

University of Leeds

SCHOOL OF SOCIOLOGY AND SOCIAL POLICY

DISSERTATION/PROJECT

Student ID number	200515692
Name	Carol J. O'Sullivan
Degree programme	MA in Disability Studies
Module code	SLSP 5606M
Module title	Research Dissertation (Distance Learning)
Dissertation Title	An Investigation into the Additional Living Costs of Disabled People: Implications for Independent Living in Cork, Ireland
Word count	15,695

Disabled students with additional support needs agreed by Disability Services should tick the appropriate box

I have been assessed as having:

Dyslexia	<input type="checkbox"/>	
Dyspraxia	<input type="checkbox"/>	
Other (please specify)	<input type="checkbox"/>	

**An Investigation into the Additional Living Costs of
Disabled People: Implications for Independent Living
in Cork, Ireland**

Submitted for MA in Disability Studies

Carol O'Sullivan

**Centre for Disability Studies
School of Sociology and Social Policy
University of Leeds**

September 2011

Acknowledgements

I would like to thank Nicola Meacle of the Cork Centre for Independent Living for trusting me with this research project. I would also like to thank all of the participants of the research for giving up their time to talk to me and for making this research possible at all. Also, thanks to Dr. Alison Sheldon for all of the good advice and guidance over the year. Finally, thanks to Diego Colombini for everything.

Abstract

This research project investigates the additional costs of living that disabled people incur as a result of impairment and a disabling society. It looks at how these costs impact on the choice and control in disabled people's lives as epitomised by independent living. It also seeks to explore the potential solutions to such costs from the perspective of the disabled people, living in Cork, Ireland. The study is conducted from a social model standpoint, based on emancipatory disability research principles. Thus, the research topic was chosen by an organisation of disabled people and controlled by them.

Qualitative research methods were ultimately used in the project in the form of a focus group and four individual interviews underpinned by secondary data. The findings reflect the experience of disabled people who participated in related studies throughout the world, but in this case the findings are directly related the experience to independent living and they showed that these extra costs consistently undermined it. Suggestions for solutions to the additional costs of living centred on the introduction of a fully rights based legislation in Ireland, the introduction of a direct payments scheme and a fundamental change in the philosophy of service provision in general.

Contents

Chapter One: Introduction.....	8
1.1 Introduction.....	8
1.2 Excluded.....	9
1.3 The Evolution of the Topic and the Research Questions.....	13
1.4 The Structure of the Dissertation.....	16
1.5 Conclusion.....	16
Chapter Two: A Vicious Circle.....	18
2.1 Introduction.....	18
2.2 Independent Living.....	18
2.3 Independent Living in Ireland.....	20
2.4 Costs and Independent Living.....	22
2.5 The Additional Costs of Living.....	24
2.6 Conclusion.....	29
Chapter Three: The Research Process.....	31
3.1 Introduction.....	31
3.2 Philosophy and Methodology: Emancipatory Disability Research.....	31
3.3 The Research Approach.....	34
3.3.1 The Focus Group: Data Generation and Sampling.....	36

3.3.2 The Qualitative Interviews: Data Generation and Sampling.....	40
3.3.3 Data Processing and Analysis.....	42
3.4 Ethical Considerations.....	43
3.5 Conclusion.....	45
Chapter Four: “It Just Adds Up”	46
4.1 Introduction.....	46
4.2 Personal Assistance Costs: “You don’t expect your PA to pay for it”.....	47
4.3 Transport Costs: “I’d love to have transport”.....	49
4.4 “It’s household costs that kill us”.....	51
4.5 Medical Costs: “There are always some items you have to buy”.....	54
4.6 Assistive Technology Maintenance: “We have to pay for the service ourselves”.....	56
4.7 Conclusion.....	57
Chapter Five: “Extortionate”	58
5.1 Introduction.....	58
5.2 Assistive Technology: “It was seen as a sort of luxury”.....	58
5.3 House Adaptations: “I’d build a house to my own specifications”.....	62

5.4 Car Adaptations: “I can’t just go on ‘carzone.ie’ you know”	65
5.5 Conclusion.....	68
Chapter Six: Solutions?	69
6.1 Introduction.....	69
6.2 Direct Payments: “I’d definitely be truly independent”	69
6.3 Legislation: <i>Not</i> “Another bloody consultation group”	72
6.4 Cost of Disability Payment: “A pipe dream”	74
6.5 Philosophy: “I had to sign under ‘patient’ even though I’m not sick”	77
6.6 Conclusion.....	79
Chapter Seven: Overview	80
Bibliography	85
 <u>Appendices</u>	
1. Focus Group Information Sheet and Consent Form.....	108
2. Focus Group Topic Guide.....	114
3. Transcript: Focus Group.....	119
4. Interview Information Sheet and Consent Form.....	187
5. Interview Guide.....	190

6. Transcript: Fiona.....	194
7. Transcript: John and Colette.....	233
8. Transcript: Don.....	289

Chapter One: Introduction

1.1 Introduction

Statistics contained in numerous reports (CSO, 2007; 2008; 2010; Gannon, Nolan, 2005; NDA, 2005) chronicle the situation of the 325,800 (CSO, 2008) people with impairments in Ireland as one of “widespread” (NDA, 2005: 96) social exclusion: evidence that they are disabled by society. It is society’s role in constructing disability that is at the heart of the social model of disability (Oliver, 1996) and it is from this perspective that this dissertation investigates one symptom of disability: the additional costs of living that disabled people incur because of impairment and disablement (Disability Resource Centre, 2010). Furthermore, as all aspects of the oppression of disabled people are interrelated and cannot be addressed in isolation (UPIAS, 1976), the way in which these costs can undermine the control and choice in disabled people’s lives as epitomised by independent living (Morris, 2003) is also explored, with potential solutions to these costs also addressed, whilst applying qualitative research methods to generate empirical data, combined with secondary data. This chapter will outline how the research topic was chosen, the research questions and objectives and the structure of the dissertation. However, I will begin with the background to

disabled people's social exclusion in Ireland as it provides the foundation for the choice of topic.

