important quality of life domain. A Swedish study asked 385 older people living at home to rate their quality of life (Borglin *et al.*, 2006) and found that those with the highest self-rated quality of life had 'excellent' or 'good' social support. Similar evidence of the importance of family and relationships was found in Grewal *et al.* (2006). All of the forty older people interviewed spoke of how important relationships and family were to them. A study which defined quality of life in old age as 'a sense of well-being, meaning and value' found that family contacts were associated with giving meaning to life, while other social contacts including friends, other relatives and neighbours were associated with feelings of self-esteem (Sarvimäki and Stenbock-Hult, 2000).

### 3.3.4 Activities

Various studies have found a positive correlation between engagement in meaningful activities and quality of life. What tends to be missing is elaboration on how the process of engagement influences quality of life. Nevertheless, almost two thirds of respondents in Bowling *et al.*'s study (2003) indicated that involvement in social activities, and local community and voluntary organisations contributed to a good quality of life. On the other hand, only 1 per cent of respondents said that a lack of activities resulted in a poor quality of life. In Farquhar's survey (1995), activities were identified by a substantial number of older people as an important influence of quality of life. Almost all of the healthy older people interviewed (95 per cent) in the study carried out by Browne *et al.* (1994) cited



social and leisure activities as a contributor to quality of life. The importance of 'having things to do' and taking part in life was discussed by all respondents in the Grewal *et al.* study (2006). Activities identified included travel, bridge, politics, continuing to work and helping other people. Activities were also associated with feelings of self-worth and having a role in life.

### 3.3.5 Home and Neighbourhood

The environmental approach to quality of life posits the theory that an individual's physical and social environments affect quality of life. Furthermore, quality of life is dependent on how an individual relates to, and perhaps adapts to, environments that are not ideal (Uzzell and Moser, 2006). If the structures that help people relate to their neighbourhoods aren't in place, then this may affect quality of life. For example, a lack of transport facilities may prevent an older person from leaving their home, thus substantially reducing their ability to interact with the local and regional environment.

Bowling *et al.* (2003) reported that 37 per cent of respondents spoke of neighbourliness as a contributor to quality of life. The main factors in the category of home and neighbourhood were: living in a safe, secure, friendly area; having friendly, helpful neighbours; and the availability of good local facilities. The availability of Council services, including refuse collections and having pleasant landscapes and surroundings, was also an important factor. Independence was also mentioned in relation to the availability of reliable and frequent transport services. Thirty per cent of respondents cited bad neighbourhoods as a negative influence on quality of life and concerns about safety and lack of community spirit were highlighted as contributing to bad neighbourhoods.

Living conditions were mentioned by 80 per cent of respondents in Browne *et al.*'s study (1994). The individuals with the highest quality of life also had the highest satisfaction with their residential environment in Borglin *et al.*'s research (2006), while Grewal *et al.* (2006) reported that the majority of those interviewed mentioned the importance of home and surroundings. Respondents cited security at home as being important, but also derived pleasure from living in their own homes and some had a degree of attachment to their home and neighbourhood.

### 3.3.6 Financial Circumstances

Bond and Corner (2004) referred to the changes in financial circumstances which have taken place over the last century. They pointed out that the number of people in absolute poverty has declined dramatically. Absolute poverty occurs when individuals cannot afford the basic necessities in life. However, relative poverty for older people has increased in many countries, including Ireland, in recent decades. Relative poverty occurs when one is financially worse off than others, but has sufficient money to live on. As individuals

are inclined to compare themselves to others, being relatively poor may detract from an individual's quality of life.

Bowling *et al.* (2003) reported that one third of interviewees in their study pointed to lack of financial worries as contributing to quality of life. Respondents compared themselves to those who were financially worse off. They identified being able to afford luxuries, such as pastimes and holidays as contributing to quality of life. Twenty-three per cent of respondents said that not having money detracted from quality of life, stating they could not afford luxuries or pay for house repairs. Similarly, finances were mentioned by 25 per cent of respondents as being a domain of quality of life in Browne *et al.* (1994). Material circumstances were also highlighted as important for respondents in Farquhar's study (1995) on quality of life.

### 3.3.7 Spirituality and Religion

Bond and Corner (2004) outlined the difference between religion and spirituality. The former is associated with powerful religious organisations, whilst the latter is a private, subjective experience. Even if church attendances have fallen, this does not mean that spirituality will have little influence on quality of life of future generations of older people. In Bowling *et al.*'s study (2003) spirituality and religion were not identified as a separate domain of quality of life. However, attending a place of worship was mentioned by respondents and was recorded by the authors under the domain of activities. Spirituality was also mentioned by respondents but it was recorded in the psychological well-being domain. There was no mention of spirituality or religion in Farquhar's survey (1995). In contrast, Browne *et al.* (1994) found that religion/spirituality was nominated as a domain of quality of life by 75 per cent of respondents in Ireland. Grewal *et al.* (2006) also highlighted religion as an important domain of quality of life for older people. A study which assessed the influence of spirituality, religion and personal beliefs (SRPB), using the WHO Quality of Life measure, found that SRPB was an influence on quality of life, but was not as important an influence as environmental, psychological or social domains (WHOQOL, 2005). However, SRPB plays a part in an individual's ability to cope with illness and stress, and maintain well-being.

## 3.4 Quality of Life and Disability

Since different disabilities affect different areas of an individual's life, we would expect to see differences in the relative importance of quality of life domains across disability groups. Methodological differences in the approach to the measurement of quality of life within

various disability groups also makes comparison difficult but some trends do emerge, however. Quality of life is analysed in respect of the following six disabilities, chosen to reflect the most common disabilities experienced by older people in Ireland: dementia, depression, intellectual disability, rheumatoid arthritis, sensory disability, and stroke.

### 3.4.1 Dementia

Direct assessment of the quality of life of individuals with dementia has proven difficult due to methodological, conceptual and practical issues. The use of traditional interview methods to assess the quality of life of people with dementia is difficult, as dementia results in cognitive impairment, thus limiting the memory, reasoning and speech abilities of the individual. Where personal interviews are carried out, it is usually with people with mild cognitive impairment. Alternative methods have been and are being developed to improve the measurement of quality of life of individuals with dementia. Proxy measures, such as observational methods, are often used to measure quality of life. Proxy respondents are also frequently used. Proxy respondents are caregivers or relatives who respond on behalf of the individual with dementia (Bond, 1999).

One of the most interesting findings from quality of life studies of people with dementia is that they generally rate their quality of life as good or very good (James, Xie and Karlawish, 2005). Their ratings are similar to those found in studies of the general public (Katsuno, 2005). In contrast, proxy respondents tend to rate the quality of life of people with dementia lower than the individuals themselves. This fact has been well-documented, leading to doubts about whether proxy responses are accurate (Bond, 1999; Brod *et al.*, 1999).

People with dementia generally perceive their physical health as good. Logsdon *et al.* (2002) found that being in good physical health contributed to the quality of life of people with dementia. Conversely, reduced physical health can have a negative effect on mood level, which in turn reduces quality of life. There was some evidence of depression in people with dementia, with depression and anxiety being negatively correlated with quality of life (Selwood, Thorgrimsen and Orrell, 2005).

Social support is important for people with dementia (Bond, 1999). Katsuno (1995) reported that people with dementia report that the stigma attached to the disease often results in social exclusion. They believed that the general public were poorly educated about dementia and this resulted in negative stereotypes. People with dementia found that others ignored them; their friends were no longer supportive and did not visit. People with dementia often prefer not to tell people about their condition in order to avoid the stigma associated with dementia and its inevitable consequences in the social sphere (Katsuno, 2005). In general, experiences of social exclusion have negative effects on psychological well-being and detract from overall quality of life.

People with dementia report that spouses, children and grandchildren are sources of happiness and satisfaction in life, with family providing emotional and practical support. It is very important for an individual's sense of well-being to know that they have someone they can count on and contact in times of confusion or crisis. Being listened to and understood by their family adds to quality of life (Katsuno, 2005). Support from family is a positive influence on mood level and frame of mind.

### 3.4.2 Depression

The relationship between quality of life and depression is complex. Emotional and psychological well-being is negatively affected by depression, which, in turn, results in a lower quality of life. Disability and depression often coincide, and data has shown that the relationship can work in both directions. Depression may result in increased disability while disability may lead to depression. The three domains of quality of life among older people that have the strongest correlations with depression are physical health, social isolation and loneliness (Bruce, 2001).

Poor health and functioning are associated with the onset of psychiatric morbidity among older people, particularly depression (Bowling *et al.*, 1996). While there is a positive relationship between declining physical health and depression, social isolation may, however, be a stronger cause of depression (Alpass and Neville, 2003). For example, Roberts *et al.* (1997) found that those who were socially isolated in the first year of their study were at greater risk of depression in the following year. Of course, it may well be that poor physical health is the cause of social isolation in the first instance.

The literature is not in agreement as to whether poor social support contributes to depression. Taylor and Lynch (2004) found that social support was strongly interrelated to disability and depressive symptoms in later life, however, Bowling *et al.* (1996) found only weak associations between social support and depression. Similarly, Alpass and Neville (2003) do not find a relationship between social support and depression.

There is an important relationship between loneliness and psychological well-being in older people, particularly in the area of depression. Loneliness can occur in both the presence and absence of social contact (McWhirter, 1990). Older people are more susceptible to loneliness because there are many changes to their social networks over time. Offspring may no longer live close by and may even live abroad. A retired person may miss social interaction at work. The loss of a spouse in later life may also lead to loneliness (Alpass and Neville, 2003). Older men may be more prone to loneliness than older women. Compared to women, more men rely on their spouses and less on family and friends for social support. Should anything happen to their spouse, older men may struggle and their quality of life may suffer.

### 3.4.3 Intellectual Disability

The study of quality of life in the area of intellectual disabilities is still emerging. Its conceptualisation, measurement and implementation are a subject of much debate. Due to the methodological difficulties in measuring the subjective quality of life of individuals with an intellectual disability, few surveys of quality of life of people with an intellectual disability have been carried out (Hensel, 2001). These methodological difficulties refer to the lack of instruments that are capable of measuring the quality of life of individuals with an intellectual disability (Vreeke *et al.*, 1997). When surveys of individuals with an intellectual disability are carried out, a form of self-selection is likely to occur with individuals who are more able to respond to questions more likely to be surveyed. The domains of quality of life that are important to people without an intellectual disability are also of importance to people with an intellectual disability. These domains are: physical well-being, material well-being, social well-being, emotional well-being and development and activities. However, the content within these domains varies for those with an intellectual disability compared to those without an intellectual disability (Petry *et al.*, 2005). In some studies in which proxy respondents were used, differences emerge between the answers given by people with an intellectual disability and their proxies (Rapley *et al.*, 1998).

Emotional well-being and family support are very important to people with an intellectual disability. Petry *et al.* (2005) found communication, security, family and social relationships to be important influences on quality of life. The Verona 2001 Declaration on Ageing and People with Intellectual Disabilities (EASPD, 2001) highlighted the importance of the family in supporting individuals with an intellectual disability; families provide a link to the wider community and provide the means for greater participation in society by people with an intellectual disability (Walsh, 2002).

Living environment and transportation can seriously affect the quality of life of an individual with an intellectual disability. Living environments must be adequately equipped to meet the needs of the individuals; they must be comfortable and safe, and the atmosphere and décor is important (Petry *et al.*, 2005). If the living environment is not properly adapted to suit the needs of the individual, the independence of the individual is likely to be compromised. Likewise with transport, which is also important for both work and leisure; its availability is crucial as is its accessibility. Participation in recreational activities and contact with people without an intellectual disability are positive influences on the quality of life of older people with an intellectual disability (Dagnan *et al.*, 1998). Janssen *et al.* (2005) found that individuals with an intellectual disability had too few opportunities to participate in recreational activities. If recreational opportunities are not available or accessible due to environmental or transport limitations, then quality of life suffers.

### 3.4.4 Rheumatoid Arthritis

Rheumatoid arthritis negatively affects quality of life with the main areas affected being physical domains, social domains and psychological domains (Strombeck *et al.*, 2000; Arnold *et al.*, 2004). One attribute specific to rheumatoid arthritis is the degree of uncertainty involved in the disease. An individual with rheumatoid arthritis may not know from one day to the next how they will feel. Rheumatoid arthritis can go into remission for weeks with the individual being pain free and resuming normal activities. However, a return of symptoms may be triggered at any time. Uncertainty has psychological implications for the individual; along with pain and fatigue, it affects the mood level of individuals and has an overall negative impact on quality of life (Wiener, 1984).

Rheumatoid arthritis also results in limited mobility for some sufferers and people may experience feelings of helplessness because of reduced mobility and increased dependence (Whalley *et al.*, 1997). Even going on holidays can prove to be difficult, as people with rheumatoid arthritis must plan every detail in order to avoid environmental disabling barriers, for example stairs. People adapt their lives in response to the illness; some may attempt to cover up their condition by trying 'to act normal' and pretend that they are not in pain in order to avoid asking for anyone's help (Wiener, 1984). Jakobsson and Hallberg (2002) found that pain increases with age for sufferers of rheumatoid arthritis, with lack of social support correlating with increased levels of pain and decreased quality of life.

Whalley *et al.* (1997) reported that individuals' moods are negatively affected by rheumatoid arthritis, leading to feelings of depression. The authors mainly attributed these feelings to chronic pain and fatigue. The inability to perform daily tasks also frustrated respondents, particularly if they were unable to participate in social activities. Some respondents in Wiener's study (1984) described how they took out their frustration and feelings of helplessness on their families and subsequently felt guilty.

### 3.4.5 Sensory Disability

Sensory impairments have a negative effect on quality of life. Scott *et al.* (1999) reported that individuals with poor vision believed that their functional status and their quality of life were substantially limited by their disability. Suffering from two vision impairments (cataracts and glaucoma) double the negative effect on an individual's quality of life (Broman *et al.*, 2002; Nirmalan *et al.*, 2005). Even mild vision impairments result in individuals having substantially lower quality of life than those without visual impairments (Franke *et al.*, 2002). Hearing impairments are also associated with lower health-related quality of life (Mulrow *et al.*, 1990; Ringdahl and Grimby, 2000).

Campbell *et al.* (1999) found that older people with sensory impairments reported poor health-related quality of life. Both hearing- and vision-impaired older people stated that their health-related quality of life was lower as a result of the impairment (Mulrow *et al.*, 1990; Ringdahl and Grimby, 2000). Mental health is important to the quality of life of older people with sensory disabilities; those with the poorest vision are more likely to rate their mental health lower (Broman *et al.*, 2002). Mood level is also affected by visual impairment (Carabellese *et al.*, 1993).

Individuals with sensory disabilities also reported feeling that they were less independent (Broman *et al.*, 2002). The principal reason for dependency in people with poor vision is that they are unable to drive; they are dependent on others to drive them or are reliant on public transport that is sometimes poor or non-existent. Social relationships are also recognised as a quality of life domain that is significantly affected by the loss of vision (Carabellese *et al.*, 1993).

Hearing loss also impacts on people's ability to connect with other people. Tsuruoka *et al.* (2001) suggested that lack of communication results in feelings of depression and insecurity among older adults with hearing impairments. They also found that hearing impairments affected communication, social and psychological elements of quality of life in older people living in nursing homes. The inability to communicate or hear what is being said can result in reduced social interaction and well-being. Communication can be improved by the use of sensory aids, which lead to higher levels of well-being. Appollonio *et al.* (1996) reported that older people using sensory aids had a higher mood level, richer social relationships and better performance in activities of daily living.

### 3.4.6 Stroke

Stroke affects both physical and psychological components of quality of life (Ahlsio *et al.*, 1984). In general, the health of older people with stroke has been found to have a negative influence on their quality of life (Widar *et al.*, 2004; Robinson-Smith *et al.*, 2000). Some older people with stroke reported a reduction in physical mobility and in energy levels (Gosman-Hedström and Blomstrand, 2003). Pound *et al.* (1999) reported, however, that after a time stroke patients find new ways of doing things. Many adapt to their new situation and take life more slowly than before in an attempt to adapt to their disability and improve their quality of life.

Widar *et al.* (2004) also found that health-related quality of life for people with stroke can be improved by good relationships and support from others. One month after a stroke, patients said that family support was the most important influence on their quality of life. After six months, respondents also identified the ability to speak as a quality of life domain because it improved communication with those who mattered (Robinson-Smith *et al.*, 2000).

Widar *et al.* (2004) pointed to the need to include relatives in the rehabilitation process so that they could provide emotional support and maintain good relationships with the patient. Pound *et al.* (1999) also found that families are the most important resource for stroke patients.

Depression was reported to have a negative effect on quality of life after stroke (King 1996; Kauhanen *et al.*, 2000). Surprisingly, married patients living at home were more likely to experience poor mental and physical health than unmarried patients living with family (Kauhanen *et al.*, 2000; Widar *et al.*, 2004). Ahlsio *et al.* (1984) found that while activities of daily living (ADL) function improves gradually with time, quality of life does not improve as ADL improves. The psychological state of an individual was as important as their physical state to quality of life. This suggests that, while physical therapy is important for the rehabilitation of stroke victims, psychological therapy may be of equal importance. However, not all of the studies found a direct link between stroke and depression. Emotional problems associated with stroke may result from a complex interaction between personal traits, social circumstances, living arrangements and functional abilities (De Hann *et al.*, 1995).


### 3.5 Conclusion

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Quality of life is a multidisciplinary concept with many different definitions and interpretations, which sometimes lead to ambiguity and confusion. It is a life-course phenomenon and is, therefore, a dynamic concept; quality of life changes over time in line with life events and circumstances. Consequently, measurement must be both objective and subjective; the latter is necessary to ensure that individual narratives and perceptions are represented in any assessment. If public policy aims to improve quality of life of older people, then it must target the domains of quality of life which are the most important to them. Good physical health is important for quality of life of older people with a disability, but so too are environment, psychological well-being and good family and social relationships.







Chapter Four  
Research  
Methodology



# Chapter Four

## Research Methodology

### 4.1 Introduction

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The purpose of this study was to understand older people's experiences of living with a disability. The study aims were to:

- examine the meanings of independence, dependence and interdependence
- identify shared and distinct factors related to quality of life of older people with a disability across the categories of gender, age, time of onset, type of disability and living arrangements
- identify common factors that contribute to quality of life as well as differences that occur across the categories of time of onset of disability, type of disability and living arrangements
- provide information to service providers regarding best practice in the delivery of services to older people with a disability
- inform and guide public policy for older people with a disability.

This chapter outlines the study methodology, the sampling strategy employed, and the approach to data collection and analysis.

### 4.2 Study Methodology

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A qualitative research approach is appropriate when exploring an older person's reality of living with a disability. It is important, however, to be explicit about the qualitative methodology employed as failure to do so is a common criticism of qualitative studies. The researchers considered various qualitative methodologies, including a qualitative

descriptive approach, grounded theory and phenomenology. On reviewing the match of these methodologies to the study aims, the researchers opted for a grounded theory approach. Grounded theory is the methodology of choice when exploring social problems or situations to which people must adapt (Benoliel, 1996; Annells, 1997; Schreiber, 2001). The area of interest of this study corresponds closely, as it focuses on how older people adapt to living with a disability and the processes they use to deal with it in their day-to-day lives. Pure grounded theory was not employed in this study. To help explain how the approach used in this study differs, a brief overview of grounded theory is provided below.

## 4.3 About Grounded Theory

The central aim of grounded theory is to develop theory (Strauss and Corbin, 1998). A grounded theory emerges from or is grounded in the data and should 'explain or give insight' into the phenomenon under study (Bluff, 2005). The theory emerges through a process of simultaneous data collection and analysis (Glaser and Strauss, 1967; Strauss and Corbin, 1998). Two techniques are central to the emergence of theory: the constant comparative technique and theoretical sampling.

### 4.3.1 The Constant Comparative Technique

In grounded theory data collection and data analysis are carried out concurrently; and the making of comparisons is the major analytic procedure employed. To begin the interviews and/or field notes are transcribed verbatim. The researcher then starts to code the data. Coding in grounded theory refers to the process by which concepts within the data are identified and named (Strauss and Corbin, 1998). Codes are compared and similar codes are grouped to form categories. A category is a 'group of concepts that stand for a phenomenon' (Strauss and Corbin, 1998). Categories are then compared and similar categories are integrated. 'New' data from subsequent interviews are compared and integrated with 'old' data or form new codes and categories. 'Old' data are re-analysed in the light of emerging ideas or hunches.

The goal of analysis is to integrate the categories into a 'larger theoretical scheme' (Strauss and Corbin, 1998). This results in the identification of a central or core category. The core category is the pivotal category around which the other categories integrate (Strauss and Corbin, 1998). A grounded theory is expressed in the form of a core category, its related categories<sup>1</sup> and their properties.<sup>2</sup>

1 A category is defined as standing by itself as 'a conceptual element of the theory' (Glaser and Strauss, 1967).

2 A property 'is a conceptual aspect or element of a category' (Glaser and Strauss, 1967). Both categories and properties are 'concepts' indicated by the data and 'not the data itself' (Glaser and Strauss, 1967).

The key texts on grounded theory outline different approaches to coding. In this study, Strauss and Corbin's (1998) approach of open, axial and selective coding guided analysis. The aim in open coding is to break down the data. The researcher goes through the transcript line by line and assigns codes. Breaking data down in this manner enables its conceptualisation. Axial coding links the data by comparing codes and clustering similar codes together to form tentative categories. Ongoing analysis facilitates the further development and integration of categories. Selective coding is concerned with identifying the core category and its relationship(s) to the other categories.

### 4.3.2 Theoretical Sampling

Theoretical sampling is the process of simultaneously collecting, coding and analysing data to generate theory (Strauss and Corbin, 1998). In grounded theory, sampling decisions are driven by the 'concepts that emerged from analysis and that appear to have relevance to the evolving theory' (Strauss and Corbin, 1998). Theoretical sampling implies that data is selectively gathered to define the emerging categories further. The aim of theoretical sampling is to 'develop', 'densify' and 'saturate' the categories (Strauss and Corbin, 1998). A theoretical sample, therefore, evolves as the study progresses and cannot be fully determined in advance.

The researcher must make some initial sampling decisions on where to start and grounded theorists use a purposive sampling strategy initially. Initial sampling decisions are taken on the grounds of what is logical and practical (Strauss and Corbin, 1998; Cutcliffe, 2000). Purposive sampling is superseded by theoretical sampling once data collection commences.

The focus of theoretical sampling changes according to the type of coding in progress (open, axial, or selective). Strauss and Corbin (1998) identify three forms of theoretical sampling:

- *open sampling* aims to keep data gathering 'open' to allow discovery. Strauss and Corbin (1998) provide some examples of open sampling approaches, for example the purposeful selection of persons, sites or events
- *relational and variational sampling* focuses on collecting data that enables the researcher to 'identify significant variations' (Strauss and Corbin, 1998). Comparison between incidents produces questions that guide subsequent data collection (Strauss and Corbin, 1998). The researcher then purposefully chooses sites or persons that have the greatest potential of maximising or minimising differences (Strauss and Corbin, 1998). It should be noted that interview questions are also adjusted on the basis of emerging concepts

- *discriminate sampling* focuses on selecting sites or persons that maximise opportunities for comparative analysis (Strauss and Corbin, 1998). This may mean returning to 'old' sites or persons or going to 'new' sites or persons to achieve saturation. Sampling at this stage helps 'fill in' the categories and 'flesh out' their relationships (Schreiber, 2001).

Theoretical sampling continues until saturation is achieved (Carpenter, 2003; Cutcliffe, 2000; Strauss and Corbin, 1998). Saturation<sup>3</sup> is achieved when no new data emerges. Saturation implies that any new data fits into the categories already devised (Charmaz, 2000) and that the categories are well-rounded in terms of their properties and dimensions (Strauss and Corbin, 1998). Reaching saturation is dependent on a number of factors including the quality of data, the scope of the study, the nature of the topic and the amount of useful information obtained from each participant (Morse, 2000).

### 4.3.3 Grounded Theory As Used in the Study

The time, resource and ethical constraints of this study did not permit 'true' theoretical sampling to be employed. Concurrent data collection and analysis permitted a modified version of relational sampling to be employed, in that analysis of initial interviews shaped subsequent interviews. Where possible, researchers deliberately included older people who have had different experiences to maximise or minimise differences (relational sampling). However, the systematic approach adopted during discriminate sampling (and to some degree relational sampling) was not possible. This was the result of two major constraints:

- the research team was reliant on gatekeepers to access the sample and did not always have access to the detailed information required to implement theoretical sampling. Gatekeepers have a responsibility to protect their constituents and some felt it was inappropriate to release detailed information to inform sampling while others did not have sufficient depth of information to inform sample selection or did not have the time or resources to identify older people who met specific criteria
- ethical, resource and time restrictions were also issues.

As a result of these constraints, the sample was decided in advance of data collection rather than evolving, which is the norm in a grounded theory study. In other words a purposive or open sampling strategy was used.<sup>4</sup> This ensured that the sampling strategy was feasible within resource and time restrictions.

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3 Morse (1995) defines saturation as 'data adequacy'.

4 Purposive sampling is a non-probability sampling strategy in which the researcher selects subjects who are considered typical of the population (LoBiondo *et al.*, 2006).

Also to facilitate the reader to get an overview of the issues involved and aid their interpretation of the findings, the literature review was presented separately in Chapters One, Two and Three and is not integrated into the findings as is common in grounded theory.

For these reasons the methodology guiding this study is described as a grounded theory approach as it was not possible to use the grounded theory methodology in full. Strauss and Corbin (1998) acknowledge that pragmatics may shape a study and this is the case here.

The study was divided into two parts: the first involved completing a scoping project to establish a sampling strategy, while the second comprised of data collection and analysis.

## 4.4 The Scoping Project

The challenge for the research team in designing this study was how to ensure that the sample of older people interviewed captured as wide a range as possible of the experiences of older people living with disability. Strauss and Corbin (1998) agree that researchers should gather data in a broad range of pertinent areas in order to facilitate the development of as many categories as possible. To develop an appropriate sampling strategy that would facilitate the collection of a wide range of data, a scoping project was undertaken. It involved:

1. reviewing the literature to identify possible sampling strategies
2. consulting key stakeholders to determine how best to access the information required to develop the sampling frame
3. Contacting gatekeepers including general practitioners (GPs), public health nurses (PHNs), carer groups and voluntary organisations for their help and advice in identifying older people with a disability living at home.

It is vital that researchers make explicit the rationale for the sampling approach adopted in a study (Devers and Frankel, 2000; Higginbottom, 2004). Six sub-samples of older people with the following disabilities were interviewed:

- dementia
- depression
- intellectual disability
- rheumatoid arthritis
- sensory disability<sup>5</sup>
- stroke.

The rationale for selecting these categories lies in the Disability Act 2005, which refers to physical, sensory, learning, mental health or emotional impairment as the main components of disability in Ireland. A comparative group of older people without a diagnosed disability were also interviewed to provide a baseline against which the various groups might be compared.

The key sample parameters are described below and were agreed in advance with the project Consultative Committee established by the NCAOP. The sample comprised:

- men and women
- a range of ages (<65 years, 65-74 years, 75-84 years, 85+ years)
- people with early and late onset of disability
- people living at home alone, living at home with family or others, or living in a residential setting
- people with medium and high dependency levels
- people living in urban and rural settings.

To be included participants had to be:

- aged 65 years or over (or 50 years or over in the case of a person with intellectual disability)
- have one or more of the disabilities listed above
- cognitively and physically able to participate

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5 For the purposes of this study, sensory disability was defined as hearing impairment/deafness and visual impairment/blindness.



- able to give informed consent
- willing to participate in the study.

The literature review and discussions with gatekeepers indicated that reliable statistical data on each of the sub-samples was not readily available at a national level. It was not possible, therefore, to locate a list of names of the full population for each disability group. In the absence of established sampling frames, alternative ways of accessing the sample were adopted. Access was gained through gatekeepers, such as healthcare professionals, voluntary and support groups, and regional and national associations. In this way, older people with one of the six disability types listed were identified. The selection of participants was guided insofar as possible by theoretical sampling. Although every effort was made to obtain purposive samples that met the six dimensions identified above for each of the sample groups, in some instances the sampling method used was convenience sampling.

## 4.5 Data Collection and Analysis

The principle method of data collection in this study was semi-structured interviews. Interviews were supported by the use of quantitative measures which provided contextual data on the sample.

### 4.5.1 The Sample

The study sample comprised of 143 older people drawn from six different counties: Dublin, Galway, Mayo, Meath, Cork and Donegal. The majority of participants were female and participants ranged in age from 51 to 91 years. The aim was to interview twenty older people in each sub-sample. Table 4.1 provides an overview of the study sample disaggregated by disability group.

**Table 4.1: Overview of study sample disaggregated by disability group**

Disability group	Participants (N)	Gender		Age			
		Female	Male	< 65 years	65-74 years	75-84 years	85+ years
Dementia	18	12	6	2	3	10	3
Depression	20	13	7	0	8	8	4
Intellectual disability	26	10	16	24	2	0	0
Rheumatoid arthritis	19	11	8	0	8	10	1
Sensory disability	20	15	5	0	11	9	0
Stroke	20	10	10	0	6	11	3
No diagnosed disability	20	16	4	0	12	7	1
<b>Total</b>	<b>143</b>	<b>87</b>	<b>56</b>	<b>26</b>	<b>50</b>	<b>55</b>	<b>12</b>

Two of the sub-samples did not reach the target of twenty participants. In these cases, illness or deterioration in a person’s physical or mental condition prevented their being interviewed. A greater number of people with an intellectual disability were interviewed than originally planned. Data from these interviews was variable and it was decided to increase the sample size to enhance the overall richness of the data. In all sub-sample groups, participants living in both rural and urban settings were included. This was considered important because it is possible that factors, such as access to transport, healthcare services, etc. might impact positively or negatively on participants’ quality of life and independence.

## 4.5.2 Qualitative Data Collection: Interviews

### 4.5.2.1 Recruitment of Participants

Potential participants were initially telephoned by the research team project manager or an interviewer. The purpose of the study was explained and individuals were asked if they would be interested in participating. In most cases a gatekeeper had already contacted the older person to ask permission to give the older person’s telephone number to the research team so they were already aware of the study. If the older person expressed an interest in participating in the study, further information on the study and a consent form were forwarded to them for their information. This information was printed in large type and was also available in Braille if required. The older person was contacted again several days later and an appointment for the interview was confirmed if s/he wished to proceed. Allowing a time lag is in line with ethical guidelines and ensured that each potential participant had sufficient time to decide if s/he wished to participate in the study or not (Haber, 2006). The project manager also contacted the participant the day before the interview to confirm arrangements and verify that they were still happy to proceed.

Prior to commencing the interview, each interviewer spent some time talking with the participant and his/her family (if present), checked again that they were happy to continue, and verified that they understood what was involved. The participant was asked to sign a consent form and grant permission for the interview to be recorded.

#### 4.5.2.2 Approach to Interviews

The researchers were conscious that participants' disabilities and/or cognitive problems could make interviewing difficult. Therefore careful consideration was given as to which interview format would be most suitable for interviewing older people with a disability and how best to support them during interviews. The literature was consulted for advice and two methods of supporting older people in interviews were identified:

- providing emotional support, i.e. assuring the older person that what they had to say was important
- providing physical supports, such as providing a list of questions in large type.

Researchers used these strategies to support older people during the interviews.

The interviewers also had extensive experience in health and social care interviewing techniques.

#### 4.5.2.3 Interview Format

Many authors (McNeely and Clements, 1994; Bray *et al.*, 1995) report that older people do not organise information as well as younger people. To help overcome this difficulty, Bray *et al.* (1995) suggest that the interview guide should be logically sequenced to make it easier for the older person to remember events sequentially. Hence an interview schedule was devised to help structure interviews. On the other hand the researcher should not be too hasty to judge that the older person has 'gone off the point'. Robinson (2000) found that reminiscence is particularly important for older people and is helpful in gaining a better understanding of participants, their value systems and the data reported. The project manager ensured that sufficient time was allocated for interviews so that participants did not feel rushed or hurried. However, this was balanced with the possibility that the participant might become fatigued and be unable to continue. Therefore, interviewers used their judgement to guide interviews so that they were not too long and tiring for participants. To facilitate this, it was decided to adopt a semi-structured format for interviewing.

In semi-structured interviews a set of questions is worked out in advance but there is flexibility in the phrasing and order of questions (Holloway and Wheeler, 2002; Hansen 2006). The researcher makes judgements as to what is appropriate to ask in context of the 'conversation' (Robson, 1993). This may include omitting or adding questions (Hansen,

2006). Semi-structured interviews are beneficial as they keep participants on track while simultaneously allowing them some degree of freedom of expression (Holloway and Fulbrook, 2001). The researchers did not want to exhaust participants and were keen to keep interviews short and focused but used their judgement to balance this with allowing participants to tell their stories in their own way and at their own pace.

#### 4.5.2.4 About the Interviews

Data was collected over a six-week period using face-to-face semi-structured interviews (n=143). Interviews lasted for between thirty and ninety minutes.

Interview schedules, comprising of open-ended questions, were developed to guide initial interviews (Appendix One). A core set of questions was used in each guide but adapted to meet the needs of the various sub-samples, for example the language of the questions used with people with an intellectual disability was simplified. The use of core questions across schedules ensured consistency. The guides were informed by a review of relevant literature and were piloted with each group (n=8) prior to the main interviews. Minor revisions were made to questions following the pilot interviews.

The use of open questions gave participants the freedom to voice their opinions and describe their experiences. Interviewers used the guide flexibly, the aim being to have a conversation with each participant. Recording the interviews ensured that a copy of participants' comments would be available, thus reducing the potential for interviewer error and enhancing validity.

Interviews were conducted by experienced interviewers. All interviewers were registered nurses and all had experience of working with older people. Interviewers with specific expertise in working with people with an intellectual disability and people with dementia interviewed these groups. A one-day training session was held for all interviewers to ensure that they were familiar with approaches to interviewing older people, the interview schedules and recording equipment. In addition, a further one-day training programme was provided for interviewers interviewing older people with dementia. This session was facilitated by an international expert in this field, Prof. Murna Downs.

The first interviews held aimed to elicit participants' stories and experiences. However, as is the norm in grounded theory, as the interviews progressed they became more focused. This is the result of data analysis guiding further data collection (Strauss and Corbin, 1998; Duffy *et al.*, 2004). In effect, this means that participants interviewed later in the study were asked different questions to those interviewed earlier as questions were guided by the emerging theory and ongoing analysis (Strauss and Corbin, 1998; Schreiber, 2001).

#### 4.5.2.5 Qualitative Data Analysis

Data collection and analysis occurred simultaneously. Analysis was divided into two stages. Initially researchers analysed grouped data, for example data from the rheumatoid arthritis disability group, the stroke disability group, etc. Analysis began with repeated reading of the transcripts to allow the researcher to become immersed in the data. Each transcript was read and assigned preliminary codes. Similar codes were then grouped to form tentative categories. This helped identify similarities and differences across the groups. In the second stage the data was analysed across the sample. A coding guide was formulated at this stage and used to re-analyse the data. During the analysis process international literature was also reviewed and this helped to inform the analysis process further. A process of continuous comparison enabled the collapse of categories and the identification of five core domains:

- health
- environment
- connectedness
- sense of self
- income.

#### 4.5.3 Quantitative Data Collection

##### 4.5.3.1 Quantitative Measures

The role of the quantitative data collection was to contextualise the qualitative analysis. The numbers interviewed in each group are too small to allow inferences to be drawn from the data itself or for any extrapolation; however, the data does provide important background information on the study population. The data gathered and scales used were as follows:

- demographic information was collected in relation to age, educational level, marital status, occupational grouping, geographical area and place of residence (Appendix Two)
- self-esteem was assessed using Rosenberg's Self-Esteem Scale (Rosenberg, 1965). Self-esteem refers to a person's sense of self-respect and self-confidence and also entails a sense of personal worth and adequacy (Rosenberg, 1979). Self-esteem is an attitude held by the individual about the self, which may be positive or negative and consists of both cognitive and affective dimensions (Gecas, 1982; Rosenberg, 1979). Rosenberg's Self-Esteem Scale is short and easy to complete. Developed initially for use with adolescents, it has since been validated for use with adults and older people (Essex and Klein, 1989). The instrument is made up of ten items or statements that

are rated on a four-point scale ranging from strongly agree to strongly disagree. The scale has demonstrated good reliability and validity, and it is widely accepted as having good psychometric properties (Baker and Gallant, 1984; Blascovich and Tomaka, 1991) (Appendix Three)

- the SF-36v2 is a 36-item self-report questionnaire that measures perceived physical functioning, social functioning, role limitations due to physical problems, role limitations due to emotional problems, mental health, energy and fatigue, pain and general perception of health (Ware *et al.*, 2000). It yields an 8-score profile of scores and is a generic measure of health that can be used to compare health scores across populations. This health survey has been extensively tested and validated (Brazier *et al.*, 1992; Garratt *et al.*, 1993). Bowling (2005) reports that the SF-36v2 scale is suitable for use with older people and, overall, validity and reliability has been shown to be good (Appendix Four)
- the Katz Index of Independence in Activities of Daily Living (Katz *et al.*, 1963) was used to determine the independence/dependence of participants in the activities of daily living. The index assesses independence in six areas: bathing; dressing; toileting; transferring from bed to chair; continence; and feeding (Appendix Five).

Every participant was not able to complete all scales. For example, Rosenberg's Self-Esteem Scale was too abstract for some people with dementia to complete. In total, 85 per cent of participants completed the scales in full.

#### 4.5.3.2 Quantitative Data Analysis

Demographic data, data from the Katz Index of Independence in Activities of Daily Living and the Rosenberg Self-Esteem Scale were analysed using SPSS v.12. Data from the SF-36v2 was analysed using software developed specifically for the analysis of such data (the SF Health Outcomes Scoring Software). Data was coded and summary measures calculated for eight components: physical functioning (PF); role physical (RP); bodily pain (BP); general health (GH); vitality (VT); social functioning (SF); role emotional (RE); and mental health (MH). Using the software, data was transformed for comparison purposes. The software also provides missing data estimation support.

## 4.6 Ethical Issues


Several authors have questioned the ethics and appropriateness of researching vulnerable groups, for example those with a severe mental illness (Usher and Holmes, 1997; Moyle,

2002). Others have argued that involving those most affected by issues is an ethically appropriate way to proceed in research, as it promotes the interests of disadvantaged groups, respects autonomy and sheds light on aspects of care that might be otherwise hidden (Seymour and Skilbeck, 2002; Murphy *et al.*, 2005). A tendency to dismiss older people's intellectual ability has been noted (Butler, 1990; Maas *et al.*, 2002; Royal College of Nursing, 2004). Many authors have highlighted that older people have a right to have their voice heard (Dewing, 2002; Hubbard *et al.*, 2003; Murphy *et al.*, 2005). Nonetheless, given some older people's potential vulnerability, careful consideration was given to the nature of informed consent.


Informed consent was obtained from all participants prior to interview. All participants were provided with verbal and written information about the study and the research team ensured that participants understood what the study was about and what participation meant prior to gaining consent. Participants were informed of their right to withdraw with no consequences.

The anonymity, privacy and confidentiality of participants were maintained at all times. Participants were allocated a study number and all interview data was identifiable by this number only. This number was also used to label quantitative data. Data were entered into the statistical programme by study number only.

Ethical approval was sought and granted by the National University of Ireland, Galway, Research Ethics Committee prior to data collection.



Chapter Five  
An Overview  
of the  
Study Population





# Chapter Five

## An Overview of the Study Population

### 5.1 Introduction

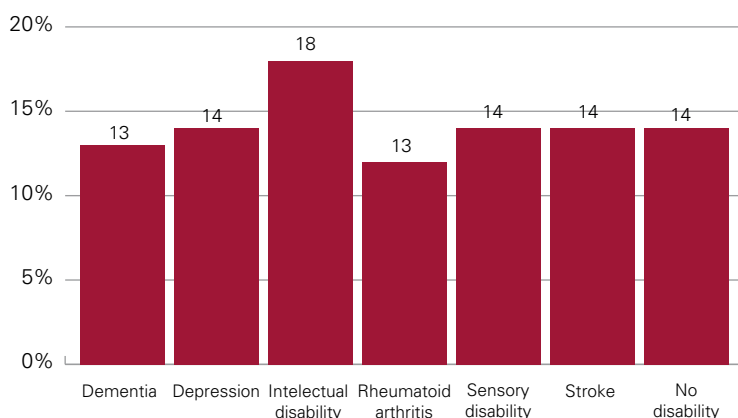
This chapter presents a demographic profile of interview participants and reports the results from three separate measures of health-related quality of life that were undertaken with participants.

88

### 5.2 Demographic Profile

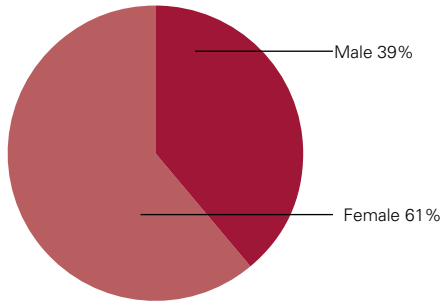
There were seven sub-groups in the sample: six disability groups and one group without a disability (Figure 5.1). The sample was stratified as follows: dementia (n=18); depression (n=20); intellectual disability (n=26); rheumatoid arthritis (n=19); sensory disability (n=20); stroke (n=20); and older people without a disability (n=20).

Figure 5.1: Distribution of sample by group



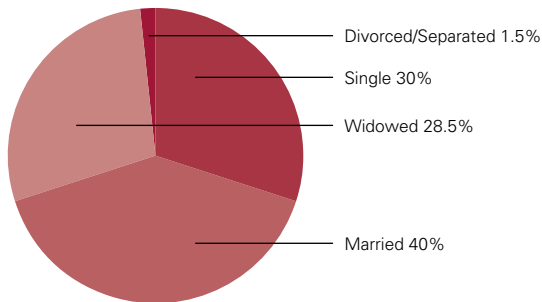
Of the sample, 61 per cent of participants were female and 39 per cent were male, which equates roughly to the distribution of older men and women in the population as a whole (Figure 5.2).

**Figure 5.2: Distribution of sample by gender**



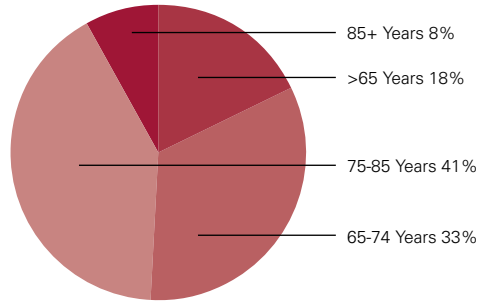
Fifty-six participants classified themselves as married, accounting for 40 per cent of the sample. Forty participants (28.5 per cent) were widowed, 42 participants (30 per cent) were single and 2 participants (1.5 per cent) classified themselves as divorced/separated (Figure 5.3). The majority of participants were, therefore, living without a spouse or partner.

**Figure 5.3: Marital status**



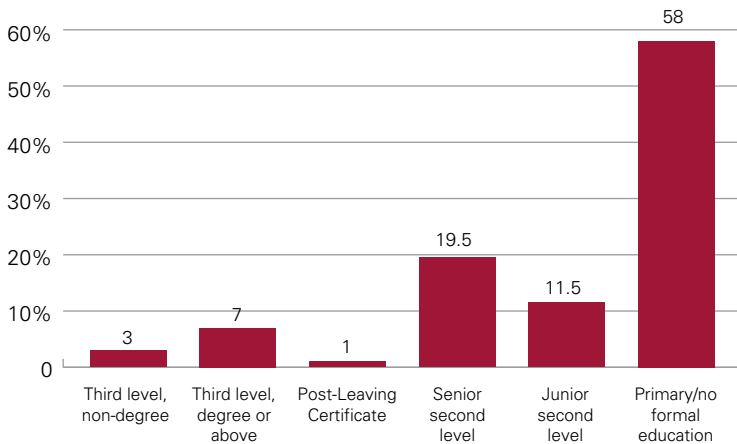
The average age of participants is 73 years, with the youngest being 51 years old and the oldest being 91 years old. Two fifths of participants (41 per cent) were in the 75-85 years group (Figure 5.4). One third of participants were in the 65-74 years group and 8 per cent of participants were in the over-85 years group. Just under one fifth of participants were in the under-65 years group. These participants were mostly people with an intellectual disability.

Figure 5.4: Distribution of sample by age



Participants were asked to identify the highest level of education that they had attained. The educational level of participants was wide-ranging, with nine participants having attained third level degrees or above (8 per cent). More participants had attended second-level education (31 per cent). However, the majority of participants (58 per cent) had received primary education only or no formal education. From these figures it is evident that the majority of participants did not have the opportunity to continue their formal schooling past primary level (Figure 5.5).

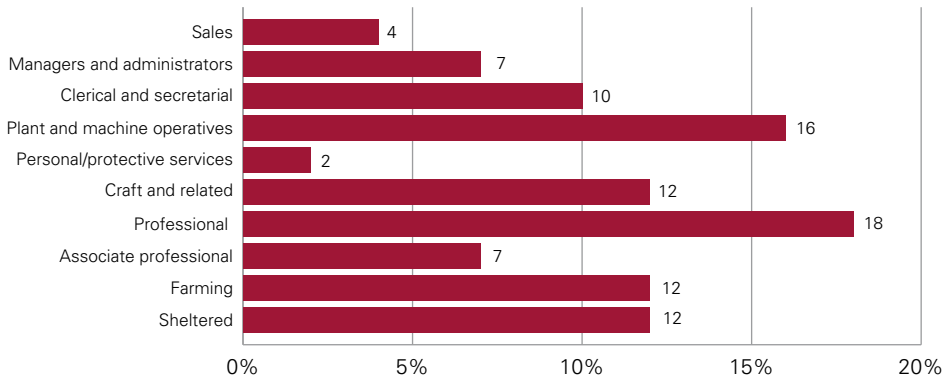
Figure 5.5: Distribution of sample by education level



Participants were also asked to provide details of the head of the household occupation/ prior occupation as a proxy measure for socio-economic status because it was not possible to ask direct questions on income. The occupational categories were taken from the General Household Survey Questionnaire used by the Central Statistics Office (CSO). Participants or their spouses had worked in a variety of occupations (Figure 5.6). As can be seen from the graph, 18 per cent of participants or their spouses had worked in professional jobs, while 16 per cent had worked as plant or machine operatives. Given the rural residence of some participants, it is not surprising that just over 12 per cent of

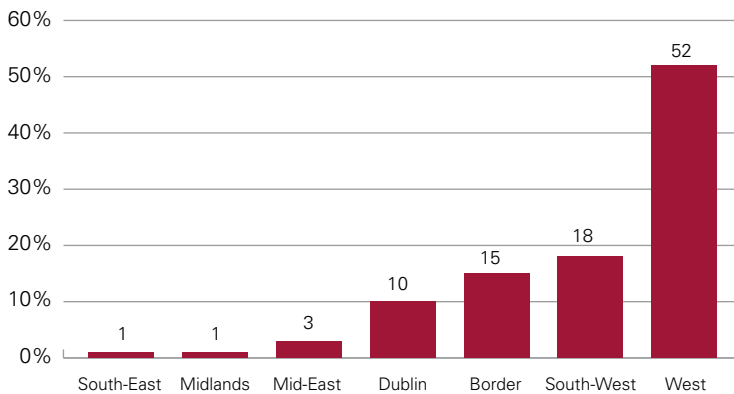
participants had a farming background. It is not known, however, whether these were large or small holdings. About 11 per cent of the sample had worked in craft or related industries, while 10 per cent had been in clerical or administrative work. Seven per cent of the sample had been in associate professional jobs or management and administration, 4 per cent worked in sales and 2 per cent had been in personal and protective services.

**Figure 5.6: Occupation/prior occupation of head of household**



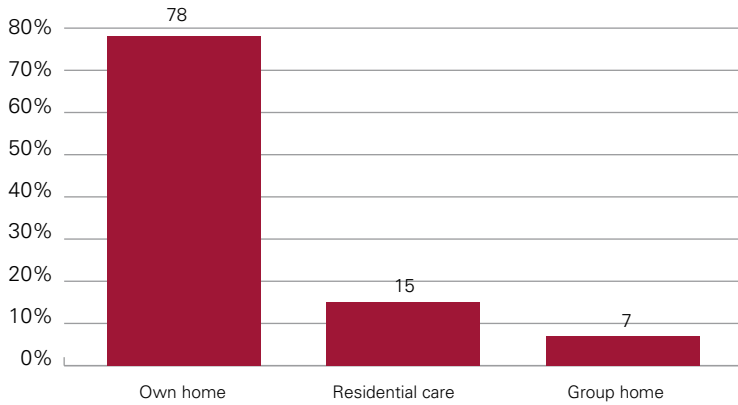
The geographical distribution of participants is presented in Figure 5.7. The majority of participants came from the west of Ireland. (The distribution of participants is given for information only as in a qualitative study of this kind geographic representation is not the goal.)

**Figure 5.7: Geographical distribution of sample by region**



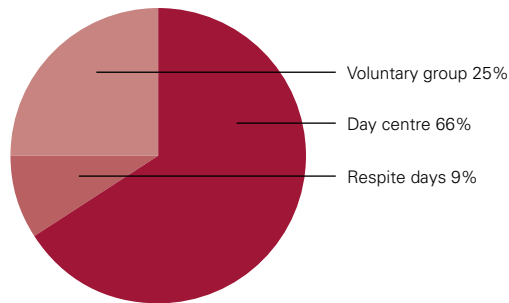
In relation to place of residence, more than three quarters of participants resided in their own homes (78 per cent), while the remainder lived in residential care (15 per cent) or in group homes (7 per cent) (Figure 5.8). Of those participants residing in their own homes, some lived in local authority accommodation, others in rented accommodation and others were homeowners. Those living in the group homes tended to be older people with an intellectual disability.

Figure 5.8: Distribution of sample by place of residence



Although most participants resided in their own homes, the majority of participants attended day centres (66 per cent), while 25 per cent attended voluntary group associations and 9 per cent availed of respite days (Figure 5.9).

Figure 5.9: Distribution of sample by attendance at centres



### 5.3 The Rosenberg Self-Esteem Scale

The scoring for the Rosenberg Self-Esteem Scale ranges from 0 to 30. Individuals with high self-esteem scores tend to have a very positive self-image while those with low self-esteem scores tend to have a neutral self-image. Table 5.1 presents the self-esteem scale for each disability group. It gives the mean score by group, as well as the minimum and maximum scores achieved.

**Table 5.1: Self-esteem scores by disability group**

Disability groups	Mean score	Min-Max
Dementia	24	19-28
Depression	18	13-27
Intellectual disability	23	18-29
Rheumatoid arthritis	22	13-29
Sensory disability	19	10-28
Stroke	19	11-28
No disability	22	17-30

All 143 participants were asked to complete the scale; however, in some instances, participants with dementia (n=7) and participants with an intellectual disability (n=7) were unable to do so. Four participants who had no disability declined to answer the statements. A total of 125 participants completed the scale and the average score across all groups was 21, with the range from 10 to 30. Self-esteem issues for each group are reported below.

### 5.3.1 Dementia

It was recognised, as evidenced in the literature, that people in moderate to severe stages of dementia may have difficulty completing self-esteem scales as they tend to have difficulty concentrating their attention on different tasks and suffer from competing thoughts which they have difficulty in expressing (Sabat *et al.*, 1999). Therefore, at the outset of each interview, researchers used their professional judgement to discern whether or not participants in the dementia group were capable of completing the scale. Seven participants were deemed not capable of completion and it was judged that the remainder could attempt completion.

The overall results for this disability group (n=11) indicate that they had the highest self-esteem score across all groups, with a mean score of 24. One possible reason for this is that some participants were not hindered in their perception of their self-worth by negative past experiences as they no longer recall such experiences. Therefore each day or moment is, as it were, a 'new beginning', allowing people to judge their self-worth more positively. However, given the wide range within the scoring (19-28), it is likely that some people with dementia were able to complete the scale using past recall. Further work would be required to determine the suitability of the scale for people with dementia.

### 5.3.2 Depression

Individuals suffering from depression (n=20) recorded the lowest self-esteem mean score across all groups of 18. The range was 13 to 27. Given the nature of depressive illness, it is perhaps not surprising that self-esteem scores are on the whole low. However, although depression is linked with low self-esteem (Mruk, 1995), the interaction between depression and self-esteem is still not fully understood. Whether low self-esteem triggers depression or depression results in lower self-esteem is not known. Furthermore, as some of this sample group lived in residential care or supervised care (n=6), it is likely that these individuals have less control of their environment, which may have a negative impact on their self-esteem.

### 5.3.3 Intellectual Disability

As with participants with dementia, the Rosenberg Scale was used selectively since there was a diverse range of abilities within this group. At interview, seven participants were deemed by the interviewers to be incapable of completing the scale. There is no consensus in the literature in relation to the self-esteem levels of people with an intellectual disability. Some researchers claim that individuals with an intellectual disability have low self-esteem, while others have found self-esteem levels to be high (Gibbons, 1985; Bear *et al.*, 1991; Bear and Minke, 1996; Ping-Ying Li *et al.*, 2006). In the present study, the mean score for this group was relatively high at 23. Participants in this group were generally happy and satisfied with their work achievements, which may account for the overall higher self-esteem score.

### 5.3.4 Rheumatoid Arthritis

Participants suffering from rheumatoid arthritis (n=19) had a mean self-esteem score of 22. The literature reveals that the severity of impairment caused by arthritis can have negative effects on self-esteem (Burckhardt, 1985). According to cognitive adaptation theory (Taylor, 1983; Taylor and Brown, 1988) individuals with chronic illness successfully adjust by developing optimistic outlooks on life and by endeavouring to regain control over the event, finding ways to rebuild or improve their self-esteem. It may be that most rheumatoid arthritis sufferers in this study have adapted and coped with their condition to the extent that, over time, chronic illness has a limited impact on self-esteem.

### 5.3.5 Sensory Disability and Stroke

Participants with stroke (n=20) or with a sensory disability (n=20) scored the second lowest mean self-esteem score of 19. The range of these groups was also similar: 11-28 (stroke) and 10-28 (sensory). This wide range indicates that some participants in these groups had very poor self-esteem while others had very good self-esteem. For these groups, it may be that the severity of the disability impacts negatively on self-esteem.

However, similarly to the rheumatoid arthritic participants, it may be that through the development of coping and adaptation strategies some participants have positively readjusted their self-esteem levels, while others could not.