1.2 Excluded

To elaborate: disabled people in Ireland are less likely than non-disabled people to have a third level qualification (Gannon, Nolan, 2010) and to participate in civil and social activities (ibid; NDA, 2004a). They are more likely to experience discriminatory practices when using public transport than non-disabled people (NDA, 2005), to live in care, to experience ill-health than non-disabled people (ibid) and to experience an inaccessible built environment (CSO, 2010; NESCS, 2009). Furthermore, participation of disabled people in the labour force in Ireland is very low (OECD, 2008) due a litany of barriers to employment (Barnes, 1992a) and even when in paid employment, a lack of educational attainment and lower levels of work experience means lower pay for disabled people (Gannon, Nolan, 2010) resulting in underemployment (Barnes, 1992a).

These factors have a cumulative impact on the overall socioeconomic position of disabled people in Ireland. Disabled people's income declined between 1995 and 2005, this illustrates that disabled people did not benefit from the so-called 'Celtic Tiger' in the same way as some non-disabled people did (NESCS, 2009), even

though it is unlikely that disabled people will benefit from a financial boom in any case (Carpenter, 2009). Moreover, disabled people had the lowest income, were at highest risk of poverty and had the highest rate of consistent poverty in 2008 (CSO, 2010). In short, there is a “pronounced relationship” (Gannon, Nolan, 2010: 170) between disability and poverty in Ireland.

Ireland is not alone in sustaining this relationship (NDA, 2010) but it does fare worse on some aspects of social exclusion when compared with Denmark, the Netherlands and Finland (OECD 2008). For example, Ireland had the lowest rate of employment among disabled people of the four countries, with the low rate of educational qualifications and the “highly fragmented” (ibid: 29) benefit system, identified as key causes of this aspect of social exclusion.

This is exacerbated by the Irish state’s “piecemeal” (Good, 2003: 141), or arbitrary approach to ‘disability’ policy making and implementation (ibid). For example, the Disability Act 2005 is the most recent significant piece of legislation that underpins policy in Ireland (ANED, 2009). This act, in brief, gives a right to needs assessment to disabled people, (DeWispalaere, Walsh, 2007) but it amounts to a “statutory entitlement” (ibid: 9) not a right to services, as the Irish state opined that for disabled people to have their rights

entrenched in law, “would deny the needs of others” (Toolan, 2003: 181) an issue that I will go on to address in chapter six.

Ireland’s social welfare system is one way in which the state attempts to meet these ‘needs’. A system that is rooted in the individual model of disability, that identifies the source of disability in the impairments of the individual (Oliver, 1996) and consequently uses medical parameters to judge an “inability to work” (McManus, 2003: 57). In 2008 there were 234,900 people on a ‘disability’ related payment (NESC, 2009) which implies a large majority of disabled people in Ireland rely on a weekly income of €188 (ibid). However, austere budgets (Department of Finance, 2008; 2009; 2010) owing to the collapse of the Irish banking sector and property market (Bergin et al, 2011) has, and will, translate into delays in social policy implementation (Department of Justice and Equality, 2009), including a prolonged series of further cutbacks to social services and social welfare benefits (Bergin et al, 2011).

To illustrate: Illness Benefit (IB), and Disability Allowance (DA) are two of the ‘disability’ related social welfare payments (Department of Social Protection, 2011) based on having made (IB), or not (DA), social insurance contributions and both have been reduced by €16.30 to €188 over the past three budgets (Department of Finance,

2008; 2009; 2011). Also to be reduced is the Household Benefits Package (Department of Social Protection, 2011), which covers some household costs. However, as these payments amount to the same as a non-disabled social welfare recipient they do not take into account the extra costs of disability (Indecon, 2004).

There are some schemes to cover elements of the extra costs of disability. For example, there are a series of tax refunds and exemptions available to disabled drivers and passengers run by the Revenue Commissioners (Citizens Information Board, 2011), a Mobility Aids Grant Scheme and a Housing Adaptation Grant for People with Disabilities administered by local authorities which allows up to €30,000 of grant aid (ibid) and the Free Travel Scheme (Department of Social Protection, 2011). The HSE (Health Service Executive) also administers schemes like the Mobility Allowance for “financing the occasional taxi journey” (HSE, 2011: unpagged). Other schemes not connected to welfare payments are the Motorised Transport Grant to purchase or adapt a car to a maximum of €5,020.50 (ibid). Both of these payments are connected and disabled people cannot receive these concurrently.

Probably the most significant element of the benefits run by the HSE is the Medical Card system, which is a means tested scheme for all

people who meet the criteria. It grants access to GP services, medicines, dental services, hospital care and community health services, such as home help, personal assistance (PA) and assistive technology, all free of charge, except for a new prescription charge of 50 cent per item (HSE, 2011). The Medical Card is the point of access of healthcare for most disabled people in Ireland as more disabled people have a Medical Card than non-disabled people due to their lower levels of income (Quin, 2003). The interconnectedness of the social welfare and Medical Card systems results in a poverty trap for some disabled people because accessing any of these additional benefits is linked to income and any increase in income can mean losing any or all of these benefits, thereby disincentivising employment (OECD, 2008), which augments the social exclusion of disabled people in Ireland (Gannon, Nolan, 2005). Hence, it is with this background of social exclusion that this topic was chosen.

1.3 The Evolution of the Topic and the Research Questions

In November 2010, I contacted the Cork Centre for Independent Living and asked if I could conduct an empirical research project on a topic of their choice, under their guidance and for their use (Oliver, 1992). In the initial meeting with the manager of the centre, we discussed many topics that could be of use to the organisation, as well as achievable in the context of a small-scale project. As I

outlined in the previous section, the current socioeconomic situation of disabled people within Irish society and the precarious nature of Ireland's economic position were the determining factors in the choice of research topic, questions and their objectives. This dissertation has three research questions and objectives at its core, which are the following.

1. What are the additional living costs incurred by disabled people in Cork?

The objective of this question is to gain an indication of the nature of the additional living costs that are incurred by disabled people living in Cork. The 'additional' or 'extra costs' mean the:

“Additional costs associated with needs related to a person's impairment and associated experience of disability” (Disability Resource Centre, 2010: 27).