## 5.4 SF-36v2

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Of those interviewed, 133 participants completed the SF-36v2 survey. Table 5.2 presents the results of the SF-36v2 questionnaire. The mean and standard deviation is given for each of the disability groups. The scores for the group of older people without any known disability are also presented. As the sample size in each group is small, it is important to treat these results with caution. The results cannot be generalised to disability populations in Ireland. Their use in this study is to provide context and background for the qualitative analysis that follows.



Table 5.2: SF-36v2 scores

	Dementia (n=16) Mean (SD)	Depression (n=20) Mean (SD)	Rheumatoid arthritis (n=19) Mean (SD)	Intellectual disability (n=20) Mean (SD)	Sensory disability (n=20) Mean (SD)	Stroke (n=20) Mean (SD)	No disability (n=16) Mean (SD)
Physical functioning	62.19 (27.75)	55.75 (34.31)	47.89 (22.44)	72.25 (25.36)	70.00 (18.64)	28.25 (30.27)	72.50 (24.36)
Role physical	80.08 (20.94)	76.25 (33.79)	56.91 (34.79)	79.38 (25.82)	78.75 (26.16)	66.25 (37.47)	87.89 (22.53)
Bodily pain	86.00 (24.25)	77.40 (24.72)	51.00 (29.81)	94.90 (12.66)	74.20 (25.21)	72.20 (31.68)	79.06 (24.60)
General health	73.75 (16.66)	53.30 (15.07)	51.53 (18.74)	75.80 (18.61)	64.25 (27.21)	61.80 (16.36)	72.31 (17.80)
Vitality	76.17 (21.19)	53.13 (13.68)	47.70 (21.57)	78.13 (23.78)	56.56 (21.70)	60.94 (23.90)	72.27 (20.02)
Social functioning	82.03 (21.88)	84.38 (21.41)	69.74 (30.14)	85.00 (23.16)	69.38 (34.05)	82.50 (26.41)	93.75 (12.91)
Role emotional	85.94 (15.73)	75.42 (34.46)	65.35 (32.66)	82.06 (21.16)	78.75 (30.53)	80.42 (26.94)	89.58 (21.62)
Mental health	83.44 (13.00)	56.50 (17.40)	71.84 (18.42)	82.50 (19.16)	77.00 (19.22)	72.75 (23.65)	82.50 (12.52)

The stroke group had the lowest score for physical functioning, indicating that this group experienced the most severe physical impairment. As some of the group were living in residential care and needed help with all activities of living this finding is not surprising. The scores of this group for role physical, general health and vitality were also relatively low, indicating that participants were quite incapacitated when compared to the other groups. The depression group had the lowest score of all groups for mental health. Scores in the depression group for vitality, physical functioning and general health were also low in comparison to most other groups.

The rheumatoid arthritis group had a score of 47.89 for physical functioning indicating a relatively high level of incapacity. This group also had the lowest scores for role physical, general health, role emotional, vitality and bodily pain. The sensory disability group had the lowest score on social functioning. This indicates that this group had most difficulty with engagement in social activities.

The intellectual disability group had the highest vitality score of all groups and the least bodily pain. Participants also scored highly on mental health, role emotional, social functioning and physical functioning. The intellectual disability score on general health was the best of any group, including the control group without any known disability. As this group was younger than all other sample groups this finding is, perhaps, not surprising.

## 5.5 The Katz Index of Independence in Activities of Daily Living

All participants were asked to complete the Index of Independence in Activities of Daily Living which is used to measure functional ability of older adults. Participants are scored in relation to their independence in carrying out six functions of daily living. Persons who indicate that they require some supervision are awarded 0 points for that activity while activities where they require little or no supervision are awarded 1 point.

The overall results for the disability groups indicated that all participants recorded high levels of independence in relation to transferring (92 per cent), toileting (90 per cent), dressing (84 per cent), continence (86 per cent) and feeding (97 per cent). The main area of dependence where participants required assistance from others was with bathing (73 per cent) (Table 5.3).

**Table 5.3: Index of Independence in Activities of Daily Living scores**

Activity	Independence	Dependence
Feeding	97%	3%
Transferring	92%	8%
Toileting	90%	10%
Dressing	84%	16%
Continence	86%	14%
Bathing	27%	73%

The table below presents data in relation to levels of dependence in each of the activities of living for each disability group (Table 5.4). As is evident from the table the stroke and the dementia groups were the most dependent.

**Table 5.4: Levels of dependence by disability group**

Activity	Dementia (n=18)	Depression (n=20)	Intellectual disability (n=26)	Rheumatoid arthritis (n=19)	Sensory disability (n=20)	Stroke (n=20)	No disability (n=20)
Transferring	1 (5%)	2 (10%)	(0%)	1 (5%)	0 (0%)	6 (30%)	0 (0%)
Toileting	5 (25%)	2 (10%)	(0%)	0 (0%)	0 (0%)	5 (25%)	0 (0%)
Feeding	1 (5%)	0 (0%)	(0%)	0 (0%)	1 (5%)	1 (5%)	0 (0%)
Dressing	7 (35%)	2 (10%)	(0%)	1 (5%)	1 (5%)	8 (40%)	0 (0%)
Continence	6 (30%)	2 (10%)	(0%)	3 (15%)	2 (10%)	4 (20%)	1 (5%)
Bathing	8 (40%)	7 (35%)	2 (10%)	3 (15%)	1 (5%)	10 (50%)	0 (0%)

### 5.5.1 Dementia

Participants in the dementia group were found to have the highest level of dependence in relation to bathing (40 per cent). This is not unexpected as some of these participants had moderate to severe dementia, and required closer supervision and more direct assistance in relation to bathing, dressing and toileting.

### 5.5.2 Depression

Similar to the participants in the dementia group, participants suffering from depression also reported the highest level of dependence in relation to bathing and the lowest levels of dependence in relation to feeding. Given the higher levels of dependence in relation to bathing, it may be that the nature of depressive illness is such that participants have difficulty in motivating themselves to engage in personal hygiene activities.

### 5.5.3 Stroke

In the stroke group, 50 per cent of participants reported that they were dependent in relation to bathing, while 40 per cent needed help with dressing, 30 per cent needed help with transferring from bed to chair, 25 per cent required assistance with toileting, while 20 per cent had problems with continence and 1 per cent needed help with feeding. This group were, therefore, the most dependent of the disability groups.

### 5.5.4 Intellectual Disability, Rheumatoid Arthritis, Sensory Disability and No Disability

Overall participants in the remaining sample groups reported low levels of dependence in relation to all the activities of daily living. The rheumatoid arthritis group had slightly more dependence than the other groups and recorded levels of 15 per cent for continence and bathing. All these groups were independent in toileting and all but 5 per cent were independent in transferring, feeding and dressing. Levels of dependence in the three disability groups were comparable to levels in the no disability group.



## Chapter Six

### Living With a Disability: Dependence and Independence

# Chapter Six

## Living With a Disability: Dependence and Independence

### 6.1 Introduction

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This chapter describes the reality for participants of living with a disability. While the experience of living with a disability is, of course, unique to each individual, the emphasis here is on painting a picture of the range of experiences of respondents focusing particularly on the complex relationships between dependence and independence. Participants' accounts suggest that living with a disability is a balancing act involving a trade-off between taking risks and having to be sensible. Some participants showed enormous tenacity in continuing to live life on their terms; these participants viewed disability as a challenge and concentrated on rising to meet it. Others were stoical, resigning themselves to a radically altered life. Participants' responses to their disability were largely determined by the severity of their symptoms; some participants had no option but to live very restricted lives. Participants mourned the loss of function/ability and feared further loss, such as an exacerbation of their condition. In this context, retaining autonomy and independence (no matter how little) was important. Participants drew strength from several sources, including their spouse, family, pets and religion. Several factors impacted on participants' experiences of living with their disability including: the severity of their symptoms; whether the onset of the disability was gradual or traumatic; their general attitude to life; and whether they had good support from family or carers. Participants' experiences of living with various disabilities differ greatly and consequently are reported separately here.

### 6.2.1 Dementia

Participants with dementia gave clear examples of the challenges and frustrations of coping with memory loss:

*Well someone could tell me something coming in here and I'd be about to tell them something and I wouldn't be able to think of what it was ...*

*My memory isn't good at all ... I don't remember a lot of what happens, five weeks ago, or six or that ...*

*Well it's very bad at the moment, you know. If I leave a thing, I won't know where it is, you know. It always comes back to me what I lose, I find out where it went. (laughing)*

These excerpts give some insight into the impact of memory loss on daily functioning and relationships. Many participants, however, did not identify that they had any problems with their memory:

*My memory is great ... Oh I could tell you what happened twenty, forty years ago.*

Some participants accounted for problems with memory as part of the ageing process:

I: *How is your memory?*

P: *Not bad ... you will find I don't know how old you are, but when you get a bit older ... (laughing)*

The ability to recall information, and express and understand language, profoundly affects and challenges communication:

I: *What does being independent mean to you?*

P: *Well, to me it is that I can do what I want to do ... Sorry, again, can I just hear that again, please?*

I: *What makes life good for you? What makes you happy?*

P: *I don't think anything. (laughing)*

I: *Nothing?*

P: *Ah I cannot think, I can't think just now.*

P: *The white thing, you know, whatever you call it, what do you call it, in the toilet, what do you call it?*

I: *The bath is it?*

P: *No, no.*

I: *The sink?*

P: *Well, the sink would be more like it, but I couldn't, I don't know what I was going to say now, I'm hopeless now.*

The latter comment would suggest that changes in self-esteem and self-concept are a feature of living with dementia. Face recognition difficulties (a symptom of Alzheimer's Disease) also posed challenges when interacting with others:

*We go back here to (name of church) ... We meet people there ... You know, when it comes to the time of the Mass time, this person called me by my christian name, you know at the time you shake hands. (laughing) Sometimes I get it very hard to recognise people but most people now seem to recognise me like.*

Problems with recall, self-expression and face recognition have the potential to undermine interpersonal relationships with family, friends and others. Perceptual problems also challenged participants in terms of their day-to-day activities:

*I thought my nose was gone that time ... I walked right into it, and I put my hand up and it was then I found it was glass. Sure I should have known it was glass, I was here about eight weeks then.*

People with Alzheimer's Disease are not always able to link the idea of the action they want to take with the motor response or coordination necessary to carry out the desired action. This was evident in some participants' accounts of the impact of dementia on their life:

*I can't play it (golf) anymore. It is just you just can't do it.*

P1: *She can't wash herself or anything or dress herself.*

P2: *Yeah, that's why I like to ask her how it looks, you know.*

P1: *She might come out with her petticoat over the top of everything or her nightie going to bed on top of everything.*

Some participants reported using strategies to combat memory loss, for example making notes:

*I kind of have to make notes of things now like. Or otherwise, well especially, then sometimes I would hardly know the day, I'd have to ask someone what day is it today.*

Not 'letting it take over' and continuing to live life as normally as possible was important to participants:

*I don't allow it to take over sort of ... I nearly always have somebody to ask anyway like, you know, the family, or I can ring up someone if it was that bad.*

P: *There has to be somebody with me like all the time.*

I: *Do you go out during the day?*

P: *I do everything out if I can ... and I keep going at that because it is for me as well ... And it is the best thing that I can do.*

Participants with dementia were very dependent on family and most expressed a preference for their main carers to be immediate family. They found 'strangers' confusing and hard to adjust to:

*... my wife has taken all the work on her.*

P: *It's nice to have company all right ... but not too many.*

I: *Why not too many?*

P: *Well, mm, you might be tired. And you might not want other people (other than family) ...*

I: *So it's nice to have people but better to have people you know? Not a lot of new people?*

P: *Not, yeah.*

I: *So the same people coming all the time would be good?*

P: *Yes, it would be better.*

I: *And do the same people come all the time?*

P: *No ... t'isn't the same one (carer) every day.*

I: *Do you have anybody calling in during the day? A carer?*

P2: *No.*

P1: *Don't need to, that's what I could do, you know, isn't it? Dusting and all that sort of things.*



I: *You feel you don't need it?*

P2: *I don't need it, because Mum gets too confused if there's too many people.*

Family also played a pivotal role in grounding or orientating participants:

*Well if you were to leave her on her own for five minutes she loses, she doesn't know who she is, where she is, where everyone is gone, so you have to be with her and update her constantly ... She gets that attention around the clock ... If I was just to walk out there now, she forgets who is in the house with her, she starts forgetting then whose house she's in. Even though right now you wouldn't think it, in the morning times now she's disorientated ... so her independence is definitely gone I think.*

P1: *In the mornings, I have my breakfast and then I sit down. Don't I?*

P2: *Yeah.*

P1: *Really, sit down, then like today I hope we get a little bit more warmth.*

Across interviews, the most common activities that participants reported enjoying were going for a walk or being taken for a drive. Again they were dependent on family or carers to accompany them. Many however described a typical day as doing 'nothing'. Time seemed to hang heavily on their hands:

*I do absolutely nothing nowadays,*

I: *What do you do during the day?*

P: *Mostly nothing. On a good day I go for a walk ... and some member of the family comes with me.*

I: *What do you do during the day?*

P: *Very little. (laughing)*

No participant expressed concerns about the future directly. However, anticipation of the future did seem to be an issue in the subtext of some participants' comments:

I: *What would make life easier for you?*

P: *Oh now ... (laughing)*

I: *A big question ...*

P: *T'is. Just I hope that God, if I get sick or that I'm taken away, not to be left, all the people that you see that's so sick and hasn't anyone.*

I: *So keeping healthy would be important to you?*

P: *Very much, yeah, if you can feed yourself and clothe yourself.*

*I wish I hadn't it (Alzheimer's Disease) ... I used to have a great memory one time.*

## 6.2.2 Depression

Most participants, when describing living with depression, talked about the 'tiredness' and 'weakness' they experienced. Lack of energy restricted their lives and they felt unable to carry out their normal activities:

*I feel kind of weak and down at times ... I'm not able to do the things I used to do, about a year ago. I don't think I would be able to do any gardening or anything, this year ... not the way I feel at the moment anyway.*

*Oh now, it's a very dull day because the depression like, you just want to go and lie down ...*

*Well I used to go ... down the town more, do my shopping and since that depression I don't have the feeling that I can do that because I can't have the power of walking that I used to have.*

Participants reported that, in addition to experiencing physical symptoms, they had little interest in social activities. Consequently, they were at risk of becoming isolated:

*I lost heart in everything ... There were some nights I was sitting in there and wanting to talk, and I used to have to leave them and go to bed.*

*When you're depressed you just feel ... in bad form, you know, and kind of isolated, you know, and you're hoping all the time to get better of it ... It's worse than any disease, depression, you know. It affects you that way, you know ...*

Completing activities of daily living, such as getting up or getting dressed, was an enormous effort for participants when they were depressed. For example, this participant reveals the effort involved in calling to a neighbour's house, even though it was something he normally did:

*My tax was up, on the motor car. And there's a girl up the road, works in car insurance office, well it took me, it must have been three nights before I went up to her house, I hadn't the guts, just hadn't the nerve to go up. I remember she wasn't there, it was just the mother, and I had to make an excuse to get out again. I said, 'my dinner is ready, I've no time to talk to you' and I was after my dinner. I just wanted to get out. The next time I see her, I must tell her, because I was even stuttering ... Like me and her could have sat and talked for an hour ... Sometime, the next time I see her, I must tell her like. She didn't know that time, I had the depression, you know.*

During the worst phase of their illness participants were highly dependent on the support of spouses and family. Day centres were also identified as an important resource:

*My sister took me down, and they took me out and made me go into houses and took me out for lunch in the car ... and then I got out of it and I came back home ...*

*The day centre was a great help to me. I thought I was hopeless going down there, but ... when I went down ... I (had) great conversations ... There were people I knew too ... I was able to talk about old things, way back years ago ... And then it got you out of bed in the morning, it got you out of bed ... It got me over it, oh it was the greatest thing that ever happened ...*

Participants spoke about the importance of 'keeping going' and not letting their depression take over:

*It's important ... to be active, and take part in everything that's going, and you know, not to just to lay back and 'I can't be bothered' sort of thing, make an effort ... I think it's great going to the centre because it keeps you, you get up and you'll have a shower and you'll dress yourself, and when you're at home you don't bother to you know, dress yourself.*

*I have to have this goal all the time.*

Participants' comments would suggest that an external motivator of some sort, such as attending a day centre or having something to look forward to, was particularly important when they were feeling 'low'.

### 6.2.3 Intellectual Disability

Participants with an intellectual disability differed from the other sample groups. They did not, nor should they, perceive that they had a disability. Some acknowledged that they suffered aches and pains but put this down to getting older. Others had had a serious health problem but they were in the minority. Most participants had a job, some worked in a sheltered workshop and others had jobs in the locality. Work gave them a sense of purpose and was a source of pride and fulfilment:

*I'm the only assembler inside on the floor you know. I couldn't, I could train the lads inside but they get, they are too slow and I'd rather get the thing done faster.*

P: *I give a hand with the sewing.*

I: *Do you do anything else in the workshop?*

P: *I do a bit of packing ... I'm great at that now.*

P: *I like working here and the work is good here, I like it.*

I: *What makes you enjoy it?*

P: *Just the way it turns out, you know, I work with the guys all day. I'm okay that way, I'm okay here.*

I: *What things do you do in your life that make you feel proud and happy in yourself?*

P: *Everything I do, every day, working here like and coming here like. I enjoy that.*

P: *Work is grand ... I enjoy it anyway like.*

I: *You enjoy it?*

P: *Yeah ... sometimes it's tiring ... but you have to keep up the good work ... that's what I would do anyway.*

Participants acknowledged that they are getting older and, consequently, there have been some changes in the way they work: some participants have retired; some have reduced their hours because of health problems or tiredness; and some continue to work full-time but with some changes in their work practices. Others felt that they had reached an age where they should be planning for their retirement:

P: *I'll be 60 in July and 65 is retiring age. There's no way I'm going to stay here till I'm 65, no way.*

I: *You'd find something else to do?*

P: *I'd just retire. I was talking to a man several years ago, he was working in the bus in CIE and he retired at 61, and he said to me, 'I want to get out while I can enjoy my retirement'. Now I intend to do the same.*

*I'm retired now ... I help to look after the birds.*

*I had a heart attack ... I'm not allowed to lift heavy things ... but the lads will help me. It's not my fault I had the heart attack.*

P: *I'm happier with the part-time now like you know, I mean things are much easier. I had to be up about half past six in the morning anyway in my full days.*

I: *Did you make the decision that you'd like to go half-time?*

P: *Well, yeah, yeah, but it's not for the sake of the money either though. It's the sake as well, it's your age and health, like. I'm not saying I am very old but that's why you have to take things much easier ... You don't have to work full-time until you're about sixty or seventy or fifty or something like. You can't do that, sometimes we'd be tired like you know ...*

Some participants had very close ties with their family and extended family. Others saw their family as a support but viewed themselves as independent and able to make their own decisions. The families of some participants lived some distance away. These people had less contact but kept in touch by telephone:

I: *Do you enjoy going up and down to your sister?*

P: *Yeah, yeah, yeah, I mean she got me the accommodation. The last time now I got it myself ...*

I: *Is it important that you have your sisters there as a support for you?*

P: *Yeah.*

I: *Would you be able to survive without them do you think, being there? How would you cope without them?*

P: *I could survive like, I mean like, I worked in (name of town), for up to five months and I mean I had to bring clothes to the laundry and all that like.*

I: *You live with your sister?*

P: *Yeah. And then my nephew stays, but he's away now. He'll be back now in a couple of months to us ... He stays with us, he's only away on a holiday but he phoned me up a couple of times.*

I: *Oh, I see ... he's living with you. And how do you like sharing your house with others?*

P: *I don't mind ... and my nieces comes up sometimes.*

I: *Do they?*

P: *Oh they do yeah, they always come up to us.*

I: *And would you go and visit them?*

P: *I do, I visit them now. I went down to (name) last Sunday and I stayed 'til yesterday.*

P: *I goes home to visit and I don't stay home, and I don't stay home at all.*

I: *Would you just go home for the day and come back up again?*

P: *Yeah, yeah.*

I: *And how come you wouldn't stay over?*

P: *It's too boring.*

I: *You prefer the big smoke?*

P: *Yeah I prefer the city ... But, I phone them, I phone them sometimes.*

I: *Do you? Is the contact with your family important to you?*

P: *Oh, yeah, yeah, they phone me and I phone them.*

I: *Why is it so important to you to keep in contact with them? Why do you think it's important to you?*

P: *Keep them in control. (laughing)*

A particularly significant event in participants' lives was the death of their parents. The death of a parent marked a radical life change: some participants moved to a community home or began working in a sheltered workshop. Participants recognised that their brothers and sisters had their own lives and responsibilities. In the main, they were positive about these changes, especially because they made friends. Some reported that they had felt lonely at home:

P: *I'll be two years now next Christmas, yeah.*

I: *And where were you before that?*

P: *At home ... with my brother, but my sister brought me up here, to get me out of the house.*

I: *When you were at home were you ...?*

P: *At home with the mother ... but she's dead now.*

I: *When your mum died, then your sister minded you, was it?*

P: *No, no, I was at home with my brother, but she was up and down and up and down ... but she asked me would I love to come up here for a couple of hours, and I said I would try it ...*

I: *Do you feel coming here has been good for you?*

P: *It is.*

I: *In what way?*

P: *You live an independent life. I was doing the work at home but, em, I'm happy here now. I'm happier now with the girls, I can talk to the girls ...*

Some participants' lives became more restricted as they grew older themselves; health problems being an important factor. Other factors included ageing parents who were no longer able to drive and siblings sometimes imposing stricter restrictions than their parents had on a brother or sister's life in an effort to protect them:

I: *Your mum is fit and active, is she?*

P: *Well she is getting old now.*

I: *How do you feel about that? Do you do a lot of minding of her?*

P: *Well, I help around sometimes but not always.*

I: *And who does the shopping and things now at home.*

P: *My mammy orders, phones into the shop. The shop brings it out.*

I: *So you don't really go into shops yourself?*

P: *Well, mammy doesn't drive anymore now so, so we don't do it anymore now.*

I: *Would you use the buses at all now yourself?*

P: *No, no, I would do with the mother, but not now.*

I: *Not now?*

P: *No, they won't let me out by myself now.*

I: *And who made that decision?*

P: *The sister.*

Participants' lives were governed by routine. For example, those who took public transport knew their bus routes and timetables by heart:

P: *I get up at seven in the morning. And I come out for the bus. You see I live in (name of town) and I go down town for the bus. The bus leaves at about ten past eight and I get into town then at about twenty to nine.*

I: *So you get on the regular public transport bus?*

P: *Ah yeah, I do, yeah.*

I: *Do you do that all on your own?*

P: *Oh I do yeah, yeah.*

I: *No problem at all?*

P: *I could do it in me sleep.*

*I always did get up around nine like. Well (if) I'm going to work like, I get up around a quarter to eight because the bus that collects comes here in the morning about half past nine you know and takes us out to (name).*

Some participants were very dependent on their families to care for them, and particularly at weekends when services were not available. Others lived independent lives. Both these participants live alone but they live very different lives:

I: *What about cooking then, at the weekend when you don't come here?*

P: *My (relative) brings it.*

I: *And the days when she doesn't come with the dinner where do you get your dinner then?*

P: *I go down to the chip shop.*

I: *Would you ever cook yourself?*

P: *No.*

I: *Any problems living out?*

P: *I love it ... I'm living on my own 33 years.*

Most participants were content living in group homes or residential settings. It was important to them that they had their own space and most had their own bedroom. Participants reported experiencing a sense of community; they made friends, looked after one another and enjoyed socialising. In many ways the staff became an alternative 'family'. They relied on them and looked to them for support and advice:



P: *We all have our own rooms.*

I: *You all have your own rooms and why would that be important to you to have your own room?*

P: *I could watch television on my own, watch it myself.*

*Well you know like I'm happy here, I can do me own thing and there's no push on me like, I can go out, there's no hassle like. They never, if I want to go anywhere, just leave 'em know and it's all right.*

P: *I went shopping last night.*

I: *Did you go down on your own?*

P: *I go with the staff only. I'm afraid, on my own ... I like the staff with me.*

However, some participants wanted increased independence and the freedom that comes with living alone:

P: *T'is okay, but in a year now and a half, I'm hoping to get a place of my own, you know it's called independent kind of thing.*

I: *So at the moment you're sharing with nine others, but you would like a place on your own?*

P: *Yeah, something that I can do myself, you know like cooking now and stuff, you know what I mean.*

I: *Why would you prefer to live on your own?*

P: *I don't know, because I like to be independent, you know. You know do my own thing.*

I: *Do your own thing?*

P: *And if I want to go out at night-time with the girls here from work here, you know even go to the pictures or even go for lunch or whatever ... instead I'm panicking of rushing back to the hostel, you know.*

Participants had very active social lives. They tended to socialise as a group and most social occasions were organised by staff:

*I go bowling, like. We have the bowling on Wednesday, that's part of the work like ... I go down to the bowling place and I meet the others.*

I: *Do you do things that make you happy?*

P: *Oh I do, sometimes I goes for a, down to, what do you call that place ... have a drink.*

I: *So you like to go out then and have something to drink?*

P: *Oh yes.*

I: *And who takes you out?*

P: *Oh the ...*

I: *Would it be someone here who's looking after you?*

P: *Oh yeah ... they take me out for a drink and come back.*

Participants lived active, happy lives; however, they acknowledged that as they aged they were experiencing more problems.