2. How do these additional living costs undermine independent living?

This research question seeks to conceptualise how these additional costs of living impact negatively on independent living, which means:

“All disabled people having the same choice, control and freedom as any citizen -at home, at work, and as a member of the community. This does not necessarily mean disabled people doing everything for themselves, but it does mean that any practical assistance people need should be based on their own choices and aspirations” (Morris, 2003: 4).

3. What could a solution to these living costs look like?

This question refers to the solutions to the additional living costs that are described throughout the previous literature. The objective is to formulate ideas from the perspective of disabled people on how these costs could be resolved and as a result prompt further debate on the issue.

Finally, the ultimate objective is to produce a report to be disseminated by the Cork CIL to use as a lobbying tool aimed at a new government to ensure that these issues remain on the political agenda in an attempt to stem the further erosion of ‘disability’ services and benefits. However, prior to this report there is the matter of this dissertation, the structure of which I will now outline.

1.4 The Structure of the Dissertation

This dissertation is divided into seven chapters, chapter two, 'A Vicious Circle' where I address independent living, independent living in Ireland and the previous research on the additional costs of living of disabled people. Chapter three, 'The Research Process' describes the philosophical basis of this research, the emancipatory disability research methodology underpinning it and the qualitative methods applied in the research. Chapter four, "It Just Adds Up" discusses the results of the data analysis relating to the ongoing, or recurrent extra costs (Tibble, 2005) of living and the impact that these have on independent living, followed by chapter five, "Extortionate" addresses the findings on the extra capital, or one off costs (Tibble, 2005) and their effect on independent living. Chapter six, 'Solutions?' considers research question three: what could a solution to these living costs look like? Chapter seven, 'Overview' is the concluding chapter and re-contextualises the research, re-examines how the research questions were answered, how successful the methods and methodology was and outlines any recommendations that arose from the research.

1.5 Conclusion

In this chapter I introduced the topic of the dissertation by firstly discussing the current socioeconomic position of disabled people in

Ireland (how the topic came to be chosen in this manner, will be explained in detail in chapter three). Also, I discussed the purposes of the project, which have the research questions at its core. Finally, I summarized the structure of the dissertation itself. However, in order to truly place the research questions, the methodology and the research methods in context, it is essential to treat of the previous literature surrounding the topic in the next chapter. This will also serve to identify where this project lies within the existing literature and how this project hopes to contribute to this rich data.

Chapter Two: A Vicious Circle

2.1 Introduction

In the previous chapter I outlined the background to the position of disabled people in Irish society, which informed the choice of topic. Here, I delve further into the meaning of independent living, the status of independent living in Ireland and the manner in which costs are dealt with in the existing literature. I will also treat of the existing literature on the additional costs of living of disabled people, with an emphasis on previous Irish reports, issues that prompt consensus and disagreement in the literature, the different methods applied in previous research and the definitions and categorisations of extra costs that inform this study. All of which provide the context for why this dissertation is relevant and worth doing.

2.2. Independent Living

In the past:

“The prevailing attitude was that people who have physical or sensory impairment, or learning difficulties need looking after, the most common service provided was residential care” (Morris, 1999: 1).

This sums up the history of how the “additional requirements” (Morris, 2003: 6) or needs of disabled people were organised until disabled people in the US and the UK during the 1970’s consolidated their knowledge in order to prevent other disabled people being placed into residential institutional care (Barnes, 2007; Evans, 2002). This saw the emergence of an emancipatory ideology and practice that is based on the empowerment of disabled people to exercise “influence, choice and control in every aspect of their life” (Hasler, 2003: unpagged). Centres for Independent Living (CIL), were established: run and controlled by disabled people, supplying services to support disabled people living in the community (Evans, 2002). Such services can focus on, firstly, adapted housing, which is a basic starting point of independent living (ibid); personal assistance (PA) services, which means “human help with everyday tasks” (Hasler, 2003, unpagged); transport to get around as required and access to an environment without limitations (Evans, 2002; Hasler, 2003).

The latter, in part, form what are described as the seven ‘basic needs’ as set out by a CIL in Derbyshire (UK) in the 1980’s (Davis, 1990) and were later expanded to ‘twelve needs’ (Morris, 2003).

These equal the:

“Areas in which disabled people have requirements/needs over and above those of non-disabled people, which must be met if they are to experience equal access to human and civil rights.”

(ibid: 7).

The remaining needs include; access to assistive technology to decrease unwanted reliance on others (Hasler, 2003); access to appropriate information to facilitate choices (ibid); an adequate income to implement those choices; advocacy, with an emphasis on self-advocacy; counselling to provide emotional support; the same opportunities for employment as non-disabled people; equal opportunities for mainstream education and training and access to healthcare provision that is appropriate to the choice and control at the heart of independent living (Morris, 2003). These needs are no different for disabled people in Ireland.

2.3 Independent Living in Ireland

However, as I mentioned in chapter one there is no right in law to have these needs met in Ireland and furthermore, there is no right to independent living in Ireland (ANED, 2009). This is not to say that the passion for independent living in Ireland is undermined by the lack of such rights, in fact CILs in Ireland have been described as almost “the heartbeat of the European movement” (Evans, 2003:

unpaged). They serve to challenge two traditional viewpoints in Ireland, first that, 'care' should be provided informally by the family (ibid), which is the most common type of assistance for disabled people in Ireland (CSO, 2010). This view is bolstered by the social welfare system which has many family 'carer' related payments, like the Carer's Benefit and Allowance and respite grants for the carer (Department of Social Protection, 2011). Second, that 'care' should be provided in residential institutions (ANED, 2009), which, for some people with learning difficulties, still means residing in a psychiatric hospital (Beadle-Brown, Kozma, 2007). In fact the National Disability Survey (CSO, 2008) revealed that there were 25,600 disabled people of all ages living in 'communal establishments' in 2006.

Moreover, CILs offer PA services, accessible transport services and educational opportunities in order to fill the void left by mainstream 'disability' service provision (McGetterick, 1994). PA services are also provided by charitable organisations 'for' disabled people like, the Irish Wheelchair Association, Cheshire Ireland, Enable Ireland and RehabCare (Egan, 2008). All are funded pre-dominantly by the government through FÁS (training and employment government agency) and by the HSE (ibid). However, these organisations have been negatively affected by the government cutbacks (DFI, 2009), indeed, a symptom of when state support for independent living is

based on resource availability and is not seen as a solution to the “social exclusion, institutional living and poverty” (Evans, 2002: 10) of disabled people. The link between a failure on the behalf of governments to invest in independent living and continued social exclusion of disabled people has been discussed in the existing literature on the topic (Jolly, 2009; Zarb and Nadash, 1994; Zarb, 2003), which I will address next.

2.4 Costs and Independent Living

The focus of such literature has been on a cost/benefit analysis of institutional ‘care’ versus independent living in the community. The conclusion is that long-term costs to the state are lower if independent living is funded appropriately (Hurstfield, Parashar, Schofield, 2007; Jolly, 2009; Simkins, 1978; Zarb, 2003). Part of appropriate state funding of independent living are direct payments schemes that have been introduced in countries like the UK, Sweden, Austria, Finland, Belgium, Holland and Germany (Egan, 2008). These were first developed by disabled people and are based on the provision of funds directly from the state to disabled people to purchase supports and services like PAs and assistive technology (Evans, 2002; Pridmore, 2006) thereby forming a “key element in the quest for meaningful independent living” (Barnes, 2007: 2). Direct payments are hugely positive; they facilitate choice and control in life;

they replace informal family care, which improves family relationships; they are empowering as disabled people are the employer or 'leader' and decide who and when people work for them; they facilitate disabled people to continue or return to work while providing employment for non-disabled people (Egan, 2010).

Nevertheless, some disabled people have reservations about direct payments, which emerged in the UK and Northern Ireland schemes (Pearson et al, 2005). For example, inconsistencies in information about schemes; a perception that it is a long and complicated process with a plethora of paperwork (Egan, 2010); difficulties in recruiting PAs and the fact that organisations of disabled people who support participants of schemes are under funded (Barnes, 2007). However, most disabled people in Ireland do not get to experience such problems as there are no official direct payments schemes in Ireland for disabled people at present, although there are some pilot projects underway (Egan, 2008; Evans, 2003) which I will treat of in more detail in chapter six.

The lack of direct personal funding of independent living in Ireland is one side to the financial barriers to independent living, with the additional costs of living that disabled people incur representing the other aspect (Morris, 2003). These two types of cost form "a vicious

circle of disadvantage” (ibid: 48) where the disabling barriers in relation to employment, for example, make it less likely that disabled people can meet their additional needs relating to independent living with their own purchasing power (ibid). This increases the probability that disabled people have to rely on public services which do not always meet those additional needs and in turn leads to spiraling personal costs of living (ibid). It is these personal costs that I will now turn to in terms of the existing research on the topic.

2.5 The Additional Costs of Living

There are four predominant economic approaches to estimating the additional costs of living that disabled people incur. First, the comparative approach contrasts spending patterns of disabled people with those of non-disabled people of similar backgrounds, an example is Matthews and Truscott, 1990 (Tibble, 2005). Next, the standard of living approach analyses the reduction in the standard of living disabled people experience when income is diverted to pay for impairment related goods and services when compared with non-disabled people on the same income (Tibble, 2005). Examples of this type of study include Cullinane, Gannon and Lyons (2008), Indecon (2004) and Zaidi and Burchardt (2003). Third, the budget standards method involves disabled people costing a sample of goods and services that are deemed to represent what is needed to

achieve a certain standard of living, an example is the Disability Resource Centre (2010) study and Smith et al (2004). Finally, the subjective, or direct survey approach, asks disabled people, to identify what they spend money on and what they would spend money on in different circumstances (Berthoud, 1991). Examples include part of the Indecon report for the National Disability Authority, Ireland (2004) and the UK studies, Thompson, Lavery and Curtice (1990) and Martin and White (1988). The latter study for the Office of Population, Census and Surveys (OPCS) was one of the largest surveys of its kind, with 10,000 disabled adults asked questions related to their spending. However, the estimation of extra costs incurred by disabled people was very low and this prompted the Disablement Income Group (DIG) to conduct follow up surveys, first the small-scale Thompson, Buckle and Lavery (1988) study, followed by the larger Thompson, Lavery and Curtice study (1990). The latter came to very different estimations of extra costs mainly due to the fact that the OPCS survey had included people who had low levels of impairment (Large, 1991) and who had not been given an opportunity to think deeply about their costs (Berthoud, 1991). During the research design phase the plan was to base this dissertation on the latter project, however, due to changes during the research process, that I will address in chapter three, I could no longer implement a direct survey approach.

Contentions were evident in the literature, for example: there is no one definition of extra costs used throughout the literature (Berthoud, 1991; Tibble, 2005). Subsequently, the literature that most informed the research were those studies that aligned themselves with the social model of disability, which still include the DIG study (1990) and the Disability Resource Centre (2010) study. It is these studies that provide the definition of extra costs that is used in the research as: costs incurred by disabled people due to impairment and experience of disability that non-disabled people do not encounter (Disability Resource Centre, 2010). These costs can be categorised further into, first, “ongoing costs” (Thompson, Lavery, Curtice, 1990: unpagged) or recurrent daily expenditure, like transport, utilities, food, personal assistance, home maintenance, medical expenses and the maintenance of assistive technology. And second, “capital costs” (ibid, 1990: unpagged) or once off or infrequent purchases like assistive technology, home adaptations and car adaptations (Berthoud, 1991).

These extra costs of living are measured in different ways and frequency in the literature and whether they are taken into account or not, depends on the approach adopted (Tibble, 2005). This gives

rise to the debate over which approach gives the most accurate estimation of cost, however, the conclusion reached is that:

“There is no single available methodology that can accurately establish the exact additional costs of specified conditions or disabilities” (Indecon, 2004: 41).