#### 6.2.4 Rheumatoid Arthritis

Most participants with rheumatoid arthritis reported experiencing severe pain at some point. A minority reported experiencing little pain. Participants categorised their pain in two ways. Some used the term 'chronic' to describe constant but tolerable pain; the acute pain they experienced during a 'flare-up' was variously described as 'fierce', 'excruciating' or 'agonising'. This pain overwhelmed and exhausted them:

*The pain in my back is bloody fierce, awful.*

*The pain is very bad and it's hot all the time ... My mobility is impaired and I'm very tired, not sleeping ... I'm physically and mentally exhausted from pain.*

*I had I suppose you would call it chronic osteoarthritis ... I had a pain in my back all my years ... I got through life with a glass of water and two codeine.*

*Well it doesn't really affect me ... At night-time now, I might get a little bit of pain or if I was out walking for a short period ... but overall ... it's not too bad really.*

Participants shaped and planned their lives around their medication. Across all interviews participants made some reference to their medication, for example what they were on, how often they took it or how effective it was in relieving their pain. Not surprisingly in the context of the severity of their pain, medications which relieved their pain were described as 'miraculous' or 'magical'. Some participants reported that they resorted to self-medication in an effort to alleviate their pain:

*My knees started getting really bad ... I had cortisone injections in both knees, and that was like magic. Instantaneously the pain went out of my knees.*

*I was trying to figure out how I could get some relief from the pain because no matter what you do there is no relief from it. So I decided to take paracetamol ... at least if I die taking them I'll die out of pain. Which I didn't. I got up for a walk afterwards when the pain eased down.*

*Now I've this blooming thing in my neck, I've dosed myself, I'm very depressed with it, I'm dosing myself with pills, you know, and that's not good either. But I have to ease the pain for a while.*

Pain, loss of dexterity and loss of strength all combined to impact on every aspect of participants' lives including their ability to self-care:

*I'm alright now but before that I couldn't lift pots out of the oven. I could cook now on the top ... I had to fill the kettle with cups of water or jugs of water, you couldn't fill it and bring it back, you couldn't ...*

*Getting dressed now what it would take ... ten minutes and wash and all. I was twenty minutes, half an hour and under severe pressure at that, you know what I mean, in my hand so then when I started the course of tablets and all that cleared up ...*

*If I go into my kitchen to cook a meal, I'm only standing for five minutes and the pain is just horrendous ... and I have to go and sit down. Now that's not much use when you're cooking, so I have to get up again and get on with it.*

*Jesus I was in an awful state. You know, to get dressed, to make a cup of tea, anything ... I didn't know what was going wrong really with me knuckles.*

Many participants reported that their mobility was reduced, which hampered them in getting around the house. In one extreme case, a participant reported that she was no longer able to go outside:

*I can't get out ... I'm waiting for ... my handy-man to get out the front door. There is a step, it's not much ... I have to ... get the taxi man to help me out. Now, the back door has more steps; I could get in and out that one and I used to go to my neighbours. I*

*used to go out to feed the birds and last Christmas Day I discovered I couldn't do it ... and (names) ... had to actually lift me down the steps. I've never gone out since. I haven't been out the door since that day.*

*Our toilet is upstairs. We don't have an en suite and I have to go up three steps to go to the loo at night and I nearly fell one night.*

Many participants were dependent on their spouse, family or carers for help in carrying out tasks:

*I help with the cooking. I do my little bits and pieces but in the line of pots or anything that's to be lifted up they (sons) do all that and strain things. I'm not capable of lifting anything now the way I've gone.*

*For all I do in the garden, it's harmless, very little. My wife's the gardener. She looks after the flowers and all that ... Any major job or that we'd get someone ... I used to do all my own painting and kept the garden at one time ...*

Participants dreaded the possibility of their condition worsening; their greatest fear was increased dependency:

*I would die if I had to ask anybody for anything. Maybe when I get worse now I'll annoy my son and my daughter-in-law. (laughing)*

*If it doesn't get, if it doesn't get any worse I won't complain, you know what I mean. Once I can get up and get round even if it may be slow or whatever, I feel good about it. I would hate to think that I would end up in a wheelchair or anything like that.*

*Don't think I'll ever get any better but if I don't get worse I'd be happy, you know ...*

The chronic pain and fatigue experienced by some participants led to their reporting feelings of depression:

*I might go for a little walk to the park near us but when I walk it's very hard. And in the afternoon I might have a light lunch at home, you know, but then I get very tired and I lie down but I don't sleep. I try and read, I can hardly see the paper but still I can't switch off, I seem to be going through this depression phase with it, you know. And I might put on the telly in the bedroom. Then I get up and try and make the dinner and I'm so tired I'm just wishing that a fairy would come and peel the potatoes, you know.*

*I get depressed and I cry sometimes ... I stopped going out, and I stopped, do you know I couldn't go to places that I loved to go to. I didn't go ... socialising and all that and I got in on myself ...*

The overwhelming pain, exhaustion, joint deformity and loss of power that participants experienced impacted on every aspect of their life.

### 6.2.5 Sensory Disability

In contrast to stroke the onset of visual or hearing problems was usually gradual. This gave the person both an opportunity to adjust over time and to gain confidence in managing the disability:

I: *When did you first start to notice that you had a problem?*

P: *I was 14 years of age ... I got a hearing aid and I never looked back really ... It doesn't bother me at all, I don't even know I have it. My doctor said originally, 'don't ever tell anybody you are deaf just tell them to speak up'.*

I: *Do you do that? Do you tell people to speak up?*

P: *Well sometimes I do ... I don't ... always say that I wear a hearing aid ... I just say, 'I can't hear you what are you talking about'. It doesn't really have any affect on my daily life; I do what I do if I wasn't deaf.*

In contrast this participant lost her hearing later in life. She responded by trying to hide her deafness and was too embarrassed to ask people to speak up. She used various strategies to 'get by' without acknowledging her deafness:

*I don't know what they are saying at the check-out. I used to pay with €20 just in case I got it wrong. It's just embarrassing. I never liked people knowing about my hearing, I suppose I should have said, but it's very awkward.*

This participant lost her vision when she was very young:

P: *I have no sight... I lost the left eye when I was a young kid ... The other did me ... So I never could say I had good sight ...*

I: *Can you tell me a little bit about how being blind impacts on your day-to-day life?*

P: *Well, I don't mind, like when you're used to it ... but you miss a lot, you miss out on a lot.*

In stark contrast, one participant woke up one morning and found she was blind. She had no warning and, unlike the participant above, no opportunity to adjust. Losing her sight was very traumatic for her:

*I woke, I got out of bed to put on the light and I thought I put it on... but there's something wrong I thought ... And I hit a chair and then I decided, 'I'll switch the lights on' ... still no response. I sat on the bed for a long time and I thought, 'am I imagining this awful darkness?' and I went to dial the number of next door. I couldn't find the numbers at all and I thought, 'oh good God, there's something wrong with me eyes'. I was gone stone blind.*

These participants' accounts show that the gradual or traumatic onset of a disability significantly impacts on the person's ability to cope with and adapt to it.

#### 6.2.5.1 Sensory Disability: Hearing

Unlike, stroke, visual and hearing impairments are hidden and this creates additional stress. Participants described how people respond when it appears that they are not listening to them:

*A lot of people think, you know, that deaf people are either inattentive or snooty, but in actual fact what happens really is it's a real struggle to hear. I just switch off, and ... you suddenly realise people are saying something to you. You have to kind of look bright-eyed ... but you actually do stop, eh, even trying to hear and it's when it gets too much.*

*Some people are very cooperative and will repeat but you find the ones that just haven't the time or don't understand. I feel it's a disability, a hidden disability and no one seems to notice. It goes unnoticed but you are there trying to struggle and deal with it.*

The strain of following conversations was a common theme across interviews:

*I find it a huge strain because I'm straining to listen and not getting it right ... I'm absolutely exhausted from just trying to listen.*

*You just don't hear; you're there in a group, you hear nothing. It's all a mumble ... I play bridge ... and you're playing and you're kind of silent. You can't contribute anything, you know, because you're missing out.*

*I'm on a couple of committees and at committee meetings ... people turn away from you. I try to position myself so that I am kind of facing everybody ... without making a big issue out of it but, eh, when they turn away ... the conversation is just lost.*

All participants noted that one-to-one communication was fine but that it was difficult to follow conversation in a group situation. This resulted in some participants avoiding social gatherings. Instead, they focused on solitary activities where their deafness was not a barrier:

*I find a gathering very difficult. I was invited to a wedding recently and I just made my excuses because it's torture going to these things ... I love gardening and don't really get involved. Groups are a big problem for me, you just cannot hear. One-to-one I can manage; with my friends now it's fine.*

*It doesn't affect me that much because I don't go out that much. I would be a very keen gardener, I spend a lot of time in the garden.*

These accounts illustrate how some participants opt to isolate themselves, which is in contrast to stroke survivors who had isolation thrust upon them. Not all participants avoided group situations, however. This participant is an active member of several groups and his approach is to be up front about his deafness:

I: *Do you avoid situations where there are groups?*

P: *Oh God. no. No but I tell them all that I have a hearing problem ... They are always looking for a chairman or something like that and I would say, 'oh look it I will do it'. I do participate ... I don't avoid any situations ...*

The lack of loop systems in public buildings also mitigated against participants involving themselves in social and religious activities:

*I don't go to the cinema anymore, I went to a couple of shows ... but they were musicals so I didn't hear what went on between the songs but I enjoyed the singing part of it.*

*I went to the ... theatre with my daughter and I fell asleep. I was so embarrassed but she was mortified. When you can't hear there is nothing to keep your interest.*

*... if I'm in an airport and they announce that your flight is called ... I can never hear what they are saying ... I could never travel by myself. I wouldn't have the confidence to travel by myself.*

*I can't hear what the priest is saying, the readings or sermon or anything, it's all over my head.*

A general lack of awareness of the needs of the deaf was also problematic:

*Some people are impossible to lip read ... especially ... if they move around the room. I remember I was doing classes ... The woman giving the instructions used to walk around the room ... If she was facing me, I could hear her and I could get what she was saying but otherwise I was lost. It was terrible.*

The inability to follow conversation in a group impacted significantly on participants' confidence. They doubted that they had heard correctly and feared looking foolish if they responded inappropriately:

*I really lost confidence ... Losing the business, that was a real blow. You just feel so stupid having to ask people to repeat what they say and getting it wrong.*

P: *You are less confident definitely. You, em, don't want to talk in company because you know you may miss what the person has said and then you are left and you have to ask them to repeat the question, which is embarrassing and you seem dumb sort of.*

I: *How have you coped with that?*

P: *Not great I suppose, really. It leaves me silent in company and I usually get the gist of what is going on and but that is it.*

*It does because you're not absolutely certain about what people have said and you are not confident enough to get up and speak in case you got the ... wrong end of the stick.*

Hearing impairment or deafness resulted in an erosion of most participants' self-confidence which in turn negatively impacted on their self-esteem and ability to participate.



### 6.2.5.2 Sensory Disability: Vision

Visual impairment was associated with high levels of disability. The degree of limitation, however, was dependent on the degree of impairment. Most participants reported difficulties with activities of daily living and other activities, such as watching television, reading and cooking:

*He has to put milk in the tea for me because I'll pour it around the, all over the table if I do it.*

*I got television glasses ... They were great when I got them first, I could sit in that chair there and watch it ... but now even sitting in that chair I have difficulty.*

*I can cook ... I wouldn't be as good at it as when I would have my sight ...*

*I: Are you able to dress yourself?*

*P: I'm fine like that, might turn it on inside out and I realise that ... (laughing)*

*So far I can look after myself. I can ... look after my clothes and keep clean ... I can't do gardening anymore. I used to love it. My constant prayer is, 'please Lord let me see flowers, let me see colour again'. I can't see colour.*

Completing activities of daily living that had previously been taken for granted required planning and recall. Being in and knowing your own place was also crucial to the person's ability to manage:

*I know my own territory ... between here and the bus ... but when they were doing roadworks... I'd be up on top of the fencing before I'd even know. They used to change around the fencing ... I'd a few near knocks ... but as long as I take my time.*

*I: Can you get around the house alright?*

*P: I can with a stick. I get about alright. Well, I know it so well now. If I was in a place that I wasn't familiar with I wouldn't be able to negotiate it.*

Participants with some vision were concerned at the possibility of their sight deteriorating further:

*One of the nights, I came down to the kitchen, I didn't turn the light on ... I wondered if I would be better off blind, like in the dark I was thinking, 'would I manage or would I be better off without this constant flickering' and I walked into the fridge. So I said, 'no I'm better off with the little piece I have' and thank God for the bit I have and hope that I'll keep it. (laughing)*

Participants relied on their spouse, family and friends to continue to live as normal a life as possible. However, those with less support were at risk of becoming isolated in their own homes:

*I depend on my neighbours ... They are so good to me ... If I need buttons sewn onto something or if I need stitching ... she'll do it for me. Or a friend, when she visits me, she'll say, 'have lined up all the things that you need mended'. ... Now I love to be able to go shopping. And I can call on a friend to do that with me.*

*My wife and I always go out together ... When we go into town, the two of us go together and if I see anything that I can't figure out what it is she'll tell me ... She is a great help to me and if we come on any dirty patches she'll guard me around.*

However, being dependent on others undermined some participants' self-esteem. This participant describes how it makes her feel 'humble' to be dependent on others:

*I really do feel I'm dependent, I feel if I go some place with somebody, I feel that I'm holding them back, even though everybody says you're not ... And I think some people are ... over-cautious with me. It makes me feel humble ...*

Not giving in and regaining some independence was important to participants:

*I'd chance it now and again ... I hate giving in, I really do hate giving in.*

*I'm coming to the stage that if my clothes are left on the chair beside the bed and water in a basin I can manage myself now, up to a point ... I try and do it anyway and if I get in to some bother, I shout and she (carer) comes in to me ...*

Visual impairment or blindness impacted on participants' ability to both self-care and participate in social activities, and some participants described feeling isolated and dependent on others to some degree.

## 6.2.6 Stroke

A sudden onset was typical of stroke; participants had little warning and consequently no opportunity to prepare. It was sudden, shocking and traumatic:

*The first one was my leg ... I just came in one day, sat down to my lunch ... and when I went to get up I had no power in my left leg, got no warning, no nothing.*

*Well I was perfect on Wednesday ..., got up blind the next morning. My wife rushed me to hospital thinking it was my eyes but, on examination, it was discovered that I had a stroke.*

*I was out shopping with my friend. We said we'd have a cup of tea ... When I stood up I felt a bit funny. My leg had gone, the power had gone, I couldn't put any weight on it.*

The severity of the stroke event that participants experienced ranged from mild to severe. This participant had a mild stroke and reported that his stroke had had no impact on his life:

*It hasn't affected me at all good, bad or indifferent ... I've no problems at all.*

Such participants were in the minority, however, with most reporting some degree of physical disability. Those participants who had suffered a severe stroke reported that it had had a catastrophic effect to the extent of feeling imprisoned either in their own bodies or homes:

I: *How do you feel about yourself since you had the stroke?*

P: *Well, days I feel very downhearted ..., I think what I was able to do ... I used to dig all that garden ... I used to grow vegetables ...*

I: *Does that make you feel down?*

P: *Yeah, yeah, you are looking at four walls ... it's like prison actually.*

*It won't take very long to describe a typical day ... I get up in the morning (spouse) washes me and shaves me and dresses me ... and I have my breakfast ... The bus collects me. When I get home in the evening I go in and talk with (spouse) ... I can't get out of the chair. I can't even sit in a chair elsewhere. I can't go for a walk or anything like that ... I'd listen to the radio, look at the television ... That's it, ...*

*I'm practically dead except I have a capacity to use some words. That is my honest statement now.*

Most people associate stroke with left- or right-sided weakness. The wider public are possibly less aware of other residual impairments, however, these include memory loss, visual impairment, difficulty in communicating with others and mood swings:

*My body wasn't touched at all only my sight.*

*I have problems ... remembering and lately I notice people tell me something, a person's name or something and I have to go back and ask again and again. That's the way I've gone.*

*There is no doubt about it, I am different. Mood swings ... but they are not bad now. In the beginning I was inclined to lose my temper.*

A stroke is a life-altering event. Not surprisingly some participants reported that they felt differently about themselves afterwards. Their comments suggest that having a stroke has fundamentally altered their sense of identity and diminished their self-worth:

*I'm not the man that I was ... I'm not even half that man. But I'm trying to fight it as best I can ... Sometimes I get annoyed with myself that I can't do this and I can't do that.*

I: *How do you feel about yourself since your stroke?*

P: *No good ... I don't feel a bit happy at all.*

I: *Why is that?*

P: *I don't know ... Sure when you can't do what you were used to doing, it must be it ... People say to me, 'oh sure you were long enough working'. That's not the point ... I don't feel that way about it ... There's nothing I can do, to put it all in a nutshell, nothing I can do, nothing.*

The latter excerpt gives insight into the loss of control experienced by some stroke survivors, with participants being highly dependent on others for help with activities of daily living or for company:

*I wouldn't go into town to shop. It's four miles from here ... so I'd wait until I would get some neighbour going. They do the shopping for me.*

*I just wait and wait and wait for somebody to come and visit me. Fortunately I have a good lot of visitors. My friends from around the church, they come and visit and give me all the news. That is what I thrive on ...*

*If I were left on me own while the brother would be gone away for a while, even to the shop, if he was too long I'd be wondering was anything happening to him ... and he'd come at the end, coming down by the window, coming home, I'd be so happy then.*

Having a stroke was clearly a watershed moment in participants' lives with most participants describing their life in terms of 'pre-stroke' and 'post-stroke'. They continuously made reference to what they had done before their stroke:

*I was a mad one before that the stroke, you know, so it has kept me down and I have the stick ...*

There is no doubt that a stroke is a traumatic event and not surprisingly those most affected by stroke experience a profound sense of sadness and loss. Most participants reported loss; loss of control over their bodies, loss of independence and loss of control over their individual circumstances:

*It was a gift, a gift from God Almighty when I could do it on my own (get to the bathroom). I hated the thought of the nurses but sure they didn't mind ... I couldn't bear it, but I had to do with it ... It was terrible surely and that time I'd rather God called me away but he didn't.*

*I'd balance my own cheque book, a thorough account, expenditure and all that. and I just can't do it now, so, eh, I just do what I can do. But only for (spouse) now I couldn't manage at all ...*

*I miss my car ... I miss going out, I miss my friends. I am not a bit independent, not a bit.*

No participant referred to their post-stroke life as having parity with their pre-stroke life.

## 6.3 Coping Strategies

Although participants' experiences varied greatly, a number of consistent strategies were identified that participants use to assert control over or adapt to their disability.

### 6.3.1 'Pacing Oneself'

Participants described how they 'paced' or phased their activities in order to conserve energy to be able to do what they wanted to do. This strategy was mostly used by participants with a physical disability:

*You overdo it one day so you lose a day the next day and I pace myself. I do enough kind of in the week ... I have a rest in the afternoon if I was going out at night.*

This participant also spoke about the need to 'be sensible' but not to the extent that it restricted her life:

*I'd say you have to be a little bit careful. Now recently we had a talk with Dr (name) and he was talking about that and he said, 'at the same time don't be so careful that you don't do things'.*

The need to be sensible was echoed by stroke survivors:

I: *Your life hasn't changed that much since you had the stroke?*

P: *No, not an awful lot, no. thank God. But I know that I'm tied down ... with the stick and I'd rather if I hadn't it but I have to have it and that's that ... I have to be sensible.*

Participants referred to the need to be sensible with a sense of regret and intimated that they were no longer free to be spontaneous.

### 6.3.2 'Getting Cute'

A key strategy employed by participants was 'getting cute', which involved learning about the condition, and their capabilities and limitations. This participant describes how she had to understand her physical limitations in order to avoid situations where she was forced to ask for help:

*You can panic about a lot of things. I sat down in the library one time and now I wasn't great ... and I couldn't get up out of the library chair. It's just you get very cute, you need to.*

'Getting cute' also meant developing strategies that allowed participants to participate in activities on their own terms, without having to disclose that they had a disability:

*In groups, now, sometimes you don't always hear. I was out last night and there was four of us at a table but this lady she speaks awful low ... and she was talking. If I get the gist of the story I am alright but if I don't ... I said to her, 'who are you talking about?' And then she turned to me and she told me but I hadn't heard her, but I just said, 'who are you talking about?' You get cute.*

'Getting cute' has potential positive and negative connotations. Working to understand one's capabilities and limitations, and to develop strategies to have greater life control is inherently positive. However, 'getting cute' in order to hide a disability because of embarrassment or shame may ultimately have a negative impact on the individual.

### 6.3.3 'Battling'

Many participants described how they 'battled' and fought the disability with the goal of either adapting to or overcoming it:

*It's up to yourself, if you have a problem, to try and overcome the problem ... If you give in to your problem, well you've had it, but try and fight your problem.*

Some participants demonstrated enormous tenacity and personal strength, and their determination was extraordinary:

*The physiotherapists were saying the stairs that you have do a bit of practice on them, up and down, and what have you. It's no problem. So I was saying to them that I'd*

*taken their advice there and I've gone down to a shopping centre and I've walked from the basement up to the roof by the fire stairs and down again, which is five flights of a building and I did okay, you know, gently doing them. So I do that and I also go upstairs on double decker buses you know to make sure that I do that. People often watch and say what is this guy doing on the stairs, struggling up the stairs.*

*In all the years, I tried to be totally independent ... It is too easy to give in, to let other people do this for you and do that for you, and then you get out of the habit of doing it. I've never asked anybody to do something, that I physically could do myself ... and it might mean slightly twitchy pains ... I went to the gym ... I've always believed from the time I found out that there is no cure for me and the one thing I tried to do was to try to keep on top of it, that I wouldn't get any worse.*

*I have friends who are hard of hearing too but they aren't ... bothering to try anymore ... Whereas I've tried lip reading classes which I find very helpful.*

Sadly, however, the result is not always a positive outcome:

*I always loved to be able to do things for myself and wash and dress and everything and so far, thanks be to God, I try to do my very best even if I have to get up a lot earlier and all because it takes me quite a time. But I hope I'll be able to do it for a bit longer but I don't know really because I seem to be getting a lot worse; my shoulder and my second arm and all that, I wouldn't be able to carry on I think ...*

A positive attitude and remaining hopeful were identified as important strategies:

*I would hope that this depression would wear off ... I'd probably be able to do more things ... I would like to get it lifting off, you know, and do different things ... I mean as long as you have that attitude to keep trying, it's good, but I don't know what you'd do, if you hadn't that ...*

*I feel it's a state of mind. If you sort of, if you give way to that then I think you can very quickly deteriorate, even though you were in reasonable health. So potentially if you are not going forward, you stand a chance of going backwards.*

*I think the whole thing is your attitude ... I could sit down in a chair and say, 'everything's fine, you know,' but I don't like to do that, so I want to be up and about. I keep going.*



Participants sometimes used humour to help them maintain a positive attitude:

*I went out one time and I sat outside ... Couldn't get up off that of course ... Two people had to haul me up but at times that kind of thing will get you down, other times you just have to make a laugh out of it.*

*Answering the wrong question, not getting it right and ... you know by people's reaction what you said is not the answer they were expecting and you have to see the funny side of it, because there's not an awful lot you can do about it really (laughing).*

Keeping cheerful or 'having a joke' was viewed by some participants as therapeutic in its own right:

*Ah sure you have to be cheerful, there's no use not.*

*Well, I joke a bit and have a laugh with people and you know have a little tease and things like that. I don't think that it does any harm ... It keeps me going.*

It would appear that an individual's struggle with their disability is influenced by their general attitude, tenacity and personal strength. Gains in the battle included being able to assert control over their situation and maintain continuity with their 'old' life.

### 6.3.4 Acceptance

The mirror opposite of 'battling' was acceptance. This is not to say that participants could not simultaneously engage in both; some did. However, participants who spoke most about acceptance were also those who were most incapacitated. These participants' lives had changed radically, for example some had moved into long-term care:

I: *Is this your home now?*

P: *It has to be, yeah.*

I: *And how do you feel about that?*

P: *Well, you just accept it. You have to accept it. Sure, what can you do? You cannot change anything, you see. I think it's all laid out for you, maybe.*

*I miss dancing a lot ... but sure, I have to accept that the same as I have to accept a lot of things ...*

*I have accepted it, instead of fighting it.*

*It's a terrible thing to happen to anybody, I wouldn't wish it on anybody. It's very hard to accept it, I'm kind of accepting it now, but I know I can't do anything about it.*

Part of the process of acceptance was acknowledging that life would not revert to normal; there was no alternative but to 'get on with it':

*There's no alternative, I mean I can't do it now so I have to accept it.*

*Oh, it's awful ... I'm just trying to come to terms with it, and you think you are and then something happens and you say 'oh I must have a read of that tomorrow and see it in the paper' or something like this, or there's something on maybe and you say, 'oh, I must go up to that tomorrow' and then you suddenly realise, what's the blooming point in going, only that it gets you out.*

Participants compared themselves with others and spoke about 'being lucky' or 'it could be worse' when making these comparisons:

*The way I look at it now is there is people a lot worse off than me.*

*I had another attack last week. I literally couldn't move. The only way I can move is to kneel on the floor and then it affects the knees. But no, it's fine, there are people worse than me out there. I just keep standing up straight.*

*The way I look at it is, if it was my sight now that had gone, well I'd feel a lot worse, that is my consolation.*

*I think, 'why should I have one?' and then I say to myself, 'I'm very lucky, I could be a lot worse' ... and yeah, you're disappointed, but what can you do? You just have to put up with it and, thank God, I'm able to get around and I'm all right.*

Participants also focused on the positive. They concentrated on what they could do rather than focusing on what they could not:

*I still can't read ... I don't like to dwell on too much of what I can't do ... I'm talking non-stop about the things that I can do.*

*If I hadn't this depression, I wouldn't have known what was going on down at that home, but you learn by your sickness too, sometimes. It brings you forward a wee bit ... when people are well enough, they shouldn't be grumbling at all.*

*You have to be very grateful for these things. As long as God gives me the energy to keep walking and I'm able to do it myself I'm fine.*

Keeping focused on the positive increased participants' self-confidence, self-esteem and self-worth.

There is a fine line between acceptance and resignation. It is suggested that some participants are so debilitated that they have no choice but to accept their disability and its impact on their lives. It is noteworthy that all participants used the terms 'accept' or 'accepting'. It may be that 'accepting it' is conceptualised by participants as giving them some element of control or choice.

### 6.3.5 Religion and Spirituality

Participants' opinions were mixed as to the importance of religion in their lives. Some viewed it as very important and explained that they drew 'comfort' and 'strength' from their religion. Others reported that it was either not important in their lives or on a par with other activities. Some drew a distinction between religion and spirituality, commenting that they were spiritual but not religious. Most participants indicated that their faith had not altered as result of the onset of their disability:

*My faith is just the same, I was never over religious now, but I love my God and I have my own religion.*

*I go in to the chapel most days, in my walk down the town from home. I go in and say the rosary, and you get awful peace, you know. And then, it's a ritual, then if you don't get in, you miss it, you know.*

*I say my own prayers and that ... I do my best like ... I wouldn't like to be like a real holier, I like to be like in social things as well like, I wouldn't be all religion like.*

*I always had my own little thoughts about religion, and I sort of felt that I don't like set prayers, a whole string of rosaries, or that kind of thing. Oh gosh, it's painful, but I have my own little chats with the Man above and I sort of try to fit in, sort of, with the Commandments.*

*It's part of my life ... If I didn't have that I'd be worse ... You see somebody in the church and you say hello to them and have a chat with them. It's better than staying inside cleaning.*

Attending Mass provided a 'social outing'. Several participants commented that they met their friends, and that it gave them a chance to catch up and keep in touch:

*I meet them on Sunday at Mass.*

*It's an outing now ... and it's some craic. You hear who's sick and who isn't.*

It is often assumed that people become more religious as they age or encounter ill-health. The data does not support this assumption. It would appear that if religion was always important in the older person's life it continued to be so and vice versa.