Not disputed in the literature is that disabled people; incur extra costs (Large, 1991); that type of impairment can increase costs (Stapelton, Protik, Stone, 2008) and that costs can increase with age (Zarb and Oliver, 1993). Nor, that expenditure is dependent on income, in other words, the more money one has, the more one spends, hence, costs increase with income (Berthoud, 1991). This is why estimating extra costs is so challenging, as one cannot assume that the person with the highest income is the best gauge of additional costs, rather, that “the true cost is the one actually experienced by this person with this income” (Berthoud, 1991: 67).

Irish estimations of additional costs were reached in the Indecon study (2004). The researchers used data from a Household Budget Survey from 1999-2000 to apply the standard of living approach and estimated extra costs to be €143 at the mid range of income per week or €136 at the average level of income. This study was

criticised for not incorporating “severity of disability” as a variable in the calculations of cost by Cullinane, Gannon and Lyons (2008: 6). Nonetheless, the latter study used the same approach but came to different weekly costs of €171.73 at the mid range of income.

The final area of agreement concerns the recommendations made in the previous literature in order to resolve these extra costs of living. All of the reports, be they written twenty years ago or last year, indicate the need for change in the status quo, either on a societal or a governmental level; in changes to social welfare ‘disability’ benefits (Smith et al, 2004; Zaidi, Burchardt, 2003); introduction of direct payments (Thompson, Lavery, Curtice, 1990) and innovations in service delivery to disabled people (Disability Resource Centre, 2010). Potential solutions to the additional cost of living via a specific benefit payment arose in earlier Irish research in a National Rehabilitation Board (NRB) study in 1995 (Indecon, 2004), that analysed 59 disabled people’s extra costs of living. This was reiterated in the Indecon study, which recommended a specific ‘cost of disability’ payment, based on individual need with a three tiered weekly payment of €10, €20 and €40 per week for disabled people with low, medium and high needs respectively. It would be means tested for low incomes and include the introduction of a tax credit for employed disabled people (Indecon, 2004). Cullinane, Gannon and

Lyons (2008) contained more generalised criticisms of the effectiveness of existing Irish welfare benefits and policies in meeting the additional costs of living of disabled people.

To conclude, this dissertation aims to add to the existing Irish literature by grounding itself in the social model of disability so that this research does not become one of the “mechanisms of oppression” (Abberley, 1992: 154), unlike the OPCS survey (ibid). Also, this research differs to most previous projects as it is under the control of an organisation of disabled people and I am accountable to that organisation. This is part of the emancipatory disability research methodology at the centre of the project (Barnes, 2001; Stone and Priestley, 1996), which I will describe in chapter three.

2.6 Conclusion

Here, I discussed independent living, in particular, its status in Ireland. I also focused on the methods that are used to estimate extra costs of living, the definitions of costs that informed this study, the issues that prompted discord and agreement within the literature and the recommendations made within the previous literature, with particular reference to the Irish context. Furthermore, because many previous reports have primarily been conducted from an economics perspective, a discipline that has:

“Largely been indifferent to the aspirations of disabled people as expressed in the Independent Living movement” (DeJong, 1985, unpagged).

This study aims to be the opposite of the latter and how this approach will be implemented is outlined in the next chapter.

Chapter Three: The Research Process

3.1 Introduction

As I discussed in the previous chapter, the topic of this dissertation is one that has been researched from the perspective of many differing methods, ranging from pure economics, to those influenced by the social model. In this chapter, I will discuss the methodological approach, which is based on emancipatory disability research; the qualitative approach to data generation, and the sampling and analysis procedures employed during the research. In doing so I will treat of why these choices were made; their strengths and weaknesses and the ethical considerations that arose throughout. To begin, I will place this project firmly in the context of the latter through a description of the philosophical assumptions underpinning the study.

3.2 Philosophy and Methodology: Emancipatory Disability Research

Emancipatory disability research is a “political commitment to confront disability” (Barnes, Mercer, 2004: unpagged) and is a relatively new methodology with no ‘how to’ books (Oliver, 1997) at the disposal of the novice researcher like myself. However, disability academics have identified six core principles of emancipatory disability research (Barnes, 2001; Stone and Priestley, 1996) which this project is attempting to adhere to, I say attempting, because Oliver (1997: unpagged) argues that the research “can only be judged

as emancipatory after the event”, if at all. Nevertheless, both the ontological and epistemological assumptions of this study make up two of those six principles of emancipatory disability research. The first principle is that the research epistemology should be loyal to the social model of disability and second, that researchers should relinquish claims to objectivity by clearly outlining their ontological and epistemological viewpoints. In practice, the ontological rationale of this research is underpinned by my experience as a non-disabled instructor of disabled students on a ‘vocational’ horticulture course. Wanting to explore the reasons why these courses seemed nothing more than a ‘revolving door’ for the disabled people who accessed them (Kitchin, Shirlow, Shuttleworth, 1998) I applied for this MA. As a result, this research is committed to the social model of disability.

This leads to the third principle which states that disabled people should be in control of research production (Barnes, Sheldon, 2007) and that researchers should be accountable to disabled people and their organisations, otherwise, research is “part of the problem rather than part of the solution” (Oliver, 1992: 105). In this case the Cork CIL is ultimately in control of this project, from the topic, to the research design, the sample of participants and the methods used, in short, it could not have happened without the CIL. I am also accountable to the University of Leeds, this is why I will write a

separate report to be used and disseminated by the CIL. An important point to make here though is that the responsibility for what I write, “could not and should not be devolved to anyone” (Priestley, 1997, unpagged). However, my one concern is, if ultimately, the content of the report will be influenced by the state ‘funders’ of the CIL, thereby creating doubts that the ‘social relations of research production’ (Oliver, 1992; Zarb, 1992) will have been altered at all.

The fourth principle states that the researcher should be committed to the practical application of the products of the research and that it should be relevant to the lives of disabled people, with an emphasis on dissemination of the research. In order to engage this principle I set up a website or a ‘blog’ about the research (www.extracosts.blogspot.com) which I had intended to update regularly. Unfortunately, these plans were interrupted once data generation began. I plan to revisit the ‘blog’ concept when the report is finished for the CIL, as it is another forum to disseminate the results in addition to the research participants, local government and national politicians.

Fifth, there should be an awareness that by only voicing experience in research, that there may be an unintended focus on the ‘personal tragedy’ view of disability (Oliver, 1996). In this case, the research

process intended to include a quantitative method (see section 3.3), as well as a qualitative approach to data generation, which would have accessed a bigger sample of people. However, this was not to be and qualitative methods were used only, with the fifth principle constantly referred to. Finally, methods of data generation that suit the aims of the research should be chosen. Ultimately, this project was driven by the research questions and the methods of data generation were chosen to seek answers to these questions as deemed appropriate by the CIL. It is the implementation of these methods that I will address next.

3.3 The Research Approach

At the outset a “simplified model of research” (Punch, 2005: 39) was adopted; which is research question led; emphasised the identification of what data is necessary to answer them and which methods to use to generate the data (ibid). This informed the original research design which consisted of a qualitative phase, a focus group, a quantitative phase in the form of a survey followed by a second focus group.

However, the design changed substantially during the research process. First, the second focus group was reconsidered because the CIL felt that it would be asking too much of the participants. It was at this point that the idea of carrying out individual interviews

was explored as a substitute for the second focus group.

Concurrently, I was preparing the questionnaire for the survey, however after several drafts the CIL was unhappy with the amount of personal questions in the survey and after a meeting and several emails, the CIL decided that it would be more suited to the aims of the research to substitute the survey with individual interviews. At the time I felt that this was a set back as I had spent valuable time preparing the survey. In hindsight, this was priceless experience of the reality of conducting research and a reminder, rightfully, that this research was not solely about meeting my MA deadlines but was about the original aims within emancipatory disability research. The net result was a research approach that used qualitative methods only and had two phases, in the form of the focus group and the second phase was replaced by individual interviews, reinforced by secondary data gathered during the literature search. It is that focus group that I will treat of next.

3.3.1 The Focus Group: Data Generation and Sampling

A focus group involves bringing people together to discuss a topic with some guidance from the moderator (Overlien, Aronsson and Hyden, 2005). This method of data generation was chosen because

it can provide a valuable “window onto the subjective experience of respondents” (Barbour, 2007: 3). Moreover, it is a collective and interactive medium with which to stimulate data from dialogue and group dynamics (Barbour, 2007; Overlien, Aronsson, Hyden, 2005; Punch, 2005) and it is compatible with emancipatory disability research (Smithson, 2000), as it does not overly emphasise the individual experience of disability (Oliver, 1996). Focus groups are also conducive to maintaining anonymity as people can talk about ‘someone else’ during the process without revealing the intimate details of their lives (Overlien, Aronsson, Hyden, 2005).

The sampling strategy used for the focus group was a convenience, non-probability strategy, that is, choosing a sample of the population because they are “close at hand” (Punch, 2005: 187). In the context of this research, the sample was disabled people who are associates of Cork CIL, chosen by the CIL. This can be seen as a weakness in the strategy, as a group should reflect diversity and not uniformity (Barbour, 2007). However, disabled people are not a homogenous group in any case (Oliver, 1996) which certainly emerged in the data analysis.

The first focus group took place in the Blackpool Public Library in Cork City on April the 14th, 2011 and is an accessible, free venue.

Every detail was organised by the CIL, including accessible transport to the venue. I was extremely lucky that it was organised for me, as I am aware of the problems that researchers encounter in the process (Barbour, 2007; Sheldon, 2001). However, my one regret is that I did not double-check if the venue provided refreshments, as what was supplied was quite meagre.

On the day, six participants turned up Susan, Eleanor, Maura, Anne, Timothy and Adrian (names have been changed to maintain anonymity). I did not seek any details of impairment or age from participants as the aim of this dissertation is:

“To demonstrate the common influence of oppressive structures and practices in the lives of disabled people whatever their chronological age or gender” (Sheldon, 2001: 22).

However, on a personal note, asking such detailed questions at the time felt intrusive, particularly as a non-disabled researcher. To attempt to alleviate my concern about my role as a non-disabled researcher (Stone, Priestley, 1996), as well as the possibility of constructing the group as the “other” to be ‘researched’ (Smithson, 2000: 110), a concern at all stages of the research, I asked the manager of the CIL, if she, or another staff member of the CIL would

like to moderate the group. However, she declined, as she felt that a person not known to the group might get different responses, this correlates with the view that a moderator of a similar background, or an 'insider' may not be ideal either (Barbour, 2007).

In preparation, I formulated a semi-structured topic guide (see appendix two) through identifying the relevant themes in the existing literature. The focus was on the three research questions, with an emphasis on the first two questions in this phase of the research owing to the original design. The function of a topic guide is to allow issues to emerge that I had not considered beforehand and provide guidance in the event of going 'off topic'. However, in practice this proved more difficult for me to adhere to than anticipated, as I lacked skill in redirecting people back to relevant material, a common problem when moderators are not experienced enough (Barbour, 2007). Also, I prepared "stimulus material" (ibid: 2) in the form of vignettes to initiate the discussion and to revert to if there was a long pause in the conversation, fortunately, there were no lulls in the discussion that required my intervention to that extent.

A problem that can arise with focus groups is the issue of "dominant voices" (Smithson, 2000: 107), where one or two people take over the conversation (Punch, 2005). This was overcome, to a degree, by

the presence of an, 'informal moderator', another participant, Susan, who knew the group and was comfortable inviting the quieter participants to speak. However, silences are important and can indicate agreement or disagreement on an issue or just reflect every day social interaction, which needs to be taken into account during data analysis (Smithson, 2000).

The discussion lasted an hour and a half and it was audio recorded on a laptop computer and participants were debriefed at the end of the session (Barbour, 2007). I took few notes during the discussion as I was perhaps too focused on which topics were being covered during the discussion. To my surprise people stayed on to chat after the formal part of the discussion was over and some participants said that they found it an interesting experience, this was reiterated in some positive feedback from the CIL also. Following the focus group, the second phase of the data generation needed to get underway, in the form of individual interviews.