## 6.4 Independence and Dependence

Participants defined independence in four ways: 'being able to do what I want'; 'being able to go where I want'; 'not having to rely on others'; and 'being in control'. They found it difficult to distinguish between these concepts and often were aware of the apparent contradictions. For example, being able to go where one wanted to go often meant reliance on others to achieve this goal. Overall, definitions divided into two main categories: those that centred on avoidance of dependence, e.g. 'being able to look after myself'; and those that centred on autonomy, capacity for self-direction and being able to make choices. Those who were self-caring tended to cite the former definition. Those who were dependent on others for help with activities of daily living tended to cite the latter. This was not always the case, however:

*Being able to look after yourself, you know what I mean. And you can go to the bathroom, and you can go for a walk and do a bit of shopping. You feel you're useful, just them few things.*

*I always say to people, 'whatever you do learn to drive' ... It's great independence ... it's a great sense of freedom. And of course, thank God, if you can get out of bed every day and walk. I always say, 'God leave me to put on my own clothes and be able to go to the bathroom'.*

*To be able to do my own thing ... When I see everybody up and going, I say I'd love to go there, I'd love to go here and I can't go ... I feel I'm dependent ...*

*I've no independence, none, I can't drive the car ... There are lots of things I can't do. I can't go out on my own, I've to get my sister-in-law ... She takes me out but other than that I can't go out.*

*Your independence is you can get up and you can go and you can make decisions ... Take my car off me and I am afraid my independence would go down.*

Participants' personal perceptions of their independence or dependence were relative to others and/or improvement or worsening of their capacity to self-care. What increased participants' independence was feeling in control and having some degree of freedom:

*I thought if I was like that I wouldn't want to be involved. But it's surprising that you can find the will to do things, even when you are thinking it's finished ... That has been a bit of a revelation to me because when I got it, I had no movement. I got very depressed, extremely depressed. I mean the idea of not being able to lift your arm ... I probably would have got accommodated and obviously I would have had to but ... if I were in a wheelchair that is a thing I can't answer for, because you never really know how you are going to be until you have the experience.*

P: *I've changed a bit over the years like. I'm able to do things now that I couldn't do years before, I've no problems.*

I: *Do you consider yourself to be very independent?*

P: *I think I am. I live with my sister but she has another job but I mean I can manage on my own.*

I: *What does being independent mean to you?*

P: *Oh well the fact that I have my electric wheelchair, and that I can get around, and that I can go out in the summertime ... I'm quite happy.*

*I've been able to control the blood sugar, through diet and exercise. Now I do feel tired at times, I mean I've had the odd, eh, say for instance my eyesight seemed to give out over night. It's good insofar as I can look after myself ... I can look after my clothes and keep clean and keep showering.*

Participants' greatest fear was increased dependence. In particular, they dreaded the possibility of having to move into long-term care. They wanted to stay at home for as long as possible. Dependence on others for help with intimate personal activities, such as going to the toilet, was repugnant to them. Some reported they would prefer to die:

*I couldn't bear it now to have to go to a nursing home. I couldn't bear it. Your independence is taken right off you ... If your people bring you in something, it's taken off you. Your pension is taken off you. You have to eat what they give you. You've no choice, all that sort of thing. Oh whatever you could do to, eh, to avoid that, at all costs, yeah, 'cos I've been in a nursing home ... I only had to stay there a fortnight so I wasn't too worried, I could get away. But those that have to stay there all their life. It's absolutely terrible, they sit there in the sitting room, all around the walls ...*

P: *If I couldn't look after myself I want to go the other way.*

I: *The other way?*

P: *Down, go away. When that day comes on me I don't want to be here. That doesn't say I'll get me wish, but that's the wish I have.*

*I dread if I have to go in to a nursing home ... They're expensive and they're well apart from that, I think I'd die if I went in them.*

Some participants were fully reliant on their spouse or family and experienced little sense of independence. They were grateful that they could stay at home but felt a burden at times:

*I feel that I've lost my independence completely. I'm not that confident in anything I really do. Sometimes that does upset me I have to say ... Also knowing that it's possibly not going to get better... I'm not anywhere near as independent as I was ... I definitely couldn't do without her (spouse) now. If she wasn't here I would be in a home ... I'm totally dependent on her.*

*God help her! I don't know, it's very unfair. She brings me to bed each night and she has to undress me, and put on my night clothes, and put me into bed, and cover me over and all the rest of it, and turn off the light ... I'm happy as I am ... but I'm not independent, I don't have the possibility of doing any of those things ... I'm totally dependent on her down to the point that even if she is doing nothing, or apparently doing nothing for me, she cannot leave the house while I'm in it ...*

In the transition from independence to dependence, having to accept help beyond that given by family was a significant milestone for participants. Acknowledging that they needed help was a tacit admission of increasing dependency and, as such, threatened self-esteem and personhood. It was not a decision they took lightly. Accepting help from family was more acceptable than seeking help from care providers. It was evident from participants' accounts that some would prefer to struggle on even when they obviously needed help:

*I was offered a Home Help after I came home from hospital. I just laughed at the idea, me having a Home Help because I can do things myself ... I like to be independent ...*

*It means having someone in, these helpers and all that, and I don't like that. I feel that I'm finished if I had that, do you know ... I don't mind having my own to help me.*

Participants also differentiated between having to accept help for which they were 'beholden' to others and 'buying' help where they were the customer and in charge. The latter was more acceptable to them. Being able to afford services kept them in control and gave them the choice. There was also some evidence that where participants accepted help from family or friends, they tried to reciprocate the care they received in whatever way they could. This was their way of 'paying back':

*I feel more independent with a taxi ... because your independence goes, you know. You can't be asking neighbours to take you into town, like, they get fed up and they don't have time anyway.*

*One of my sons is cutting the grass for me and they keep saying, 'we'll look after it'. But they're doing their day's work and I don't think that's right, so a nephew said, 'I'll look after you' and I said, 'right, I'll pay you for your time'.*

*My daughter ... does the shopping for me and she picks up the pension ... I like to baby-sit till she comes back.*

*I help my sister at home in the house ... I does everything for my sister, every weekend, hoovers and polishes and all.*

Independence and self-reliance may be promoted by the allocation of resources or appliances to support older people, for example these participants were given a new lease of life by having an electric wheelchair. Sadly, others will not benefit in the same way; some because they cannot afford it:

*I had a little money saved so I thought I might as well give myself a bit of comfort, because I was finding the manual chairs much too exhausting. I couldn't use the left hand to push so, if I was going down a corridor, I had to sort of grab a rail and pull myself down, and it was tiring me so much that I didn't. When I saw a lady passing by in a chair something similar to that, I said, 'why the heck don't I get that chair, a chair like that?' So I made enquiries and this chair was produced, and I found I could operate it without any bother at all ... I can get out if I want to. I don't feel so much a prisoner ...*

*They have given me the use of the electric-powered wheelchair which I think I can manage quite well, provided I don't get too impetuous. If you get too impetuous, you can do a lot of damage with those things. They are very sensitive to use ... I can manage it. I've done no damage yet. I only asked the girl yesterday if she was a driving instructor would she give me a licence and she said, yes, without question.*

Participants tended to define independence as the absence of dependence. Most important to them was not being reliant on others, having choice and maintaining a meaningful social identity and role.

## 6.5 Conclusion

This chapter focused on the reality for participants of living with disability. Each type of disability brings in its wake particular difficulties. It was evident from participants' accounts that having a significant disability, irrespective of type of disability, impacted on their quality of life and independence. People were aware of the difference between independence and dependence, but these two concepts were not always perceived as opposites. It was possible to be independent and dependent at the same time. People valued being able to do things for themselves, but they also valued equal relationships and reciprocal arrangements. Participants used varied coping strategies to regain and retain control of their lives. The following two chapters explore further the relationship between disability and quality of life.







## Chapter Seven

# Exploring Disability and Quality of Life Relationships: Health and Environment



# Chapter Seven

## Exploring Disability and Quality of Life Relationships: Health and Environment

### 7.1 Introduction

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This chapter is the first of two, which explore disability and quality of life relationships. These relationships are undoubtedly complex as there is interplay between disability and quality of life. The relationship is not linear and responses to disability are moderated by a number of factors which will be discussed below. The analysis of data complemented by the international literature revealed five domains of quality of life as being important for people with a disability in this study: health; environment; sense of self; connectedness; and income. This chapter focuses on the first two domains: health and environment domains, while Chapter Eight will examine the domains of sense of self, connectedness and income.

### 7.2 Health

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Health perceptions were gathered using the SF-36v2 and all participants discussed their health and described the impact it had on their day-to-day activities. Some participants with very poor health and whose impairment was extreme were unable to wash, dress or feed themselves other participants were fully independent in all activities of daily living. Participants' accounts revealed that health mattered for quality of life and that disability

impacted on health, but it was also evident that perceptions of health changed with increasing physical disability. This section is divided into two parts: changing perspectives of health; and the impact of health on day-to-day activities.

### 7.2.1 Changing Perspectives of Health

Some participants suggested that health was very important to quality of life. These participants were, on the whole, in relatively good physical health and had little difficulty with physical functioning:

*It's very important ... to have your health. I feel sorry for people ... who have bad health. I would hate it. I would always pray that I would die standing up, that I would be able to keep going ... because I think it is tough luck on people who are confined or who are people who have had a stroke or anything like that. I really think it is tough luck on them.*

*Well, I have my health and that's the main thing. I'm working and able to walk and stuff like that.*

*Your health is your wealth.*

Other participants, however, with significant physical impairments perceived health more in terms of their abilities. One participant with multiple disabilities commented:

*I like to judge it on how much I can walk and if I can walk a fair bit without having to sit down ... It is great because I always loved walking.*

Focusing on abilities was also evident from this participant's account of her health:

*Well, it's not bad. I can get up and I can wash myself and dress myself so far ... I'm able to go into the bathroom in my wheelchair and get undressed, get washed and everything, but I can't have a shower myself. I can't do that and the nurses do that for me. They do that for me but apart from that I can do nearly everything myself, but I'm very slow.*

Many participants with significant disabilities, therefore, did not perceive themselves to be in poor health. Most participants with dementia perceived their physical health to be good but their memory poor. Some participants also compared themselves to others with greater disabilities and concluded they were not so bad after all:

*I'm not too bad, I suppose there is ones worse.*

*Sure when I can feed myself, when I see people that have to be fed, you know, when you can do that ...*

Many participants perceived health to be relative to the health of others and were thankful for what they could do for themselves:

*I say to myself, 'I'm very lucky, I could be a lot worse'. Thank God I'm able to get around and I'm all right.*

*I'm healthy, thanks be to God. So far so good. I know plenty of people who have loads wrong with them and they are only seventy, you know what I mean. They can't walk right or they can't bend down; different things that causes these things. Rheumatism, I have friends crippled with rheumatism much younger than me. So you would be thankful to God that you have the use of your limbs which is a great thing.*

It is evident from these accounts that there was great diversity in perceptions of health and the importance attached to good health. As participants' physical functioning declined, they redefined health in terms of their abilities rather than absence of illness and many judged their health in relation to others.

## 7.2.2 Impact of Health on Day-to-Day Activities

Participants' health affected their lives in two main ways: dependence/independence in activities of daily living; and ability/inability to maintain the home.

### 7.2.2.1 Dependence/Independence in Activities of Daily Living

There was great diversity within and across disability groups in the extent to which participants were able to undertake activities of daily living independently. This was evident in scores for the Index of Independence in Activities of Daily Living reported in Chapter Five. Physical health, mental health and independence were inextricably linked, with those with greater disabilities having higher levels of dependence on others. Some participants had very poor physical health and were unable to undertake some or all of the activities of daily living and were, therefore, totally dependent on others for help, which they found frustrating and depressing:

P: *I'm not healthy, no ... I can't do much now ...*

I: *Do you need assistance in getting yourself washed and dressed?*

P: *I do.*

I: *You can't do any of that yourself?*

P: *Not at all.*

Other participants reported that their physical health had deteriorated to the point where they needed support to walk:

*It's just the legs. They are not moving for me. I'd love to run, I'd love to walk, but I can't do those things now, you know. I can walk around now with the stick, just up and down the bungalow there, like you know, but the nervousness is still there, because of the falling.*

Some participants were able to undertake activities of daily living, such as washing and dressing, but their mobility was very restricted and they could not leave their homes or walk around shops or town:

*I don't go out much ... I used to go to town but I can't go now because I can't get around. I can't get round the shops ...*

From participants' accounts, it was clear that poor physical health and dependence were related, however participants' perceptions of the impact of health problems on quality of life were also shaped by the extent to which they perceived that they could help themselves. Some participants believed that pushing themselves would help them to get better. They were determined to do things that would help them regain as much of their health as was possible:

*Well, the way I am, I always loved to be able to do things for myself and wash and dress and everything. And so far, thanks be to God, I try to do my very best even if I have to get up a lot earlier and all because it takes me quite a time.*

Participants described the effort they made to try to regain function and the determination with which they approached this:

*I was determined to keep going ... so I can get out and about ... I take a stick with me but I try not to use it. I'm mobile to that extent. And I'm also pretty self-sufficient, as well. I mean, I can wash and dress and cook and I can iron and do a bit of light gardening. The physiotherapist gave me a series of exercises, which I do anyway, but probably the best way to get exercise is to do what you would ordinarily do. In other words, if you are going to do a task, do it. Don't use your left hand, use your right hand. So that is the way I approach it. So I mean you could have probably tried to do it*

*with your left hand or do things totally differently but I didn't want to do that on the basis that, well, that is not going to improve things.*

*So they took me back here and I was down in the gym every day ... I had to be fed here and washed and all the rest of which was terrible. So it took a while, I think about three weeks. One day I saw a finger moving and then I got the arm as far as a dessertspoon and eventually after I don't know how long, I was able to eat with a spoon my dinner ... The physiotherapist gave me things to work on and I did my own exercises an hour every day and I was determined to get better. So eventually this arm came back and it was good until last year and I asked to leave the nursing home.*

Participants also described the importance of getting on with life and not focusing on the disability; they suggested that a positive mindset was very important as it determined the impact the disability had on the quality of life:

*There are people that will give up and turn themselves almost into invalids, but it's not part of my make-up. I just don't do that and I don't say to anybody ... When somebody says, 'how are you?', I'll say, 'fine'. There's no point in saying to them, 'oh, I have a pain in my back and a pain somewhere else', because all they'll do is start to tell you about the pains they ...*

Participants also suggested that motivation was important in order to retain or regain independence. Sometimes this motivation came from the individual but on other occasions it was provided by the family:

*But I need to make that effort to get up the stairs as well, you know ... I'm a bit more positive about it now, with the second bout I got than I was during the first because I just sat down and, you know, spent a lot of time in bed ... and not actually feeling sorry for myself but ... Only for my wife moaning and groaning, eventually it got me out of bed, you know, and got me doing small things for myself, you know.*

Sometimes, however, participants felt powerless and unable to help themselves. For some, this was due to a lack of knowledge but for others it was a lack of motivation. Participants who were depressed found it particularly difficult to stay motivated:

*P: I have only average health at the moment, I couldn't say good or very good, average that would be because of depression, yeah, because of the tablets.*

*I: How does your depression affect you on a daily basis?*

*P: In the mornings you'd have to take your tablets. After you'd take your tablet, you would feel sleepy for the morning ...*

*No I'm not able to do the things I used to do, about a year ago ... I liked the gardening, yeah, but I don't think I'll be able to do it this year, not the way I feel at the moment, anyway.*

Other participants lacked knowledge about what was required to regain or retain independence. These participants expressed the need for information that was concise and centralised, and for the help and support of health professionals. They reported that information was often lacking or fragmented, and that support from health professionals was difficult to access:

*They didn't tell me that there was anything available for me, whether it was the fact that I was coming home ... I don't think there's any service to tell you that these services are available for you.*

*I didn't realise until recently that actually with arthritis you do need to rest, where as you're inclined to fight it.*

For many participants, accepting that they needed help was also difficult; they struggled to maintain as much independence for as long as possible but at times had to concede that help was required. Sensitivity to needs was, therefore, vital as many participants did not want others to take over but to help under their instruction.

#### 7.2.2.2 Maintaining the Home

Some participants found their disability had affected the extent to which they were capable of maintaining their home. Maintaining the home is comprised of three components: doing the housework; keeping the house in good repair; and gardening. Some participants were able to maintain their home themselves; this included housework, decorating and essential maintenance:

*Well, I usually do my housework and, if the day is good, I like to be working outside in the garden.*

*I do everything for myself, you know. I do my own housework, my own washing ... of course, the washing machine does the washing but I do everything.*

Many participants, however, reported that their ability to do housework had decreased since the onset of disability:



*I just do the bathroom and the toilet because I said, 'well, I'm not doing the housework now'. If the girls wanted to do it, it's up to them. I did my best. I'm going to be 79 this year and I do get very tired. And two years ago I had a bad pneumonia and I was hospitalised, so that is the way it is.*

Some participants lived with a spouse or family member who was also ageing and they were very concerned about the impact on the other person's health of having to perform the majority of household tasks.

Sometimes participants who were unable to undertake household tasks did not have family members who could help them; these participants wanted outside help:

*I'd like somebody to come in, one hour a week and give it a good clean because the rest of the week I could manage myself. That's all I'd want, lifting the vacuum cleaner and going around the house and upstairs ... I find that hard.*

Many participants had had or did have the services of a Home Help (see Section 7.3.3).

Many participants reported that undertaking essential maintenance and repairs was just not possible. Some participants lived in properties that were quite old and needed regular repair. Family members often carried these out these tasks or organised others to do so. Participants who were living alone or who had few family links found getting this work done difficult and two particular problems were identified: trying to organise such work, especially for participants with sensory or intellectual disabilities; and limited resources to pay for the work required:

*But I can't get around to organising it, I'm still going from week to week and ... I'm saying I will do it but come Friday, I have done nothing again this week, it annoys me.*

A few participants were able to maintain their gardens without help, however the majority could no longer do so. Some of these participants were able to do some light gardening but found digging or mowing the lawn impossible. Some participants were able to pay for others to undertake this work but others did not have the resources to do so and were frustrated at having to let their garden deteriorate:

*My hobby was the garden and now it's gone wild ... I did have a person used to come in with me and help me out ... because I've a big garden at the back and it's gone wild. I'd a gorgeous garden at the back, I'd a most beautiful garden ...*

It was evident from participants' accounts that disability impacted on their ability to undertake activities of daily living and maintain their homes. Poor physical health increased participants' dependence on others but the overall impact of poor health and dependence on quality of life was more complex. Responses to physical limitations were influenced by a number of factors including motivation, information, support and income.

## 7.3 Environment

Participants reported that the communities in which they live, their physical environment and the amenities that they had access to were important components of quality of life. Participant accounts revealed that living circumstances were very diverse, both within and between disability groups. Some participants lived in the communities in which they had been for most of their lives, others had recently moved to new areas. Some participants lived in towns while others lived in rural communities. All participants with an intellectual disability lived in group or residential homes, while some participants who had had a stroke or severe depression were living in long-stay facilities.

Environment is comprised of three elements: the physical environment; the social environment; and the care environment. The physical environment explores participants' perceptions of the impact of housing on day-to-day activities and describes participants' experiences of accessing local amenities. The social environment examines the impact of participants' social networks and local community social support on overall quality of life. The care environment details key caregivers and participants' experiences of accessing services.

### 7.3.1 Physical Environment

#### 7.3.1.1 Living Environment

Participants lived in a variety of accommodation types: some owned their own homes; some lived in local authority accommodation; some lived in rented accommodation; while others lived in residential facilities. Disability for some participants meant that they were no longer able to go upstairs, use a bath and walk unassisted. The living environment was, therefore, of great importance as it either facilitated participants to maintain independence in activities of daily living or compounded their dependence on others.

In order to maintain independence, many participants reported that they required home modifications following the onset of disability. It should be noted in this regard, while participants living in their own homes or local authority accommodation could have

their accommodation adapted, those living in rented accommodation could not. Many participants reported that their homes had been adapted to improve accessibility.

The extent of people's physical disabilities varied across and within groups and, to some extent, this dictated the modifications required. Some older people were wheelchair-bound and needed ramps, while many reported that more accessible bathrooms were necessary. Some participants, particularly those who had rheumatoid arthritis or who had experienced loss of function following a stroke, found they could no longer negotiate stairs or needed rails or other supports to do so. Some participants reported that they had moved their sleeping accommodation downstairs and this required downstairs facilities, such as toilets or accessible showers, to be added.

The experience of home adaptation varied considerably across the country. Some participants were able to access support through the Disabled Grants Scheme to assist in these modifications:

*Oh yes, they gave me support for a shower ... a seat. Now, it's only a small one, it's very difficult. And there's a step, you know, just one we put in ourselves in a small bathroom many years ago, but they put in the rail and that. I can manage that. They gave me a rail to go on the back and the doors.*

Others had great difficulties accessing these services:

*We had to get it because he couldn't come down the stairs. We also had to get a gate, you know like for children, in case he would fall down the stairs. If he turned a particular way he could fall down the stairs, so then we had to get a rail and the stair-gate. It's nearly three years before they come to put the rest of that bit of rail on the stairs, put a bar inside the door and a bar there, and they put a bar in the shower.*

Some people found that the wait to have their homes modified was so unacceptable that they had the modifications done themselves. In these circumstances, participants often reported that it was their family who paid for and organised them:

*We had a situation where we had a shower in the bath and it was useless. So the bath is gone now since I came in here. There's a new walk-in shower, which we christened last Sunday morning. And there's a new sink and there's a new toilet, and it's been tiled and this is all done by the family.*

*No, we adapted the house at the time of building. We built the house and we are trying to get it finished because my father had died and Mum had had a stroke ... and being diagnosed with Alzheimer's ... so we had to adapt the house when it was being built, so every room we can get a wheelchair in.*

Participants without the financial resources or family to organise things for them often struggled. Some reported not being able to leave their homes until such time as modifications were made:

*I can't get out ... I'm waiting for ... my handy-man to get out the front door. There is a step, it's not much ... I have to ... get the taxi man to help me out. Now, the back door has more steps; I could get in and out that one and I used to go to my neighbours. I used to go out to feed the birds and last Christmas Day I discovered I couldn't do it ... and (names) ... had to actually lift me down the steps. I've never gone out since. I haven't been out the door since that day.*

In addition, some participants who had bought their own homes found that they could not have them adapted by the local authority. They believed that the authority was not interested in helping because they were home-owners:

*I suppose the way we are living in an older cottage like this. Maybe in the new ones that they're building now ... that is all installed in them, but like it wasn't in these and they'd be damp. Now that we have kind of paid our way, we own them, they don't come back to do anything for us, so that's it.*

Financial assistance to carry out modifications was an issue for many participants. One participant found that they were ineligible for grant funding because the adaptation required was upstairs:

*If we were putting it in downstairs we'd get a grant, but because we were putting it in upstairs they wouldn't give us a grant.*

The layout of the living environment was very important to many participants with a physical disability because familiarity and a particular furniture layout helped them to manoeuvre. Participants with a visual impairment found the familiarity of the home environment particularly important and reported that they could manage to navigate around their own homes but found it very difficult to negotiate unknown environments without help:

*I get about alright. Well, I know it so well now. If I was in a place that I wasn't familiar with, I wouldn't be able to manage to negotiate it.*

It was evident that some participants had great trouble in getting their homes modified within an acceptable timescale. Modifications, however, were essential to enable participants who had poor physical or mental health to live as independent a life as possible. Without these modifications participants reported that they were housebound and more dependent.

### 7.3.1.2 Local Amenities

For many participants, the place in which they live was very important to their quality of life. They described their connection to the area, identified it as where they were from and many had a profound sense of place. Some participants, while living most of their adult lives away from their home place, returned in late adulthood drawn by this sense of place and belonging. Participants felt it was very important to be able to live where they belonged, even when amenities were some distance away.

All participants described the amenities that were available to them in their local areas including shops, post offices, churches, recreational facilities and walking areas. Access to shops, recreational facilities and local amenities were identified as important to quality of life by participants. In some areas, shops were only a few hundred yards away and some participants with reasonable physical health could walk to these. For other participants, the nature of their disability made it more difficult, and sometimes impossible, to access amenities.

In many cases, transport was crucial and transport was an issue raised by many participants. While most participants had a free travel pass, few participants were able to use it. They reported that public transport was too far away or inaccessible to participants who needed special aids or ramps to board:

*My wife drives a car, fortunately. It would be hard to get on public transport with that (a walker) ... even though it folds.*

*We still have to get a taxi because you see how crippled I am with the arthritis, like. I wouldn't be able to walk down the road now. Well, I'd be able to walk down but it would be very bad. I suffer so much, the pain would be so much.*

Transport was an even greater issue for older people living in rural areas. In these areas, shops, churches, banks and recreational facilities were often far from the participant's

home. Participants reported that in many areas public transport was infrequent and it could not be accessed close to their homes. Participants felt, therefore, that a car was essential:

*Without the car you would be housebound. I would be, I'd be very slow getting out.*

For some participants, the costs associated with running a car were a problem:

*I live down the road ... it would be nearly three quarters of a mile from the town. I get my pension, I can survive, barely. I think when you run a car, it makes it much more difficult and I have to have a car. I'd be lost without it.*

Some participants were not able to drive and had to depend on family, friends or neighbours to drive them:

*I've tried to cope with my arthritis but if I was on my own and living alone I think I wouldn't be able to be on my own, stay on my own, because you see I wouldn't be able to go out for a bit of shopping or my bit of pension. I wouldn't be able to go to collect that because it's a long way from here down the village isn't it.*

*There are no shops close by. You have to go (by car). Oh yeah, transport is a nightmare, nobody has any transport ... but now older people that didn't learn how to drive, they have to depend on their neighbours to get them to church, go for the pension, do their shopping, you know. It's a nightmare.*

For participants living in isolated rural areas, delivery of groceries was not an option as this service was unavailable.

Other participants had no option but to take taxis when going to town for shopping. They found this very expensive and some struggled to meet the costs:

*I go to town and I go down to the bank in town. I get a taxi. I've to get a taxi everywhere and that's expensive.*

*It's expensive enough now, I'll be honest with you. And it will be more expensive I suppose now with the price of oil, the taxis.*

In some rural areas participants reported that there was locally arranged transport, which would collect people and take them to day centres or church:

*I like the evening Mass and I used to take a taxi. But that got too expensive, so I knew that the minibus passes here anyway, so I got on to that .*

The capacity to access local amenities, therefore, depended on where you lived, the extent of physical disability, having access to a car and financial resources. It was evident that participants living in isolated rural communities and those with poorest health had most problems.

### 7.3.2 Social Environment

The social environments in which participants lived were also very varied. Some participants lived in group or residential homes, others in the centre of a town, while others lived in the countryside. Some participants had lived in their community for much of their adult lives while others had only recently moved. A number of participants had returned to Ireland after working in England for most of their lives. Some participants lived in older established communities in towns; some participants had good social networks, while others had few. Participants identified a good social environment as important to their quality of life but some reported that communities were changing and were perceived to be less supportive. Disability made it more difficult for some participants to remain active in their communities, however participation was influenced by many factors.

Some participants socialised with neighbours and were supported and helped by them. They described how the families in their neighbourhood had aged together and how they had supported, helped and befriended each other:

*I'm there since 1968. It's a long time, isn't it? It's 36 years or more, so I know the neighbours inside out.*

*Well you see it has changed. It is amazing the way it has changed. Well, of course, it isn't amazing because that is the way. We are here now for about thirty years and the youngsters were small at that time. I was very much involved in the Residents' Association when the youngsters were small for many years ... and there was 150 children. Now there is no more than 3 or 4 in the seventy houses, 3 or 4 kiddies under ten ... Most of the people now are like ourselves, kind of like ambulant geriatrics.*

*We've very nice neighbours. Very nice other people around, across the road and everything who are very friendly, you know, very friendly, you know, very friendly to talk to you.*

*The neighbours come in ... Some of them come every day. A neighbour there, she's on her own as well, her husband died and she'd be a lot lonelier than me and she comes in to me.*

Some participants, however, reported that their communities had changed and that the neighbours they had known had either died or left. They perceived that the community had changed fundamentally and that most people living in the locality were now strangers:

*I'm not sorry to be leaving ... It's where I was born and reared but it's changed beyond recognition. They are all strangers, you know. You could walk down the town and you wouldn't see three faces that you'd know. They are all strangers. So my whole life has changed.*

*They're nearly all strangers now, strange houses, I don't know who they are.*

Some participants reported that the houses around them were occupied by young families who worked all the time or by students who had little connection or commitment to the neighbourhood:

*No, I've no neighbours really. I had but I never see her. It's not because they don't like me but then I had another one and she used to work from when the children were small and, but I haven't seen her for a long time. She has her own commitments.*

*Oh yeah, we have been here for quite a while. It must be about 14 years. The situation here was when we moved here there were older people next door and then we got on better with the older people. They were of an older era and were more friendly. But since then they have died. Their houses have, of course, been bought up and refurbished and everyone is totally on their own. I'm not complaining. That is happening all over, anybody would tell you that. That is just a social thing. So we've been accustomed to that. I'm not worried about it. I don't have too much contact now. I might object to that as well, you want your privacy. So it's a balance.*

Many participants, particularly those living in rural areas, lamented what they perceived to be changing social practices. They described how 'visiting', which was a feature of their childhood, does not take place anymore. They believed that people were too busy now to be bothered with 'visiting' but missed the companionship and fun that was part of this practice. One participant, when asked what would enhance her quality of life most, suggested a return to this practice:



*Well it would be nice now if there was company because years ago everyone went visiting. But the young ones that's growing up today and the young married couples and they have no time for visiting.*

Many of these participants were lonely and felt that the lack of people visiting was a loss for them. They referred to the 'busyness' of modern life and suggested that some people have little time for others.