3.3.2 The Qualitative Interviews: Data Generation and Sampling

The individual interview is "a very good way of accessing people's perceptions, meanings, definitions of situations and constructions of reality" (Punch, 2005: 168). Interviews also allow the researcher to clarify issues that arise elsewhere in the research (Barnes, 1992b) in particular, where information is more sensitive to discussion in front

of a group. Furthermore, the interviews introduced some flexibility around the barriers that prevented some people's participation in the focus group for some of the sample, like PA availability.

The sampling strategy mirrored that of the focus group. The CIL supplied me with a list of people who gave permission for me to contact them, with a view to arranging an interview in a time and place of their choosing. Out of six people, five agreed to be interviewed, while one person cancelled due to ill health. Thus, the overall sample size for the whole study was ten people and represents the main weakness of a small scale study such as this one and has implications for the generalisability of the study (Gibbs, 2007), meaning that this study can be indicative only.

The informants were: Don, (interviewed on 7/06/11) Fiona, Colette and John (all interviewed on the 30/05/11), the latter are a married couple with whom I did a joint interview. The interviews covered all three, research questions. All informants chose to be interviewed in their own homes, into which I felt warmly received. Moreover, I felt privileged to be invited into a person's most private space, given that I was a virtual stranger who had everything to gain academically (Seymour, Garbutt, 1998) from the interaction, a gain that may not

necessarily be reciprocated by the outcome of the research (Oliver, 1997).

In practice, interviews are a collaborative process during which both the interviewer and interviewee are involved in creating meaning (Silverman, 2006). This was reflected in how the interviews proceeded, as they were not as consistent as I intended, even though I had prepared a semi-structured (Punch, 2005) interview guide (see appendix five). In reality, questions were asked as topics emerged and informants covered topics that were relevant to them. The interviews lasted between 1 to 1.5 hours, with a debriefing session at the end and were audio-recorded on a laptop. I am not sure if the interviews were a positive experience for all of the interviewees but I did get encouraging feedback about the questions asked during the interview, via the CIL, from two participants. The next step was to prepare the data for analysis.

3.3.3: Data Processing and Analysis

Prior to data generation, a provisional codebook was compiled in order to establish a descriptive structure of potential themes that could arise within the data (Barbour, 2007). These codes were divided into broad themes and specific themes, which were informed

by the literature on additional costs and independent living and formed the “a priori” codes (ibid: 120). The first step in data preparation was the transcription of the audio recordings into written format. Each line of transcript was given a number to aid with coding and then labelled line-by-line with a theme, guided by the codebook (Burke-Johnson, Onwuegbuzie, 2004). Meanwhile, allowing for the “in vivo” (Barbour, 2007: 120) codes, or codes that emerge during data analysis, to be identified. I then grouped the codes into categories in order to form a hierarchy of codes (Gibbs, 2007). A table of summaries was developed of the coded text, also known as the “data display” stage (Burke-Johnson, Onwuegbuzie, 2004: 22). This enabled me to find patterns in the data and “produce explanations” (Gibbs, 2007: 4) through induction: general explanations from the themes in the data. Or deduction: when a specific situation is unravelled from the general picture (ibid). However, producing such explanations is a subjective exercise and open to many interpretations (ibid) imbedded in the ontology and epistemology of the research, therefore, I must highlight that this is only *one* way in which this data can be analysed (Smithson, 2000).

In conclusion, to increase the validity of the study and to adhere to the elements of emancipatory disability research it is necessary, following the data analysis, to return to the participants of the

research with the findings, this is known as respondent validation (Gibbs, 2007). I was unable to do so within the time scale for the dissertation, but it will be completed for the report for the CIL.

Hence, I cannot be sure if my analysis of the data is consistent with those of the research participants (Barnes, 1992b).

3.4 Ethical Considerations

There are many ethical issues to be considered during a qualitative research process (Silverman, 2006). First, during both phases of the research it was crucial that potential research participants were fully informed to avoid any unnecessary intrusion, offence, or confusion about the research (Social Research Association, 2002). The participants of the focus group received information about the research beforehand through the CIL. In relation to the individual interviews, I emailed, or posted where appropriate, each informant a copy of the information sheet and the consent form prior to the interviews taking place (see appendix four). Nevertheless, the topic of the research, its aims and uses and the likelihood of it being of benefit to participants were reiterated on the occasion of the focus group and interviews to ensure that I obtained informed consent (see appendices one and four), as much as that is possible (see Silverman, 2006: 330). All participants in both phases of the research were assured of its voluntary nature and that it would be

audio-recorded with their permission only. Participants in both phases were debriefed at the end, which allowed people the time to highlight any concerns that they had and request any further information via the contact details that I provided.

Confidentiality and anonymity are issues that arise throughout the research (Wiles et al, 2008). In the focus group, confidentiality of the discussion and the identity of participants were assured through a commitment of both the participants and the moderator. Similarly, I made a commitment to the interview informants that identities and data would be confidential throughout the research process (Social Research Association, 2002), as well as the data being stored on a password-protected computer in a private residence. Also, all of the transcripts were anonymised and any identifying information was deleted throughout (British Sociological Association, 2002). There is also an ethical responsibility to be true to the data in the transcripts and care needs to be taken that it is not altered during transcription (Gibbs, 2007). Therefore, I sent a copy of the relevant transcript (see appendices three, six, seven, eight), to each of the person involved in the research for comment, or to alter anything that they had said during their respective interviews or focus group. However, no participant requested any changes to their transcripts or contacted me with any questions after the event. In conclusion, the aim was to

follow as closely as possible the strengths of the ethical agenda of emancipatory disability research (Barnes, 2008).

3.5 Conclusion

This research process evolved under the control of the Cork CIL, the project changed as the organisation saw fit, which symbolises the philosophy and methodology guiding the research. In this chapter, I described the latter, as well as outlining the qualitative methods, a focus group and four interviews, that were applied in this project. Furthermore, the ethical issues that arose throughout the process were discussed. I also treated of the data analysis procedures. It is the findings of which I will discuss in the next three chapters, beginning with the ongoing additional costs incurred by disabled people and the way in which these costs affect independent living in chapter four.

Chapter Four: “It Just Adds Up”

4.1 Introduction

As I outlined in chapter two, there is no doubt that disabled people incur extra costs of living when compared to non-disabled people.