For some participants, security and safety were important issues. These participants did not feel safe and some had experienced regular break-ins:

*In my former address, I had two break-ins within six months of each other ... It was an inside job, both times ... I felt more threatened by the first break-in than the second break-in ... I was out for the first break-in and I came back and all my stuff around the place ... I'm in this new place, as I was saying. I feel much safer in the new place than I did in the old place.*

*Well I suppose the way to answer that would, I think, be to say that it's as safe as anywhere ... I'd lock the doors when the girls leave in the daytime maybe. You know, when it's just falling night-time or something. Anyway they're never open. It's too dangerous anywhere today. You don't know who's passing, although the house across the road there was done not too long ago. They were away on holidays.*

Another participant described how her area, which was once very safe, had changed:

*Well it's changed a bit ... My neighbour was mugged the other morning, going down to Mass, nine o'clock Mass, and she just pulled across the road there.*

Many participants were very conscious of their security and had had alarms fitted to their homes:

*We don't have many dogs and it's not every house has a burglar alarm. I haven't got a dog but I will have an alarm because I think I have left it too long. You get these villains coming around and ringing the bell and getting no answer, and then they are in. If you really want to get into any house you could, particularly at the back with no great hardship. But that is going to cost me a few bob. I was thinking of going Phonewatch as being a good system.*

*I live on my own but I have security and I have a panic button and I have all that goes with it, you know.*

Other participants felt very safe in their neighbourhoods and had not experienced any security problems. Many of these participants lived in rural environments:

*That front door is open because I can't hear anyone coming in. It's very safe to live and even when I was living on me own now, when my husband was taken away, I wasn't afraid, no.*

*Oh it's safe, I'm here thirty years and I never found any problem.*

*It's a lovely place to live, it's very quiet, there's no hassle at all.*

It was evident that participation in the community was an important element of quality of life of participants. Disability, however, undoubtedly made participation more challenging as participants often had to overcome physical limitations in order to participate. Community changes, an increase in those working outside the home and fears about personal safety resulted in some participants feeling lonely and isolated.

### 7.3.3 Care Environment

For most participants, the care environment was home but for some it was a residential care facility. Participants described the role of family and health services in providing care, and the impact that this had. Family and friends were identified by most participants as central to their care. Participants described many incidences of family and friends organising services, undertaking tasks within the home, helping participants with activities of daily living and giving vital emotional support. For some older people, a spouse or partner with whom they lived with was their daily carer. The carer role of the family was vital to some participants who believed that they would not be able to live at home without their help:

*There's nobody coming in, I've tried to cope with my arthritis but if I was on my own and living alone, I think I wouldn't be able to be on my own, stay on my own ...*

*I've no independence at all. I've someone bringing up my tea, someone bringing up my dinner. Me that was so active, I've my family pestered and watching and worrying and worrying them as well. They're on that phone every other second of the day and, if they're not on that, they're coming in here at lunch hour. You know it's so unfair because they're so good.*

Participants were concerned about the long-term impact that caring for them might have on their families. One participant whose husband also had a disability relied on her daughter to prepare meals, do housework and manage their complex medication. She was concerned about the burden of this and her daughter's capacity to continue doing this as she had a full-time job and lived over an hour away. Participants also worried about the future particularly if anything was to happen to their family carer.

Some participants lived alone and were dependent on outside services for care. Others had no immediate family in the vicinity, either because family members had relocated elsewhere or because the participants had returned to Ireland leaving family behind. These participants worried about what would happen if they needed someone in an emergency:

*P: Well, I suppose since I was ill and since my brother died, you know, so suddenly, it brought home to me that if something would have happened to me, and I would hope that I wouldn't, it wouldn't happen without somebody being near me or you know, that kind of, I suppose you would call it fear.*

*I: Fear?*

*P: Living on your own and thinking, 'well if anything should happen to me on my own' ... I must get one of these, you know bells that they have.*

All participants with dementia lived at home; the role of the carer was vital as many of these participants could not be left alone. Carers explained that there was a need for constant vigilance:

*If you were to leave her on her own for five minutes she loses, she does not know where she is, where everyone is gone, so you have to be with her to update her constantly.*

It was also evident that many families were struggling to provide constant care, and were often tired and stressed by their caring role. While participants did have help from voluntary or statutory agencies it was not sufficient:

*The Health Board pays for a lady to come in for an hour and a half in the morning to get her dressed and washed and that and we pay her to stay longer to get the dinner. Then we get a lady from the Alzheimer's Association for an hour in the afternoons but I would look after her at weekends.*

*Oh yeah, we've care two hours every morning ... Five mornings a week ... Oh God, it's great, we'd be lost without it ... Oh we could do with more, but it's not easy to get more, you know.*

For families, therefore, access to respite care facilities was vitally important. Respite care was generally provided by voluntary agencies. The service was really welcomed by families who were able to take a much-needed break or attend family functions:

*You see you can get a respite if we're going to a wedding or going anywhere. He was away there for a week now and he'll be going now on Wednesday again, and he'll not be back until the following Monday.*

Many participants described the need for responsive services. Responsive services were those that were focused on what participants needed, were readily available and easy to access. A few participants who had been in hospital and were discharged home identified the rehabilitation team as crucial to their recovery. They reported that the team had been coordinated, focused and motivating. In contrast, they found little support after the rehabilitation period and they reported services to be fragmented, uncoordinated and unsatisfactory:

*Well I don't know of any support there is to, we'll say, help people like me. To see, can I walk, I mean there's nobody, nobody, just nobody and no organisation.*

Many participants required the services of a Home Help. A few participants had found the service to be good, the person sensitive to their needs and described the Home Help as a friend:

*She's such a lovely person, I love her coming in. It's wonderful when she's here. She's so cheerful. She's so cheerful and friendly, and she's a great talker and everything about her.*

The majority of participants, however, who needed the home help service found it poorly organised and lacking the capacity to accommodate specific needs. Participants reported that they were unable to exercise choice if the person was unsatisfactory. Some participants suggested that they were unclear about the services that Home Helps would and would not provide:

*Now she (supervisor) was a Home Help herself, so how could she assess me? It should have been the Superintendent, PHN or someone like that and she sat down and she proceeded to tell me what a Home Help should not do. But she never told me what she should do.*

Some participants who found the Home Help unsuitable had found that when this person was withdrawn no replacement was found and they were left to struggle on alone. For example, one participant who was blind found that cleaning equipment was not put back in its place and work was not done:

*She went and left the Hoover in the middle of the floor. I rang (supervisor's name) and told him what was happening, and that ...*

While the Home Help was withdrawn, no replacement was found despite a number of requests.

Other participants when offered the services of a Home Help were reluctant to accept as they perceived this to be the slippery slope to losing their independence:

*They do be telling me I should get a Home Help but ... while you're middling active, but I suppose the day will soon come when I'll have to.*

*No, thanks be to God. I don't want them. When that day comes on me, I'd better go away.*

Participants with an intellectual disability who lived in group homes or residential care described their carers as friends. They reported that staff were caring, helped them do the things they could not do themselves, and helped them organise and plan their lives. Group homes are not staffed during the day as residents generally work but this meant that participants could not stay there even when they were ill, which participants considered as a problem.

Some participants who had had strokes also lived in residential care. They reported that they felt safe and that staff were kind but they found life lonely and difficult. They also reported that there were no call bells to alert staff to their needs:

*There are no bells in any of the wards and, well, the Sister has given two of us two lights for reading, so that is a help. The lights are poor. The food is a bit, it's good, but it can be a bit monotonous.*

Some participants reported that there were not enough showers or toilets and there were few interesting activities:

*There is no such thing as a period being laid out to do anything, do any activity, anything at all, for the rest of the day, other than at 12 o'clock we go for lunch. We would be back from lunch at about 12.45. I would, anyway, and from that until 5 o'clock, you sit around and you may talk to different people. There wouldn't be very many. I thought when I was coming in that there would be something. I'm interested in painting and I thought that might be one activity that I would be engaged in. But there's nothing, there's no way that you as an individual or as a person can take any activity.*

Some participants found the lack of personal space a real loss and, while they believed they were well cared for, they missed living at home.

The majority of participants attended day centres for some days of the week. For participants, particularly those with depression, day centres provided vital companionship and motivation:

*Oh I'm more positive about myself, but the day centre was a great help to me. I thought I was hopeless going down there ... Well, it's a very quiet place up here ... But when I went down, I'm a very good mixer like you know ... There were people I knew too, some of them in there permanently like, I was able to go up and talk to them, talk about old things way back years ago.*

*Well to me it's important ... to be active, and take part in everything that's going, and you know, not to just to lay back ... And I think it's great going to the centre because ... you get up and you'll have a shower and you'll dress yourself. And when you're at home you don't bother to, you know, dress yourself and that, and it also makes you keep the wardrobe in shape. If something's getting too old go and get yourself something new, you know that type of thing.*

Some participants with dementia also attended day centres for some days of the week. For their families, the day centre provided much-needed support and respite. The centres were, however, some distance from participants' homes and transport was not usually available. Families, therefore, had to bring and collect participants, which often took a significant amount of time.

Participants also found it difficult to know what they were entitled to in terms of services and support. They struggled to access the services they needed, found that information was inconsistent, and reported that when help was given it was often not prolonged and finished before participants felt they had made progress. They often found out information by chance from neighbours:

*If you work it out for yourself, like well and good. But there's lots of people now that I say to, 'why didn't you get this and why didn't you get that, and why didn't you go about such a thing?' and they said, 'nobody ever told us about it'. That now is something that really ... there should be more publicity.*

Some participants suggested that visits from a PHN would be helpful to them. Some participants were struggling to manage their medication, while others needed home modifications and advice about how they could best manage physical incapacity. While some participants reported that they had received support and advice from the PHN, many others reported that they never or rarely saw them:

*No the only time she came here was when I got a hand operation way back and she used to come then to dress it. Twice a week or that for two weeks.*

*She did come once and I've never seen her again. She asked me all sorts of questions and promised me all sorts but not one thing came.*

These participants suggested that they needed the support of the PHN to help them manage their various health problems.

Many participants reported that cooking meals was a problem for them. Sometimes meals were prepared by family members but this was not always possible. Some participants had food delivered by a meals-on-wheels service. While some participants reported that this service was good, others reported that they had had real problems. For some it was the quality of food, for others it was the lack of service, particularly at weekends, that caused problems as they had to try and make arrangements for days when the meals were not available:

*I get the meals-on-wheels on Monday, Wednesday and Friday.*

*I get meals-on-wheels three days a week. I'll get my dinner today now over there. She gives me dinner, that neighbour, but I pay her for it. I'll pay her for the other two days, I go over to her for it.*

A few participants had lunch cooked by a local restaurant. They reported the food to be very good but the problem was the delivery of the food. Participants had either to send a taxi for it or get it collected. Participants were concerned about the cost of this and suggested that this service should be part of the HSE remit:

*What the HSE could get going is to get someone to go to a restaurant, get the lunch. Even then you pay for it yourself but to deliver it is the problem to people who can't collect it, who are housebound and can't go. That's one big thing.*

It was evident from participants' accounts that some participants had great difficulty in accessing the services they needed. Sometimes information was lacking but often people did not know how to get the services they required. It was also evident that support for family carers was crucial.

## 7.4 Conclusion

This chapter focused on two domains of quality of life of people living with a disability: health and environment. It was evident from the findings in each section that disability impacted significantly on participants' quality of life. Poor physical and mental health made it more difficult for participants to undertake activities of daily living and increased the possibility of becoming more dependent with a disability. The environment mattered across a number of dimensions, particularly in respect of the physical environment and the care environment. Appropriate housing and good transport links were essential for independence and autonomy. The absence of appropriate and flexible care services also hindered participants attempts to remain independent. The interplay between components was evident and responses to disability were moderated by a number of factors, such as personal attributes, family support, community engagement and income. These issues are considered in their own right in the following chapter.








## Chapter Eight

Exploring Disability  
and Quality of Life  
Relationships:  
Connectedness,  
Sense of Self and  
Income



# Chapter Eight

## Exploring Disability and Quality of Life Relationships: Connectedness, Sense of Self and Income

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### 8.1 Introduction

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This chapter continues to explore disability and quality of life relationships. It focuses on the further three domains of quality of life identified by participants: connectedness, sense of self and income. They are, however, more complex than that because they are also factors that have the potential to mediate between disability and quality of life. They may determine a person's overall response to their disability and the impact of that disability on them.

### 8.2 Connectedness

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This section examines how relationships, activities and place are perceived to impact on the quality of life of older people with a disability. In particular, it focuses on the importance of companionship, family relationships, intergenerational contacts, activities, and general links between people with a disability and the community.

Connectedness to others was identified by most participants as key to quality of life. For participants, however, connectedness was not just about social relationships but about participation in activities both in the community and at home. Physical and intellectual disability, because it was often accompanied by increased dependence on others, impacted significantly on participants' relationships with others and the extent to which participants could engage in social activities. Results from the SF-36v2 survey revealed that the mean for social functioning was well below average, indicating that participants found this aspect of their lives challenging. The overall impact of disability on connectedness was, however, moderated by a number of factors: family and companionship; friends and companionship; isolation; and recreational activities.

### 8.2.1 Family and Companionship

Family was identified as central to many participants' quality of life. Family provided friendship, love and support, as well as practical help. As reported in Chapter Five, 40 per cent of participants lived with a spouse or partner and many others with a relative. Often this companion was the person with whom they socialised outside the home and was key to enabling the participant to maintain outside social links with friends and community. Other participants lived close to family and had close and frequent contact with their families:

*I see a lot of the family. I have eight children and grandchildren. They are all around but two are away, one in Dublin and one abroad.*

*I don't know what happens if you haven't family around and at the same time they can't give up their jobs. Now (names) came over here and stayed with me.*

*I have nine grandchildren who come in every day.*

Sometimes this contact was by phone rather than face-to-face contact:

*Oh, my daughter rings. We ring and talk to my son every Sunday night; he rings me or I ring him.*

For these participants having family was important; family provided support when it was needed which contributed significantly to the participants' quality of life. For some participants, family was the main focus of their lives:

*The only interest I have is my daughter and her husband ... They keep me company and sit beside the bed and talk. It's the only thing that keeps me any way sane to hear these things. I know it's all self-centred but that is the way it is.*

For some participants maintaining contact with family members was difficult. This was usually because family members had moved away from Ireland, but some participants cited their family's work commitments as a reason why they saw little of them.

Some participants assisted in looking after their grandchildren; they enjoyed doing this and, while it was sometimes tiring, they felt they were reciprocating for the support and help they were given:

*I have eight children and I've three daughters living in town there. And I might go to them in an afternoon or I go to them for lunch. And they might come out, maybe in the afternoon ... One of the girls, she has young children, so she goes to the swimming with one of the little kids and she leaves the other two with me for an hour or so.*

All participants who had children and grandchildren described their pleasure in watching their children and grandchildren grow.

Participants who had an intellectual disability often entered residential care following the death of a parent with whom they had lived. Some participants reported that their siblings had helped them make the decision to enter residential care and many maintained close relationship with their brothers and sisters.

Some participants, however, were not married or had no living close relatives. Some of these participants had cared for older parents during their early years while others had worked outside Ireland and returned following retirement:

*There's no one, I'm the ... last member of the family.*

*We had no family ... not having any family meant that you weren't mixing, I was working, he was working and then while both parents were alive we nearly went down to them every weekend. That we were gone out of town, so I really didn't know many people in town, you know that kind of way.*

For these participants it was often friends who provide companionship and support.

## 8.2.2 Friends and Companionship

For some participants, it was friends who provided the companionship in their lives. Participants described the importance of friends in their lives and the role friends played in helping them:

*I do, I have a good social life. I've lots and lots of friends. We go to (name) the odd time. We might just go for a walk and listen to my friends talking about their problems. Then I'm very involved in this walking. I meet a lot of friends. I do a lot of things, I am very active. I'm a fairly active person.*

*I have one or two friends who call in and very often they would say, 'oh, how is the briquette situation?'. And they would bring them in as far as the scullery and you know so ... I have great friends that way I must say ... and I have good neighbours.*

*I go out to my nieces, unless they're away somewhere. Ah, sure I've loads of friends around, they come in or bring something in.*

Sometimes this help was practical, such as shopping or housework, but at other times it was encouragement and support that helped to keep participants motivated. For people with an intellectual disability, living in residential care had brought them in close contact with others and this was often noted as a very positive aspect of living in residential care.

## 8.2.3 Isolation

Some participants lived in isolated communities and had done so all their lives. However, disability compounded the problems of living in an isolated area, as there were few neighbours or amenities. Engagement with others required planning, resources and motivation. Sometimes the nature of a person's disability affected their capacity to socialise with others; participants with a sensory disability often found crowds uncomfortable while participants with depression found they lacked the motivation to socialise:

*You feel, when you're depressed, you just feel very, in bad form, you know. And kind of isolated, you know. And you're hoping all the time to get better of it ... I think it's ... worse than any disease, depression, you know. It affects you that way, you know. But then I go visiting sometimes.*

Some participants found living alone very hard. In some instances, it was evident that these participants were still grieving the loss of a long-term partner:

*I'm living alone. I have nobody to talk to, you know, to go over your things ... and you're so lonely. I have to depend on the television all the time for company. That's the worst part of being old and living on your own.*

Some participants reported that ageing of family and friends had also led to a reduction in social contacts as it became more difficult for people to visit:

*The people that used to call are now the wrong age. They are unable to call now. They used to call in their younger years, they used to call regularly. It's limited now.*

Another participant who was living in long-stay care also reported that she was very lonely and lacked companionship:

*If you want anything, well, you speak to the nurse or the Sister in Charge. But it is, it's very lonely. There's nobody bothers with you. You just come down here and you do your own thing ... it's not like being at home. You're well cared for and everything, but it's not the same.*

It was evident that family and friends were important to the quality of life of older people with a disability. Disability, however, also impacted on a person's capacity to socialise. For some participants a lack of family support often resulted in feelings of loneliness and isolation.

#### 8.2.4 Recreational Activities

There was great diversity in the extent to which participants engaged in recreational or social activities. Some participants had a very active social life while others did very little. The extent of engagement depended on many factors but was undoubtedly influenced by the extent and nature of a person's disability. Some disability groups found participation in social activities more difficult than others. Participants with a sensory disability found it difficult to undertake group activities and many described how they had given up group social activities outside the home because they found group situations too stressful. Participants with depression also found group activities difficult but some participants enjoyed the companionship provided at day centres.

Participants engaged in a range of recreational activities including painting, reading, writing, bingo, dancing, singing, exercise classes, active retirement associations (ARAs), watching TV, cards, bridge, golf, scrabble and gardening. For some participants recreational activities were an opportunity to meet others and develop friendships:

*She'll take me out the second Wednesday of the month. Another friend she'll take me out the first Wednesday of the month ... Then (name), she'll take me out the third Wednesday of the month and then (name), she'll take me out the fourth Wednesday of the month.*

*Oh I have a lot of friends ... They can come to the house and visit me or I play a lot of bridge. I play three times a week.*

Many participants had joined ARAs and found the associated recreational activities enjoyable. These participants commented that they had developed new interests as a result of attending these groups and had made new friends:

*I do think the ARAs are great because we get talks, like I would know more now of what maybe I should have (entitlements).*

*It is a splendid thing really, I am in it now for seven years and we meet as I say weekly and we generally try and get a good presenter every week. I would give a talk myself or I would do some bit of writing or something for it ... and then they have all sorts of activities ...*

*The ARA ... go on holidays and things like that.*

Many participants with an intellectual disability reported that they enjoyed visits to the local public house and organised trips. Participants reported that staff in the residential facility organised these trips and accompanied participants.

Disability, however, made it more difficult to engage in recreational activities due to limited physical capacity, sensory problems, transportation issues and motivation. Some participants found they were unable to pursue the recreational activities they had enjoyed when they were younger. Some of them had developed new home-based interests, such as writing, watching TV or reading. Other participants attended day centres and found the recreational activities offered sociable and enjoyable:

*We get together and play bingo. We have dinner there and a cup of tea when we get in there. We have a chat with each other and it's lovely, passes the time ... breaks up the day.*



Three other factors impacted on participants' engagement with recreational activities: mental health problems; withdrawal because of disability; and the poor adaptation of public buildings to meet the needs of participants with a physical disability.

Some participants who were depressed found it very difficult to engage in recreational activities and avoided social situations:

*It has changed to what it used to be. It has changed with the tablets and all that. I used to go up (name). I used to be social with the boys and all that has stopped. I can't now, I don't associate, I used to go up there.*

*Oh it would be ... sitting down thinking back all the time, you know, so, it annoys me that way, you know. And then other times it clears away and I'm alright you know. But I feel, I feel sometimes very bad, you know. But when the depression lifts, I'm ok.*

Other participants with depression found that company helped them. One of them explained that being with people helped him to feel more positive; he particularly enjoyed talking to other men of his own age as most of the men his own age in his area had died. Participants with depression, however, could only attend psychiatric day centres if they were receiving treatment for depression; once they started to feel better they were discharged, leaving them with no social outlet.

Participants with a sensory disability also reported that they avoided group activities because they found them very difficult. Participants who had hearing problems found it extremely difficult and embarrassing when they could not follow conversations:

*I'd rather really not go where there's a big group because. you know, it's an absolute trial and ... big gatherings and going to meet people in pubs ... It's always so noisy that ... it isn't a pleasure anymore. It's a real trial because I find it so stressful to be constantly kind of ... instead of relaxing and chatting ... I'm on the alert all the time and people must think I'm crazy because I kind of watch them to see what they're saying.*

*Well, I find gatherings very difficult. I was invited to a wedding recently and I just made my excuses because it's torture going to these things, then someone died and I really could not go. I felt bad about that.*

Other participants with significant physical limitations found that they were no longer able to pursue activities that required good physical health or dexterity:

*I used to do embroidery. Oh, I was brilliant at it, but I can't do that now. I haven't the power in my hands.*

*I can't get out of the chair. I can't even sit in a chair elsewhere. I can't go for a walk or anything like that you know.*

Some participants in residential care reported that few recreational activities were provided for them. They suggested that the days were long and dull but that staff were busy and had little time to organise such activities.

It was evident that recreational activities were important to participants but for some participants engagement in activities were made more difficult by physical and mental disabilities. Lack of engagement, however, often compounded a person's mental health problem.

## 8.3 Sense of Self

Sense of self is key to a person's well-being; it relates to a person's identity and sense of who they are. It develops over time but is forged by life experiences; it can be shaped and reshaped by life-altering events. Personal identity is derived from an individual's unique attributes and is expressed in many different ways that are unique to that individual. Disability has the potential to threaten a person's sense of self because it may lead to role changes, dependency on others, isolation and lack of opportunity to express the things that are important to the individual. Personal attributes may also be questioned. Retaining a sense of self for many participants when faced with disability is a challenge and two components emerged in this regard: role identity and social identity.

### 8.3.1 Role Identity

Many participants had worked all their lives, and expressed pride and satisfaction in the work they had done. The types of work that participants had been engaged in varied; some participants managed their own businesses, others worked for private and public companies, while others worked in sheltered accommodation or in the home. Many participants reflected on their working life and were very proud of what they had achieved:

*I've always been very conscientious about my work you know and I take pride in what I'd done.*

*I worked until I was 66 ... I worked with my two hands, I was a goer. I suppose that kept me going.*

Many participants had worked outside the home until retirement, and giving up work was their decision upon reaching retirement age. While the change of role at retirement may not have been easy for all participants, many participants were able to make the transition smoothly, and use their skills and talents to undertake other activities and roles:

*I worked for 45 years and I was quite happy working but I found that retirement was a whole new life, do you know? That I could do all the things that I wanted to do, that I really wanted to do, because while you were working it was from meeting to meeting, get ready for one meeting and clearing up after it and so forth and that was fine. But I found when I retired, I would say now probably it was the happiest time of my life, of the lot. I am retired for the last 14 years and I am never busier ...*

Disability had forced some participants to retire as they could no longer manage the day-to-day demands of their work. These people often experienced great difficulty in adjusting; the loss of role was compounded by the physical loss suffered as a result of the onset of disability.:

*I ran a business ... as a limited company and I had to dismantle that. Because I could see how I couldn't deal with this and then have the ongoing business, contracts, designs, problems which couldn't be avoided. At that particular time I suppose lots of people were saying, 'you are making a good recovery'. And I was going along that, getting back into work was the thing and everything would be okay in no time. So I realised then that I can't contribute ...*

*It was twenty years ago, I had a business and I found I could not hear so well. It was not so bad at first but then it started going really downhill. I had to give the business up in the end. I was really sorry about that. It really affected me.*

For these participants the loss of role was accompanied by a loss of confidence and they described the struggle they had to regain this. One participant suggested that he felt cheated out of his normal retirement because he could no longer do the things in retirement that he had been looking forward to.

For many participants their role within the family was central to their identity. They took great satisfaction in the achievements of their children and grandchildren, and in the contribution they had made within the home:

*When my children were growing up, I was always there when they wanted me ... and then they are independent as well and they are doing pretty well.*

*I'm great, like you know. I'm a very, very lucky woman and I thank God for it every day. I'm a very lucky woman, with me children and everything.*

Some participants described how they took great pride in their homes and all they had done. Physical and intellectual disability, however, impacted fundamentally on what participants could and could not do. Many participants found that their role had changed from the person who managed the home to the person requiring help with some or all activities of daily living.

### 8.3.2 Social Identity

Social identity is derived from being part of groups, clubs and society, and the experiences that arise out of group participation. These experiences can influence how people view themselves and can help build a person's self-esteem. For some participants group participation was very important but for others it was not. Physical or intellectual disability impacted profoundly on many participants' capacity to participate in group activities. Many participants had been active members of social groups and some participants had lead roles within these groups. The extent to which participants participated in groups varied across and within disability groups.

Some participants found group activities were too difficult and had withdrawn from them:

*I think you can get a bit wrapped up in yourself. I had a good life, I had a busy life, I had a great golfing life, and I'm so glad, you know. It never occurred to me that I'd lose my sight. But then it's not lost totally. I can do things. Now I wouldn't want to be in any group, that wouldn't suit me.*

Other participants were actively involved in groups and some had key roles:

*We have a care group ... There is only four or five of us on the committee ... and I'm the Treasurer ...*

It is evident from participant accounts that disability impacted greatly on the extent to which they were able to retain a sense of self. A change in role and in social participation threatened participants' sense of self and they had to adjust to new circumstances.

Financial resources were identified as a quality of life domain by study participants:

*I think the independence both from health and financial are terribly important do you know ...*

Disability undoubtedly impacted on financial resources. Some participants with a longstanding disability reported that their working life had been curtailed because of the nature of their disability. Some participants who were employed prior to the onset of disability reported that they had had to leave their jobs as they were not able to meet the demands of the role.

There was great diversity in the financial circumstances of participants. Some had good financial resources and pensions, which enabled them to pay for what they required, afford holidays or engage in expensive pastimes, such as golf. Most importantly, for participants who needed care and therapeutic services, good financial resources enabled them to buy these services as required.

Some participants described their need for equipment, which they described as crucial to the quality of their lives but could not afford to buy. For example, participants with a visual impairment described the need for magnifying devices which enabled them to watch television or scanners to read mail, while participants with a hearing impairment identified the need for a good digital hearing aid. Some of this equipment was supplied by voluntary organisations and participants expressed their deep gratitude to these organisations for their support, help and advice. Participants, however, reported great difficulty in acquiring hearing aids as they found them very expensive. Three problems were identified in this regard: that people aged less than seventy years were not entitled to hearing aids under the Medical Card Scheme; that people who had lived in the UK and who have a half pension are not entitled to any contribution towards hearing aids; and the quality of the hearing aids supplied under the Medical Card Scheme is unsatisfactory. These issues resulted in many participants having to pay for these devices themselves and they found this a struggle:

*Well I don't know, I do have a medical card now, which I didn't have. I don't know whether I'd be entitled to a hearing aid on that ... I certainly couldn't afford to buy any now.*

*I have worked in London and I worked in Dublin and I have a half pension. And the people who have full PRSI now can get their hearing aid for €750 for each hearing aid, whereas they give the person with the half pension nothing.*

One participant reported that it was beyond his means to buy a hearing aid and he was waiting for 18 months until he qualified for a medical card to get the hearing aid he needed.

Income also impacted on participants' capacity to purchase services, such as home help, physiotherapy, cooked meals and nursing care. These could be bought by participants who could afford to do so but were beyond the means of many participants. Sometimes the cost of transport to services was a problem, even when the services were free. Participants reported that transport to services, such as chiropody, was not provided. One participant who lived in a rural area found the cost of a taxi greater than paying for the service at home:

*The services are nil full stop. There isn't even a health clinic in it. The chiropodist I ring him ... I pay for everything, even though I've a medical card. Now if I want a chiropodist I would have to get a taxi ... which I'm not able to do and I would have to get a taxi home and I've made it up that it's cheaper for him to come to my house and do my toes than for me to get a taxi in and a taxi out for €50, and that's about every nine or ten weeks, I'm paying for everything and I've all the services set up myself, but as regards the HSE, no ... I asked recently for an OT ... I was told that I would be on a year waiting list.*

Some participants reported that it was very hard to manage on a pension and there was little room for luxuries, such as going on holidays. They also worried about increasing oil prices and unanticipated bills:


*It's difficult, you know, to have enough to keep going ... You know, you're inclined to be scrimping and scraping ... The pension ... it's only recently it's gone up to €200 a week. What would you do with €200?*

*Hopefully we won't go hungry but we don't have money to go on holidays or, as I say, 'we're not hungry and we never were ones for going on holidays anyway'.*

It was evident that good financial resources enabled participants to control and manage their lives in ways that was not possible for those with few financial resources. The capacity to buy services for those with a physical disability may mean that those with good resources can and do access better care. Lack of transport to access public services increased hardship for those who were less well off.


## 8.5 Conclusion

This chapter focused on three domains of quality of life of people living with a disability; connectedness, sense of self and income. It was evident from the findings in each section that disability impacted significantly on participants' quality of life but also that connectedness, retention of a sense of self and income were factors which could accentuate or moderate the impact of disability on quality of life. The relationships between disability and quality of life were extremely complex, each influencing the other. Connectedness was identified as important to quality of life. Family, friends and community matter for people with a disability. People with a disability who are isolated and lonely report a lower quality of life. Retaining a sense of self was challenging as participants adjusted to new circumstances and roles, but maintaining one's identity and independence is very important for quality of life of people with a disability. Financial independence is also important for quality of life and those who struggle to meet the daily costs of living tend to have a lower quality of life than those who have an adequate income. Financial resources allow independence and choice for people with a disability, which is very important when public resources are inadequate and social care services are fragmented.



# Chapter Nine

## Conclusions





# Chapter Nine

## Conclusions

### 9.1 Introduction

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The interface between ageing and disability has profound implications for public policy. In spite of the provision of appropriate medical treatment for many of the diseases associated with old age, some older people remain incapacitated to some degree, and require varying levels of long-stay care and help, often over lengthy periods of time. In addition, an increasing number of adults with an early onset disability are surviving to older age; indeed people with an intellectual disability have had the most impressive increase in life expectancy in recent decades. It is timely, therefore, to consider the well-being and quality of life of all people as they grow older, including people with an early onset disability. That consideration must include the social dimensions of incapacity because in some cases dependency is created and sustained by weak social relationships and impoverished social conditions. It is not disability that creates dependency; rather it is the failure of social structures and processes to facilitate autonomy and independence for people with a disability. What follows is an effort to make sense of the narrative that has gone before in earlier chapters. That narrative is so strong and so personal that any attempt to generalise the material as a guide to policy is fraught with difficulty. People respond to ageing and disability in their own unique way. Nevertheless, there are some lessons from this study that can help to shape future policy, particularly at the interface between ageing and disability.

### 9.2 Living With a Disability

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The qualitative data in this study reveals that disability is lived and experienced in a very personal way by people. Disability may be strongly influenced by social conditions, social processes and social structures but it is experienced alone. People with arthritis feel pain; people with stroke suffer loss; people with depression are not able to cope. People report difficulties with walking, climbing stairs, seeing, hearing, communicating and coping. The

intensity with which these disabilities are experienced will influence the ability of older people to remain independent in older age. Loss and decline accompanies disability and impacts on the individual's sense of self and identity. People may be unable to recognise themselves or their former selves when confronted with debilitating levels of pain and discomfort. They find it hard to continue, particularly when confronted with multiple disabilities.

And yet, as this study reveals, people do maintain self-identity and preserve meaning in their lives. They find new levels of resolve and spirit within themselves that allow them to adapt to their impairment and adjust their expectations. Of course, all of our lives and actions are influenced by our mental outlook, attitudes and personality characteristics (Gabriel and Bowling, 2004). Therefore, a person's psychological resources have a significant impact on how disability is perceived and accommodated. Some people consider themselves independent, even when the nature of their disability might suggest otherwise to an impartial observer. This ability to find compensatory strategies has been labelled 'selective optimisation with compensation' (Baltes and Baltes, 1990). There is some evidence that the ability to implement coping strategies in response to disability is associated with higher levels of life satisfaction and improved quality of life (Freund and Baltes, 1998). This is certainly the case for many of the participants in this study who have adopted multiple adaptive strategies to deal with disability, some of which can only be interpreted through a life course perspective. People draw on lifetime experience to make the best of what they have now, rather than focusing on negative aspects of their lives. The attitude is one of adjusting, of accepting and of making the best of things in the face of adversity.

People also tended to compare themselves with others and make comparisons with those who (in their view) were worse off than themselves. For many people, though not all, there is always likely to be someone worse off, a reminder that life is not that unbearable yet. The rationalisation of disability through comparison with others in worse circumstances is an attempt to come to terms with the disability and reach some reconciliation with the constraints imposed through reference to others less fortunate than themselves. People's subjective valuation of quality of life can be significantly enhanced if they compare themselves to people worse off than themselves rather than to healthy individuals. For example, Heidrich and Ryff (1993) found that subjective valuations of quality of life in older women were high regardless of health state, because the reference point for these women was those with health problems rather than healthy individuals. Social comparison may also be informed by a pervasive view among older people that since impairment is a normal part of ageing they are not disabled in the same way as younger people with similar impairments, and consequently are better off. The ability to rationalise disability in this way may be particular to older people and may explain, to some degree, why disability is less politicised in older age.

It is not difficult, therefore, to see how people's subjective assessment of their quality of life is sometimes more positive than objective measures. The existence of this so-called 'satisfaction paradox' is well established in gerontological literature (Walker, 1980) and it is again evident in this study. What for many younger people without a disability would be an intolerable life is portrayed in a more positive light by older people experiencing the disability. People look for positives and search for new meanings; anything to make sense of their current predicament. Our research also suggests that it is easier to come to terms with disability if people are given time to adapt to their disability and that sudden-onset disability can have devastating consequences for people. There may well be an age effect behind the 'satisfaction paradox' reflecting reduced expectations of this and previous older generations. If that is the case it is unlikely to last indefinitely as expectations and demands expand rather than contract among future age cohorts. Future generations may find it more difficult to come to terms with disability, even though they may spend less time in disability than the current older generation.

### 9.3 Social Model of Disability

Social health for older people comprises a definition of individual well-being that is distinct from both physical and mental health. Social health is concerned with older people's ability to function as members of the community and includes measures of people's connectedness to others in terms of interpersonal interactions and social participation. The social model of disability distinguishes impairment from dependency. It refers to the possibility that dependency is created through social forces and social structures impacting on the ability of older people to take control of their own lives. Economic deprivation can also prevent people being able to participate meaningfully in economic and social life both absolutely and relative to prevailing social standards. The disability movement has been much more successful than the ageing sector in identifying and overcoming social obstacles to independence and in promoting social policies that respect the rights of younger people with a disability. In the ageing sector, older people are largely excluded from decision-making and are rarely consulted when it comes to service provision or placement decision-making. Their problems tend to be personalised and, very often, medicalised.

Participants in this study were conscious of the limitations imposed on their autonomy and independence by social forces and structures. Access to services was inequitable with participants dependent on the vagaries and vicissitudes of the health and social care system. Some people were dependent on voluntary organisations for critical equipment, such as sensory aids. Others paid for services, such as chiropody, rather than continue to

wait indefinitely for public provision. People also complained about physical barriers to their independence, such as poorly designed houses and public buildings. Housing was an area of artificially created dependency for participants. Many people's lives could be improved through adaptation of existing dwellings. The absence of public transport also created an artificial dependency for some older people. Some participants reported having to pay for taxis to enable them to access health and social care services. People could not visit family and friends because of poor public transport, particularly in rural areas. Many participants also spoke about the absence of information as a barrier to accessing services and to participation generally; many of them simply did not know what their entitlements were.

There are strong arguments, therefore, for the adoption of a broader definition of dependency that incorporates physical, mental, social and economic functioning. There is much the ageing sector can learn from the disability movement in the development of a social model. Yet, organisations for people with a disability are not working with older people to any great extent in Ireland, especially given the number of older people with a disability in the population. While there are difficulties in orchestrating this relationship, not least the potential resistance among older people to being labelled 'disabled' and the ongoing focus within the disability movement on younger people, increased integration is necessary. Much has already been achieved in the context of recent equality legislation and through the Disability Act 2005. But much more remains to be done to find some common ground between older people and people with a disability. The adoption of the framework articulated by the NCAOP in *An Age Friendly Society: A Position Statement* (NCAOP, 2005) is a necessary condition for greater integration but it is not a sufficient condition. It must be accompanied by greater disability awareness and equality work with groups representing older people and with agencies providing services to older people (Priestly and Rabiee, 2002). Bridges must also be built between the ageing and disability sectors at all points along the continuum of care, with much more emphasis on promoting disability equality among people of all ages.

## 9.4 Ageing and Disability

One of the important aspects of the research was the issue of whether there are particular age-related aspects to disability. One has to be cautious in this regard as we did not interview younger people with disability in the study, thereby making comparisons across generations difficult. Nevertheless, some points can be made on the impact of age on disability. The first point to note is the importance of both the personal and social for older people with disability. The NCAOP (2005) argued that older people in Ireland cannot be understood through a single version or theory of ageing and the importance

of this insight is confirmed in this study. Ageing cannot be characterised in terms of a deficit model that sees older age simply as a medical problem, or by a heroic model which suggests the denial of ageing and the continuation of a life of unlimited economic and social opportunities. Older people with a disability want to be independent, but they are conscious of the range of personal and social limitations and constraints imposed by their condition. Theirs is a post-medical, post-social world where biological, psychological and social conditions combine in a complex way to determine well-being and quality of life. Ageing with a disability cannot, therefore, be understood without a forensic and ethnographic examination of the person and the community in which they live.

One of the advantages of a person-centred approach is that it allows consideration of all of the factors that make life different for an older person with disability than for a younger person with disability. We have already suggested above that life-course experience may help older people rationalise their disability in more positive terms than younger people with disability. Conversely, age may also confer disadvantages. Ageism is a pervasive fact for older people with disability. It leads to prejudice and discrimination and ultimately a different experience between younger and older people with disability. Ageism exacerbates the potential for exclusion that disability presents. Older people tend to be placed last in the queue for health and social care services. They experience difficulty in achieving referrals to specialist rehabilitative services. There is evidence of rationing by age through delay rather than through overt denial of services. The data in this study suggests that one of the key features of being old with a disability in Ireland is waiting. People wait for services and appointments that sometimes never come.

Older people are also very conscious of the losses that accompany age. They lose family and friends. Their life is characterised by diminishing social networks, sometimes leading to isolation and loneliness. In some cases, people are dealing with the onset of disability at the same time as mourning the loss of a loved one. They can be fearful of a future without the support of family and friends. They are acutely aware of the various thresholds associated with their disability and are conscious of the impact that changes in their own condition or their social networks can have on their ability to cope and continue to live independently. Changes to the local neighbourhood can exacerbate the isolation sometimes felt by an older person with a disability. New people may move in, leading to new relationships having to be formed, which may be difficult for older people if disability reduces the opportunities for social contact. Communication may diminish and potential solidarity relationships may never develop. Social connectedness declines, as does quality of life.

Just as there is no agreement on dependency, there is no consensus on a definition of quality of life for older people. Recently, there has been an increasing awareness of the importance of a phenomenological approach to the study of quality of life whereby people are asked to make sense of their own lives in the context of the culture and value systems in which they live and in relation to their own lifetime objectives. In this approach, not only is quality of life multidimensional but it must also reflect the narrative of people's lives as interpreted by themselves and others. A wide range of studies have shown that people are consistent in the domains they identify as being important for the quality of their lives (Brown *et al.*, 2004). These domains include: health; psychological well-being; social relationships; emotional well-being; activities; home and neighbourhood; financial circumstances; and spirituality and religion. The domains identified by older people with disability in this study overlap significantly with the findings on quality of life from the general ageing literature.

The following is clear from our research:

- health, measured both subjectively and objectively, strongly influences the quality of life of people with a disability
- physical functioning matters for quality of life of people with a disability
- an accessible home and community environment has a positive influence on quality of life of people with a disability
- people strive to maintain a sense of self and identity in the face of disability
- psychological factors, such as personality, loneliness and feelings of powerlessness, influence quality of life of people with a disability
- social factors matter with social connectedness having a positive effect on quality of life of people with a disability
- economic deprivation damages the life chances and quality of life of people with a disability.

Each of these elements is amenable to intervention to a greater or lesser degree. The overall objective for policymakers should be the identification and elimination of factors outside the control of individuals that undermine capabilities and performance in all aspects of life. This would be a major step towards enhancing the quality of life of older people with a disability. The current emphasis on quality of care is not enough to ensure

that quality of life objectives are met. A person-centred, multifaceted, multidisciplinary, holistic approach is needed across the life course. The focus must be on nurturing and developing the internal resources of individuals over their lifetime within a supportive economic and social environment. People experience disability differently, depending on their psychological, economic and social resources which influence their role and function in society.

## 9.6 Policy Issues

The NDS has the potential to bring about improvements in the lives of older people with a disability. The commitment to need assessment in the Disability Act 2005 will address some of the information problems in the disability sector. A personal advocacy service will also benefit people with a disability. None of this will make any difference, however, if the Act is not implemented equally across all age groups. Even within the terms of the Disability Act, need assessment, individual service plans and redress will likely occur later for older people with a disability than for younger people. Similarly, the development of personal advocacy services envisaged in the Comhairle (Amendment) Bill 2004 may not reach the most isolated or vulnerable people. These people may simply be outside the health and social care system, through choice or through neglect. Effective monitoring systems should be put in place to ensure that vulnerable older people receive the same treatment as younger people in the implementation of the Act. Otherwise, the potential exists for 'statutory age discrimination' to occur.

Currently, there is no nominated body in place to oversee the implementation of the NDS. Whatever monitoring structures are established, they must be overseen by an agency with specific responsibility for older people. Furthermore, any implementation framework should be linked to the development of a comprehensive information system on older people with a disability. Without proper information systems that link need to resources, it will be difficult to monitor the implementation of the strategy. Even when need is acknowledged, resources may not exist to deal with the need that has been identified. There is a lack of clarity around entitlements for older people in relation to various services, which makes it difficult to allocate resources or to engage in priority-setting. In addition, current organisational structures and funding arrangements are sectorally based around distinct client populations that do not support complex integrative provision and funding models that cut across disability and ageing. There is no culture of integration or models of coordination within the social care system that might bring the various strands together. Action on entitlements and integrative structures are central to developing the interface between ageing and disability.

The role and importance of the person with a disability must be emphasised at all times in health and social care. Care should be person-centred and specific to the diverse needs of older people. This points to the need to develop comprehensive and localised systems of information on the needs of older people with a disability, including the development of local centralised information centres where older people with a disability can access information on entitlements and allowances. The development of the first national disability survey by the CSO is an important development in regard to developing the information base in Ireland but it is not enough. We need integrated information on older people with disability that covers every aspect of their lives, including data on family relationships and social networks. We need to understand more about attitudes to disability among older people and their perceptions of the social conditions that cause social dependency. Data on the economic circumstances of older people is also critical to understanding care patterns and care trajectories into the future. Information is necessary to both understand and create the conditions in which people can live independent but connected lives. Data on what people can and cannot do in a physical sense is only part of the story. The elimination of economic and social constraints to independence requires the development of much more complex datasets.

The older person should also be centrally involved in all decision-making with respect to what care is provided and how care is arranged. This approach will allow the social, emotional and psychological needs of people to be given equal weighting to the physical and health needs in the provision of services. This should be done through careful monitoring of the affects of different types of care and stimuli on older people with a disability in different settings. A central message of this research is that every disability story is different even if key quality of life domains are the same for most people. For people with dementia especially, the care process must always seek to protect and nurture the sense of self that the older person retains. The narrative of the lives of people with dementia must be highlighted through careful dialogue, interventions and therapies that seek to connect with the wholeness of the person's life and not just the dementia component.

Connecting with other people is also an important part of healthy living. So many participants in the survey felt cut off from other people. Their disability made it difficult to keep in contact with others, or people reduced contact with them because of their disability. The latter happened more often for people with dementia and depression than it did for the other groups. Connecting with other people is important irrespective of the type of disability. Connecting people with a disability with family, friends and communities should be a key objective of ageing policy.

People with a disability also wanted to reciprocate care and support from family and friends. They wanted to give something back. The social model of disability has been very



successful in empowering younger people with a disability to take control of their own lives and maintain equal relationships with family and friends. The disability movement has succeeded in removing disabling barriers and providing enabling supports so that people can continue to be part of their community. This approach facilitates higher levels of social contact for younger people with a disability and has resulted in improved quality of life for that group. The absence of a similar model for older people means that their potential for participation in social, civic and cultural life is weaker. Their dependency is exacerbated; their potential for reciprocity is reduced. This can only be changed through the development of new connectedness indicators at HSE level that could be used to track the impact of policy on maintaining and developing the social world of people with a disability.

Preventing dependency should be a key goal of public policy. The objective of dependency prevention is to give every individual the greatest possible opportunity of remaining free of disability in older age or, if they do acquire a disability, of being as independent as possible. Healthy ageing and dependency prevention requires an investment at an early age in healthy living. For many people, disability is not inevitable, and investment in health promotion and primary care could significantly reduce the numbers of people suffering from stroke and depression in future years. Any reduction in disability in the future will have significant implications for social spending on health and social care, thereby potentially justifying increases in expenditure in these areas now.

The prevention of physical dependency and mental incapacity can be encouraged at primary, secondary and tertiary levels. Primary prevention lies first and foremost in the diagnosis and treatment of causal illnesses through vaccination, screening programmes and the identification of potential risk factors, particularly in the home. Investment in suitable housing for dependent older people and the adoption of appropriate assistive technologies and smart homes are examples of two practical primary preventive measures for people living at home. The concept of 'livable communities' has been proposed by the NCAOP and the NDA as a way of integrating the needs of older people and people with a disability in the development of a society for all ages. This incorporates the integration of older people with a disability into community life through accessible and affordable housing.

Community care programmes can also make an important contribution to the prevention of dependency. The key element in community care provision is that services are comprehensive and flexible, with provision determined by service users rather than by providers. Unfortunately, the lesson from this study is that key services do not exist, particularly in respect of community rehabilitation services. People often have to avail of private sector services, which leads to further inequities. Even where services exist they are poorly coordinated and weakly integrated. There is almost no cross-over between

disability services and age-related services. The weakness of community care for older people is generally not challenged in policy circles, but it still does not lessen the impact of the absence of such community-based services on the quality of life of people with a disability. For all the recent rhetoric about home care packages, it is hard to escape the conclusion that the community care system has failed older people with a disability.

Secondary prevention entails identifying the onset of new illnesses or the worsening of an existing illness that has become chronic. Proper assessment and rehabilitation services are crucial for successful secondary prevention. People spoke highly of hospital-based rehabilitation services, but also complained about the problems that occur when these services are not available or when they are discontinued. For stroke patients, rehabilitation is usually between six and twelve weeks. It can end abruptly leaving older people confused and isolated.

Tertiary prevention requires an effective geriatric medicine service, based on a multi-disciplinary model, to take stock of all risk factors through appropriate evaluations and therapeutic measurement of older people with a disability living at home and in residential care. Palliative care services are an important element of tertiary care services but are rarely available in acute hospitals or in long-stay facilities.

Overcoming ageist attitudes within society is the first step in preventing social dependency in old age. Public policy must continue to challenge ageism and ageist behaviour through effective legislation, regulation and public information campaigns on ageing with a disability. Groups advocating on behalf of older people for equality and human rights have much to offer here, but they need to connect more with their counterparts in the disability sector who have been more successful in challenging discriminatory practices and policies. Ironically, those with the most severe ageist attitudes can sometimes be older people themselves, some of whom have low expectations in regard to what society should do for them. Training and education programmes need to target all age groups if progress is to be made in combating ageism and exclusion.

## 9.7 Final Thoughts

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This report examined the issue of ageing and disability, with specific focus on quality of life. The numbers of older people with disability will increase in the future in line with the ageing of the population. So too will the number of people entering old age with a disability. It is important that all older people with a disability, whatever its source, receive adequate care and support services as they are a particularly vulnerable group and at risk of

discrimination. Disability tends to have a negative influence on quality of life. Sometimes, however, the affect of disability on quality of life can be mediated by forces outside of the disability. The psychological nature of the individual may enable them to cope well with their disability. Environmental and social support may lessen the impact of any disability on quality of life. So, while disability carries the potential to reduce quality of life, mitigating factors may serve to reduce, if not eliminate, the negative effects of a disability.

Older people are more likely to experience social isolation due to changes in their social networks over time. Policy also needs to encourage and support social interaction and connectedness. Infrastructure needs to be put in place that allows older people with disability to stay in touch with their communities. This infrastructure includes: housing modifications and design, transport and the adaptation of new technologies and supports which facilitate 'intimacy at a distance'. Family support remains a strong positive influence in older people's lives. Family support promotes emotional well-being and helps the individual cope with their disability. Unfortunately, families can often live far away from the person with disability, making it imperative that assistive technology is used to facilitate ongoing communication.

Public policy has a vital role to play in improving the quality of life of older people. Health and social services need to work together to ensure that older people with a disability get the services they need. Practical interventions, such as hearing aids, reading glasses, rehabilitation, barrier-free housing and transport can yield huge benefits for older people with a disability. These services are, for the most part, not expensive, which makes their absence all the more incomprehensible. These services are also much more available for younger people with a disability, suggesting considerable age discrimination. Advocacy services are much weaker for older people with a disability than for younger people with a disability which may explain some of the inequalities in provision. A more person-centred focus would help to integrate ageing and disability services. This would facilitate a single shared assessment of health and social care needs of older people linked to a system of care and case management. There are numerous other potential opportunities for cooperation and integration between the ageing and disability sectors, particularly in the areas of housing and transport. In summary, there are huge benefits to be gained from the integration of public policy for ageing and disability services in this country.



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# Appendices





# Appendix One

## Interview Schedule

### Interview Schedule for People with Dementia

My name is ... . I am from the Department of Nursing and Midwifery Studies, NUI, Galway. We are doing a study examining quality of life issues (or what makes life good) for older people. This study is funded by the National Council on Ageing and Older People. I am also interested in what you think is important for your quality of life and for the quality of life of older people in general.

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<b>Health</b> <i>Focus:</i> Physical and mental health, perceived changes following onset of illness/disability.	<p>How would you describe your health?</p> <p>How would you describe your memory? (If the person identifies memory or remembering as a problem explore how this impacts on their day-to-day life.)</p> <p>Could you describe for me a typical day now?</p> <p>How has life changed for you ... ? (Use the person's wording, pick up issues from their answers to the first two questions.)</p>
<b>Self-esteem</b> <i>Focus:</i> Psychological/emotional well-being.	<p>How do you feel about yourself as you've gotten older?</p> <p>Are you able to do the things that make you happy or that you enjoy?</p>

<p><b>Environment – own home</b>  <i>Focus:</i> Physical environment of the home, impact of the physical structure of the house on ability to manage/self-care</p>	<p>What is it like for you living here?</p> <p>Is there anything you'd change?</p> <p>Is it easy for you get about the house/your home? Can you get upstairs for example? (Explore further if necessary, for example accessibility of bathroom/shower, etc.)</p> <p>Has your house/home been adapted to make it easier to manage/get around? If yes, how? If no, do you feel it needs to be adapted? (e.g. plugs at a higher level, access to bathroom, etc.)</p> <p>Some people tell us that they find it hard to maintain their house (i.e. general up-keep, the garden, the housework). Is that a problem for you?</p>
<p><b>Environment – community</b>  <i>Focus:</i> Environment in the neighbourhood, range and accessibility of facilities.</p>	<p>Is this a good place to live? Are the shops nearby? (Explore local amenities, e.g. parks, to get a sense of what is important to the person and whether they are accessing them.)</p> <p>Is it easy for you to get there? (i.e. outside the house, for example, to go to the shops, collect your pension, meet your neighbours). If no, how do you manage?</p>
<p><b>Feeling secure</b>  <i>Focus:</i> Perceived safety and security.</p>	<p>Is this a safe place to live?</p> <p>Who do you call or contact if you need help?</p> <p>Can they get to you quickly?</p>

<p><b>Self-reliance</b>  <i>Focus:</i> Ability to self-care, range and availability of services and other supports.</p>	<p>Are you able to look after yourself? i.e. dressing, washing, cooking. If no, how do you manage?</p> <p>If you need help, who helps? What helps? (e.g. aids/appliances).</p> <p>Is that help available to you seven days a week?</p> <p>Is there help that you need that you are not able to get at the moment?</p> <p>Is there any other help that you would like? (e.g. home help, aids/appliances etc.)</p>
<p><b>Independence/dependences</b>  <i>Focus:</i> Personal definition of independence and dependence.</p>	<p>What does being independent mean to you?</p> <p>Has your health/diagnosis/illness (use person's own wording) affected your independence? If yes, in what ways?</p> <p>What would help you to be more independent?</p> <p>What does 'being dependent' mean to you?</p> <p>Would you describe yourself as being dependent now? If yes, in what ways?</p>
<p><b>Self-determination/purpose in life</b>  <i>Focus:</i> Control and autonomy.</p>	<p>Can you plan and make decisions about your day? (for example, Home Help or PHN or Meals-on-Wheels arrive at a time convenient to the person).</p> <p>Are you still able to do the things that are important to you?</p>
<p><b>Activities/continuity of old self</b>  <i>Focus:</i> Opportunities to participate in social activities and recreation.</p>	<p>What kinds of activities are there available in this area/community for people to take part in? Do you get involved/attend?</p> <p>Are you still able to take part in the things that you enjoy? (for example hobbies, go to the pub, attend football matches).</p>

<b>Connectedness</b> <i>Focus: Relationships with friends and families.</i>	<p>Do you keep in contact with your family and friends?</p> <p>How do you keep in touch? (Visit, telephone, e-mail).</p> <p>Do you have many visitors? (Ask for examples). Do you see them often?</p> <p>Do you have visits from anyone else? (Neighbours, voluntary groups).</p>
<b>Spirituality</b>	<p>Is religion important to you? If yes, is it more important as you grow older? In what ways?</p> <p>Is attending Mass/service important to you? If yes, are you able to attend?</p>
<b>General</b>	<p>Is there anything else that we haven't asked you that you think is important for your quality of life?</p>

## Interview Schedule – People with an Intellectual Disability

My name is ... . I am from the Department of Nursing and Midwifery Studies, NUI, Galway. We are doing a study examining quality of life issues for older people. This study is funded by the National Council on Ageing and Older People. I'm interested in what you think is important for a good life.

<b>Health</b> <i>Focus: Physical and mental health, perceived changes following onset of illness/disability.</i>	<p>What do you do all day?</p> <p>Is there a difference between what you do now and what you did ten years ago?</p> <p>How would you describe your health? Are you very healthy or have you some problems? If yes, tell me more?</p>
<b>Self-esteem</b> <i>Focus: Psychological/emotional well-being.</i>	<p>How do you feel about yourself?</p> <p>Are you able to do the things that make you happy or that you enjoy?</p>

<p><b>Environment – own home</b>  <i>Focus:</i> Physical environment of the home, impact of the physical structure of the house on ability to manage/self-care</p>	<p>Where are you living?</p> <p>What is it like for you living here/there? Did you choose to live here/there?</p> <p>Is there anything you'd change?</p> <p>Is it easy for you get about the house/your home? Can you get upstairs, for example?</p> <p>Is your bathroom easy to get to/use? Are you able to take a bath/have a shower, for example? Are you able to take a bath/have a shower as often as you'd like?</p> <p>Has your house/home been adapted? If yes, how? If no, do you feel it needs to be adapted? (E.g. plugs at a higher level, access to bathroom, etc.)</p> <p>Some people tell us that they find it hard to maintain their house? (I.e. general up-keep, the garden, the housework). Is that a problem for you?</p>
<p><b>Environment – community</b>  <i>Focus:</i> Environment in the neighbourhood, range and accessibility of facilities.</p>	<p>Is this a good place to live? Are the shops nearby? (Explore local amenities, e.g. parks, to get a sense of what is important to the person and whether they are accessing them.)</p> <p>Is it easy for you to get there? (I.e. outside the home, for example, go to the shops, collect your pension, meet your neighbours). If no, how do you manage?</p>
<p><b>Feeling secure</b>  <i>Focus:</i> Perceived safety and security.</p>	<p>Is this a safe place to live?</p> <p>Who do you call or contact if you need help? How do you call for help?</p> <p>Can they get to you quickly?</p>

<p><b>Self-reliance</b>  <i>Focus:</i> Ability to self-care, range and availability of services and other supports.</p>	<p>Are you able to look after yourself? I.e. dressing, washing, cooking. If no, how do you manage?</p> <p>If you need help, who helps? What helps? (e.g. aids/appliances).</p> <p>Is that help available to you seven days a week?</p> <p>Is there anything that would make your life easier?</p>
<p><b>Self-determination/ purpose in life</b>  <i>Focus:</i> Control and autonomy.</p>	<p>How do you decide what you do each day?</p> <p>Can you plan and make decisions about your day?</p> <p>Are you still able to do the things that are important to you?</p>
<p><b>Activities/continuity of old self</b>  <i>Focus:</i> Opportunities to participate in social activities and recreation.</p>	<p>What kinds of activities are available for people to take part in? Do you get involved/attend?</p> <p>Do you still do the things that you enjoy? (For example hobbies, go to the pub, attend football matches).</p>
<p><b>Connectedness</b>  <i>Focus:</i> Relationships with friends and families.</p>	<p>Have you parents or brothers or sisters or friends?</p> <p>Do you see your family and friends?</p> <p>Do you see them often?</p> <p>Do you have visits from anyone else? (Neighbours, voluntary groups).</p>
<p><b>Spirituality</b></p>	<p>Is religion important to you? If yes, is it more important as you grow older? In what ways?</p> <p>Is attending Mass/service important to you? If yes, are you able to attend?</p>
<p><b>General</b></p>	<p>Is there anything else that I haven't asked that you think is important for a good life ? (i.e. quality of life).</p>

## Interview Schedule – Mental Health Problem

My name is ... . I am from the Department of Nursing and Midwifery Studies, NUI, Galway. We are doing a study examining quality of life issues for older people with a disability. This study is funded by the National Council on Ageing and Older People. I'm interested in your experiences of living with .... (disability). I am also interested in what you think is important for your quality of life and for the quality of life of older people in general.

<p><b>Health</b> <i>Focus:</i> Physical and mental health, perceived changes following onset of illness/disability.</p>	<p>When did you find out you had ...?</p> <p>How does your ... (diagnosis/illness) impact on your day-to-day life?</p> <p>How would you describe your health?</p> <p>Could you describe for me a typical day now?</p> <p>How has your life changed since your ... (diagnosis/illness)?</p>
<p><b>Self-esteem</b> <i>Focus:</i> Psychological/emotional well-being.</p>	<p>How do you feel about yourself since ... (diagnosis/illness)?</p>
<p><b>Environment – own home</b> <i>Focus:</i> Physical environment of the home, impact of the physical structure of the house on ability to manage/self-care</p>	<p>What is it like for you living here?</p> <p>To what extent can you get about the house/your home? Can you get upstairs, for example? (Explore further if necessary, for example accessibility of bathroom/shower, etc.)</p> <p>Has your house/home been adapted? If yes, how? If no, do you feel it needs to be adapted? (E.g. plugs at a higher level, access to bathroom, etc.)</p> <p>Some people tell us that they find it hard to maintain their house? (I.e. general up-keep, the garden, the housework). Is that a problem for you?</p>

<p><b>Environment – community</b>  <i>Focus:</i> Environment in the neighbourhood, range and accessibility of facilities.</p>	<p>Is this a good place to live? Are the shops nearby? (Explore local amenities, e.g. parks, to get a sense of what is important to the person and whether they are accessing them.)</p> <p>Is it easy for you to get around? (I.e. outside the house, for example, go to the shops, collect your pension, meet your neighbours). If no, how do you manage?</p>
<p><b>Feeling secure</b>  <i>Focus:</i> Perceived safety and security.</p>	<p>Is this a safe place to live?</p> <p>Who do you call or contact if you need help?</p> <p>Can they get to you quickly?</p>
<p><b>Self-reliance</b>  <i>Focus:</i> Ability to self-care, range and availability of services and other supports.</p>	<p>Are you able to look after yourself? I.e. dressing, washing, cooking. If no, how do you manage?</p> <p>If you need help, who helps? What helps? (E.g. aids/appliances).</p> <p>Is that help available to you seven days a week?</p> <p>Is there help that you need that you are not able to get at the moment?</p> <p>Is there any other help that you would like? (E.g. home help, aids/appliances etc.)</p>
<p><b>Independence/dependences</b>  <i>Focus:</i> Personal definition of independence and dependence.</p>	<p>What does being independent mean to you?</p> <p>Has your (diagnosis/illness) affected your independence? If yes, in what ways?</p> <p>What would help you to be more independent?</p> <p>What does 'being dependent' mean to you?</p> <p>Would you describe yourself as being dependent now? If yes, in what ways?</p>



<p><b>Self-determination/ purpose in life</b> <i>Focus:</i> Control and autonomy.</p>	<p>Can you plan your day as you'd like? (For example, Home Help or PHN or Meals-on-Wheels arrive at a time convenient to the person).</p> <p>Are you still able to do the things that are important to you?</p>
<p><b>Activities/continuity of old self</b> <i>Focus:</i> Opportunities to participate in social activities and recreation.</p>	<p>What kinds of activities are there available in this area/ community for people to take part in? Do you get involved/ attend?</p> <p>Are you still able to take part in the things that you enjoy? (For example hobbies, go to the pub, attend football matches.)</p>
<p><b>Connectedness</b> <i>Focus:</i> Relationships with friends and families.</p>	<p>Do you keep in contact with your family and friends?</p> <p>How do you keep in touch? (Visit, telephone, e-mail.)</p> <p>Do you have many visitors? (Ask for examples). Do you see them often?</p> <p>Do you have visits from anyone else? (Neighbours, voluntary groups.)</p>
<p><b>Spirituality</b></p>	<p>Is religion important to you? If yes, is it more important as you grow older? In what ways?</p> <p>Is attending Mass/service important to you? If yes, are you able to attend?</p>
<p><b>General</b></p>	<p>Is there anything else that we haven't asked that you think is important for your quality of life?</p>

## Interview Schedule – Older People Without a Diagnosed Illness/Disability

My name is ... I am from the Department of Nursing and Midwifery Studies, NUI, Galway. We are doing a study examining quality of life issues for older people with a disability. This study is funded by the National Council on Ageing and Older People. To help us to better understand the issues for people with a disability we wanted to talk to some people without a disability to gain their perspectives on what is important for them. I am also interested in what you think is important for your quality of life and for the quality of life of older people in general.

<p><b>Health</b> <i>Focus:</i> Physical and mental health, perceived changes following onset of illness/disability.</p>	<p>How would you describe your health?</p> <p>Could you describe for me a typical day? (Explore a typical week if appropriate.)</p>
<p><b>Self-esteem</b> <i>Focus:</i> Psychological/emotional well-being.</p>	<p>How do you feel about yourself as you've gotten older?</p>
<p><b>Environment – own home</b> <i>Focus:</i> Physical environment of the home, impact of the physical structure of the house on ability to manage/self-care</p>	<p>To what extent can you get about the house/your home? Can you get upstairs, for example? (Explore further if necessary, for example accessibility of bathroom/shower, etc.)</p> <p>Has your house/home been adapted? If yes, how? If no, do you feel it needs to be adapted? (E.g. plugs at a higher level, access to bathroom, etc.)</p> <p>Some people tell us that they find it hard to maintain their house? (I.e. general up-keep, the garden, the housework.) Is that a problem for you?</p>
<p><b>Environment – community</b> <i>Focus:</i> Environment in the neighbourhood, range and accessibility of facilities.</p>	<p>Is this a good place to live? Are the shops nearby? (Explore local amenities, e.g. parks, to get a sense of what is important to the person and whether they are accessing them.)</p> <p>Is it easy for you to get there? (I.e. outside the home, for example, go to the shops, collect your pension, meet your neighbours.) If no, how do you manage?</p>

<p><b>Feeling secure</b> <i>Focus:</i> Perceived safety and security.</p>	<p>Is this a safe place to live?</p> <p>Who do you call or contact if you need help? How do you call for help?</p> <p>Can they get to you quickly?</p>
<p><b>Self-reliance</b> <i>Focus:</i> Ability to self-care, range and availability of services and other supports.</p>	<p>Are you able to look after yourself? I.e. dressing, washing, cooking. If no, how do you manage?</p> <p>If you need help, who helps? What helps? (E.g. aids/appliances)</p> <p>Is that help available to you seven days a week?</p> <p>Is there help that you need that you are not able to get at the moment?</p> <p>Is there any other help that you would like? (E.g. home help, aids/appliances etc.)</p>
<p><b>Independence/dependences</b> <i>Focus:</i> Personal definition of independence and dependence.</p>	<p>What does being independent mean to you?</p> <p>How would you rate your independence?</p> <p>What does 'being dependent' mean to you?</p> <p>Would you describe yourself as being dependent now? If yes, in what ways?</p>
<p><b>Self-determination/purpose in life</b> <i>Focus:</i> Control and autonomy.</p>	<p>Can you plan your day as you'd like? (For example, Home Help or PHN or Meals-on-Wheels arrive at a time convenient to the person.)</p> <p>Are you still able to do the things that are important to you?</p>
<p><b>Activities/continuity of old self</b> <i>Focus:</i> Opportunities to participate in social activities and recreation.</p>	<p>What kinds of activities are there available in this area/ community for people to take part in? Do you get involved/ attend?</p> <p>Are you able to take part in the things that you enjoy? (For example, hobbies, go to the pub, attend football matches.)</p>

<b>Connectedness</b> <i>Focus: Relationships with friends and families.</i>	<p>Do you keep in contact with your family and friends?</p> <p>How do you keep in touch? (Visit, telephone, e-mail.)</p> <p>Do you have many visitors? (Ask for examples). Do you see them often?</p> <p>Do you have visits from anyone else? (Neighbours, voluntary groups.)</p>
<b>Spirituality</b>	<p>Is religion important to you? If yes, is it more important as you grow older? In what ways?</p> <p>Is attending Mass/service important to you? If yes, are you able to attend?</p>
<b>General</b>	<p>Is there anything else that we haven't asked you that you think is important for your quality of life?</p>

## Interview Schedule – Physical Disability

My name is ... I am from the Department of Nursing and Midwifery Studies, NUI, Galway. We are doing a study examining quality of life issues for older people with a disability. This study is funded by the National Council on Ageing and Older People. I'm interested in your experiences of living with a... (disability). I am also interested in what you think is important for your quality of life and for the quality of life of older people in general.

<b>Health</b> <i>Focus: Physical and mental health, perceived changes following onset of illness/disability.</i>	<p>When did you have your ....? or When did you find out you had ...? or How long have you been ...?</p> <p>How does your (illness/disability) impact on your day-to-day life?</p> <p>How would you describe your health?</p> <p>Could you describe for me a typical day now?</p> <p>How has your life changed since your ... (illness/ disability)?</p>
<b>Self-esteem</b> <i>Focus: Psychological/ emotional well-being.</i>	<p>How do you feel about yourself since ... (illness/disability)?</p>

<p><b>Environment – own home</b>  <i>Focus:</i> Physical environment of the home, impact of the physical structure of the house on ability to manage/self-care</p>	<p>To what extent can you get about the house/your home?          Can you get upstairs, for example?</p> <p>Is your bathroom easy to get to/use? Are you able to take a bath/have a shower, for example? Are you able to take a bath/have a shower as often as you'd like?</p> <p>Has your house/home been adapted? If yes, how? If no, do you feel it needs to be adapted? (E.g. plugs at a higher level, access to bathroom etc.)</p> <p>Some people tell us that they find it hard to maintain their house? (I.e. general up-keep, the garden, the housework.)          Is that a problem for you?</p>
<p><b>Environment – community</b>  <i>Focus:</i> Environment in the neighbourhood, range and accessibility of facilities.</p>	<p>Is this a good place to live? Are the shops nearby? (Explore local amenities, e.g. parks, to get a sense of what is important to the person and whether they are accessing them.)</p> <p>Is it easy for you to get there? (I.e. outside the home, for example, go to the shops, collect your pension, meet your neighbours.) If no, how do you manage?</p>
<p><b>Feeling secure</b>  <i>Focus:</i> Perceived safety and security.</p>	<p>Is this a safe place to live?</p> <p>Who do you call or contact if you need help? How do you call for help?</p> <p>Can they get to you quickly?</p>
<p><b>Self-reliance</b>  <i>Focus:</i> Ability to self-care, range and availability of services and other supports.</p>	<p>Are you able to look after yourself? I.e. dressing, washing, cooking. If no, how do you manage?</p> <p>If you need help, who helps? What helps? (E.g. aids/appliances.)</p> <p>Is that help available to you seven days a week?</p> <p>Is there help that you need that you are not able to get at the moment?</p> <p>Is there any other help that you would like? (E.g. home help, aids/appliances etc.)</p>

<p><b>Independence/dependences</b>  <i>Focus:</i> Personal definition of independence and dependence.</p>	<p>What does being independent mean to you?</p> <p>Has your (illness/disability) affected your independence? If yes, in what ways?</p> <p>What would help you to be more independent?</p> <p>What does 'being dependent' mean to you?</p> <p>Would you describe yourself as being dependent now? If yes, in what ways?</p>
<p><b>Self-determination/purpose in life</b>  <i>Focus:</i> Control and autonomy.</p>	<p>Can you plan your day as you'd like? (For example, Home Help or PHN or Meals-on-Wheels arrive at a time convenient to the person.)</p> <p>Are you still able to do the things that are important to you?</p>
<p><b>Activities/continuity of old self</b>  <i>Focus:</i> Opportunities to participate in social activities and recreation.</p>	<p>What kinds of activities are there available in this area/ community for people to take part in? Do you get involved/ attend?</p> <p>Are you still able to take part in the things that you enjoy? (For example, hobbies, go to the pub, attend football matches).</p>
<p><b>Connectedness</b>  <i>Focus:</i> Relationships with friends and families.</p>	<p>Do you keep in contact with your family and friends?</p> <p>How do you keep in touch? (Visit, telephone, e-mail.)</p> <p>Do you have many visitors? (Ask for examples). Do you see them often?</p> <p>Do you have visits from anyone else? (Neighbours, voluntary groups.)</p>
<p><b>Spirituality</b></p>	<p>Is religion important to you? If yes, is it more important as you grow older? In what ways?</p> <p>Is attending Mass/service important to you? If yes, are you able to attend?</p>
<p><b>General</b></p>	<p>Is there anything else that we haven't asked that you think is important for your quality of life?</p>

# Appendix Two

## Demographic Survey

Code:

### 1 Region:

Border  Midlands  West   
Dublin  Mid-East  Mid-West   
South-East  South-West

### 2 Place/Residence:

Own Home  Residential Care  Group Home

### 3 Attendance at Centres:

Day Centre  Respite Days  Voluntary Group

### 4 Gender/Age:

Male  Female

Age \_\_\_\_\_ Years

### 5 Marital Status:

Single  Married

Widowed  Divorced/Separated

## 6 Highest Level of Education Attained:

- |                               |                          |                      |                          |
|-------------------------------|--------------------------|----------------------|--------------------------|
| No Formal/Primary Education   | <input type="checkbox"/> | Lower Secondary      | <input type="checkbox"/> |
| Post Leaving Cert             | <input type="checkbox"/> | Upper Secondary      | <input type="checkbox"/> |
| Third Level – Degree or above | <input type="checkbox"/> | Other                | <input type="checkbox"/> |
| Third Level – Non Degree      | <input type="checkbox"/> | Please Specify _____ |                          |

## 7 Please check the occupation group of current/previous employment or that of your spouse or partner

- |                                 |                          |                                      |                          |
|---------------------------------|--------------------------|--------------------------------------|--------------------------|
| Sales                           | <input type="checkbox"/> | Managers and Administrators          | <input type="checkbox"/> |
| Clerical and Secretarial        | <input type="checkbox"/> | Plant and Machine Operatives         | <input type="checkbox"/> |
| Personal and Protective Service | <input type="checkbox"/> | Craft and Related                    | <input type="checkbox"/> |
| Professional                    | <input type="checkbox"/> | Associate Professional and Technical | <input type="checkbox"/> |
| Other                           |                          |                                      |                          |
| Please Specify _____            |                          |                                      |                          |

## 8 Disability

Please check whether respondent suffers from a longstanding health problem or disability (NB longstanding refers to 6 months or more)

Yes  No

National Disability Authority (NDA) (2005a) **Person-Centred Planning in the Provision of Services for People with a Disability in Ireland**, Dublin: NDA.

National Disability Authority (NDA) (2005b) **Submission by the NDA to the NESF on Care for Older People**, Dublin: NDA.



# Appendix Three

## Rosenberg Self-Esteem Scale

Code

Below is a list of statements dealing with your general feelings about yourself. Please consider the statement and circle the response that you think best matches your view.

	Strongly Agree	Agree	Disagree	Strongly Disagree
On the whole, I am satisfied with myself.				
At times, I think I am no good at all.				
I feel that I have a number of good qualities.				
I am able to do things as well as most other people.				
I feel I do not have much to be proud of.				
I certainly feel useless at times.				
I feel that I'm a person of worth, at least on an equal plane with others.				
I wish I could have more respect for myself.				
All in all, I am inclined to feel that I am a failure.				
I take a positive attitude toward myself.				

Thank you for completing these questions!

# Appendix Four

## SF-36v2

# Your Health and Well-Being

Code

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. Thank you for completing this survey!<sup>6</sup>

For each of the following questions, please tick the one box that best describes your answer.

1. In general, would you say your health is:

Excellent

Very good

Good

Fair

Poor

2. Compared to one year ago, how would you rate your health in general now?

Much better  
now than one  
year ago

Somewhat  
better  
now than one  
year ago

About the  
same as  
one year ago

Somewhat  
worse  
now than one  
year ago

Much worse  
now than one  
year ago

<sup>6</sup> SF-36v2™ Health Survey © 1992-2002 by Health Assessment Lab, Medical Outcomes Trust and QualityMetric Incorporated. All rights reserved. SF-36® is a registered trademark of Medical Outcomes Trust.

3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
<b>Vigorous activities</b> , such as running, lifting heavy objects, participating in strenuous sports	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Moderate activities</b> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lifting or carrying groceries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Climbing <b>several</b> flights of stairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Climbing <b>one</b> flight of stairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bending, kneeling, or stooping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Walking <b>more than a mile</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Walking <b>several hundred yards</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Walking <b>one hundred yards</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bathing or dressing yourself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. During the **past 4 weeks**, how much of the time have you had any of the following problems with your work or other regular daily activities **as a result of your physical health?**

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Cut down on the <b>amount of time</b> you spent on work or other activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Accomplished less</b> than you would like	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Were limited in the kind of work or other activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Had <b>difficulty</b> performing the the work or other activities (for example, it took extra effort)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. During the **past 4 weeks**, how much of the time have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Cut down on the <b>amount of time you</b> spent on work or other activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Accomplished less</b> than you would like	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did work or other activities <b>less carefully than usual</b>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

Not at all	Slightly	Moderately	Quite a bit	Extremely
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. How much **bodily** pain have you had during the **past 4 weeks**?

None	Very mild	Mild	Moderate	Severe	Very severe
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

9. These questions are about how you feel and how things have been with you **during the past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time **during the past 4 weeks**...

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Did you feel full of life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Have you been very nervous?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Have you felt so down in the dumps that nothing could cheer you up?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Have you felt calm and peaceful?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did you have a lot of energy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Have you felt downhearted and low?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did you feel worn out?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Have you been happy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did you feel tired?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10. During the **past 4 weeks**, how much of the time has your **physical health or emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

11. How TRUE or FALSE is **each** of the following statements for you?

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
I seem to get ill more easily than other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am as healthy as anybody I know	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I expect my health to get worse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My health is excellent	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you for completing these questions!

# Appendix Five

## Katz Index of Independence in Activities of Daily Living

Code

Instructions: Below are statements that deal with your general needs.

Please consider the statement and answer the response that you think applies to you.

Activities	Independence:	Dependence:
Points	1 point	0 points

### Bathing

	Points
Baths self completely or needs help in bathing only a single part of the body, such as the back, genital area or disabled extremity	
Needs help with bathing more than one part of the body, getting in or out of the tub or shower.	
Requires total bathing.	

### Dressing

	Points
Gets clothes from closets and drawers and puts on clothes and outer garments complete with fasteners. May need help tying shoes.	
Needs help with dressing self or needs to be completely dressed.	

### Toileting

	Points
Goes to toilet, gets on and off, arranges clothes, cleans genital area without help.	
Needs help transferring to the toilet, cleaning self or uses bedpan or commode.	

### Transferring

	Points
Moves in or out of bed or chair unassisted. Mechanical transferring aides are acceptable.	
Needs help in moving from bed to chair or requires a complete transfer.	

### Continence

	Points
Exercises complete self control over urination or defecation.	
Is partially or totally incontinent of bowel or bladder.	

### Feeding

	Points
Gets food from plate into mouth without help. Preparation of food may be done by another person.	
Needs partial or total help with feeding or requires parenteral feeding.	

Thank you for completing these questions!







# Terms of Reference



# Terms of Reference

The National Council on Ageing and Older People was established on 19th March 1997 in succession to the National Council for the Elderly (January 1990 to March 1997) and the National Council for the Aged (June 1981 to January 1990).

The functions of the Council are as follows:

1. To advise the Minister for Health on all aspects of ageing and the welfare of older people, either at its own initiative or at the request of the Minister and in particular on:
  - a) measures to promote the health of older people;
  - b) measures to promote the social inclusion of older people;
  - c) the implementation of the recommendations contained in policy reports commissioned by the Minister for Health;
  - d) methods of ensuring co-ordination between public bodies at national and local level in the planning and provision of services for older people;
  - e) methods of encouraging greater partnership between statutory and voluntary bodies in providing services for older people;
  - f) meeting the needs of the most vulnerable older people;
  - g) means of encouraging positive attitudes to life after 65 years and the process of ageing;
  - h) means of encouraging greater participation by older people;
  - i) whatever action, based on research, is required to plan and develop services for older people.
2. To assist the development of national and regional policies and strategies designed to produce health gain and social gain for older people by:
  - a) undertaking research on the lifestyle and the needs of older people in Ireland;
  - b) identifying and promoting models of good practice in the care of older people and service delivery to them;
  - c) providing information and advice based on research findings to those involved in the development and/or implementation of policies and services pertaining to the health, well-being and autonomy of older people;

- d) liaising with statutory, voluntary and professional bodies involved in the development and/or implementation of national and regional policies which have as their object health gain or social gain for older people.
3. To promote the health, welfare and autonomy of older people.
  4. To promote a better understanding of ageing and older people in Ireland.
  5. To liaise with international bodies which have functions similar to the functions of the Council.

The Council may also advise other Ministers, at their request, on aspects of ageing and the welfare of older people which are within the functions of the Council.

# Membership

**Chairperson:** Dr Ciarán Donegan

John Brady

Noel Byrne

Kit Carolan

Oliver R Clery

Jim Cousins

John Grant

Dr Davida de la Harpe

Eamon Kane

Dr Ruth Loane

Dr Michael Loftus

Fiona McKeown

Sylvia Meehan

Mary Nally

Paddy O'Brien

Eileen O'Dolan

Mary O'Donoghue

Paul O'Donoghue

Prof. Eamon O'Shea

Pat O'Toole

Bernard Thompson

**Director:** Bob Carroll