Here, I discuss the findings of the data analysis from the perspective of these extra costs. The first broad category of costs is discussed:

the ongoing additional costs. In the literature and in the data

analysis, the costs that emerged were those relating to personal assistance, transport, household bills like groceries, utilities and maintenance, medical costs and maintenance of assistive technology. Each cost is addressed individually whilst being considered from the perspective of the second research question: how do these additional living costs undermine independent living? During the analysis, particular attention was given to the twelve needs of independent living (Hasler, 2003) where possible, and more generally to the broader meaning of choice and control as discussed in chapter two. A key element of facilitating this choice and control is personal assistance, which I will treat of first.

4.2. Personal Assistance Costs: “You don’t expect your PA to pay for it”

Personal assistance is a “means to the end” (Morris, 2003: 7) to achieve independent living and is one of the ‘twelve needs’ (Hasler, 2003), as discussed in chapter two. This was reiterated in previous ‘extra costs’ research where PAs were viewed as the “most valuable resource” for disabled people (Disability Resource Centre, 2010: 45). However, as it is a need that non-disabled people do not have, it can

be a source of additional costs for some disabled people (Large, 1991; Smith et al, 2004). The latter source revealed additional costs when disabled people employ PAs through direct payments and incurred costs associated with sick pay, maternity leave and employers' liability insurance. In the Irish context, even though direct payments are at a pilot stage, there were reports of indirect costs accrued by participants in the project (Egan, 2010). Other expenses accrue when disabled people pay directly for PA hours themselves, particularly when attempts are made to subsidise the state sponsored PA hours. In fact, the Indecon (2004) report revealed that 25% of households were spending private income on personal assistance hours. Don outlined what happened to him when he did exactly that:

Don: "I ended up paying everything, every penny of disposable income I had, as well as my savings, on PAs..." (Interview).

Therefore, as some disabled people are on a limited income like the 'disability' related social welfare payments and have to budget for *all* living expenses, they may not be in a position to augment their PA hours with their own money: because people cannot spend what they do not have (Berthoud, 1991). The result is a void in the choice and control over their lives due to insufficient PA hours (Pridmore, 2006)

this was apparent in the analysis of both data sources and was clearly illustrated by Fiona:

Fiona: "There is only a certain amount of hours and I've no social hours at all, all my hours are for necessities, that's like cooking dinner, personal care, going to bed, getting up, after that then I have to make my own fun, you know" (Interview).

Other sources of extra PA costs concerns paying for a PA while participating in social activities (Large, 1991; Smith et al, 2004), whether this was in the form of a trip to the cinema, a train journey, a weekend away or a holiday (Egan, 2010), it was a substantial source of extra costs for most research participants:

Susan: "It's not even going on holidays it's-

Timothy: -it's going anywhere.

Susan: Going out on a Tuesday night or something-

Timothy: -it could be going anywhere, that's right" (FG).

Furthermore, Colette and John saw the additional costs of paying for a PA while socialising as prohibitive to engaging in some social activities, for example, when they go to the cinema they must pay for two PAs, which in the Cork context amounts to €36 per film. These

extra costs are not considered in any 'disability' payment (see chapter one) and do not stop at personal assistance related costs either. Even reaching a venue where social activities take place can be a source of extra costs for disabled people when compared with non-disabled people (Frisch, 2001), such transport related costs are discussed next.

4.3 Transport Costs: "I'd love to have transport"

The interviews revealed that people had experiences of additional transport costs in two respects, first, with taxis and second, with car ownership, which also arose in previous research (Disability Resource Centre, 2010). Additional costs associated with the use of public transport was not an issue in itself, due to the Free Travel Scheme (see chapter one) but did arise in terms of the "transport chain" (Wilson, 2003: 11), which means all aspects of the journey to reach a chosen destination, including the distance to the bus stop or the condition of the footpaths. Resultantly, some participants were obliged to use taxis, with all of the interviewees speaking of the additional cost of taxis, despite the Mobility Allowance (see chapter one), which seemed to be used to purchase other essential items, for example, Don bought incontinence sheets with his allowance. For John and Colette it goes towards their fuel costs, as well as loan repayments, for the minibus that they purchased which also costs

them extra in terms of having to provide open insurance so that their PAs can drive it, an experience echoed in previous research (Egan, 2010). However, in the past, John and Colette's taxi costs amounted to an exorbitant €37 for a ten-minute journey: when a taxi for a short trip is so expensive it is not surprising that taxis are considered, a luxury by Maura.

Maura: "For me it's doing without luxuries like make-up, or a present for my birthday now would be money for a taxi. Put it into a taxi account" (FG).

Such transport costs have repercussions for equal opportunities for employment (Wilson, 2003). This was discussed in the focus group, when Susan pointed out how the transport costs involved in getting to work for some disabled people can undermine the financial viability of taking up employment at all:

Susan: "You might get a job but the transport costs might be prohibitive..." (FG).

Therefore, if transport costs are prohibitive, then they can impact on the available choices in life (Tisato, 1997). Accessible transport provision is one of the key determinants of the realisation of full

independent living for disabled people (McGetterick, 2003) and if it costs too much then it is not accessible. Hence, a lack of accessible transport can prevent access to the environment and thereby undermine independent living (NDA, 2004b). The resultant social exclusion means that some disabled people spend more time at home, thereby incurring extra heating costs, for example (Smith et al, 2004). However, this is just one of many extra household expenses, which are explored next.

4.4 “It’s household costs that kill us”

Additional household costs incurred by disabled people include heating and electricity and are well documented which can accrue, like the above example through social exclusion, but, also because of impairment (Thompson, Lavery and Curtice, 1990; Indecon, 2004; Smith et al, 2004). This was reflected in the data: John estimated that their electricity bill comes to €500 bimonthly, in the winter, which the Household Benefit Package (see chapter one) does not cover, he explains one reason why their costs are so high:

John: “I have quite a bad chest complaint, it’s just, I have to stay warm, if I don’t I get very ill and I end up in hospital and then if I’m in hospital I contract other illnesses, it’s a vicious circle, so it’s warm, almost tropical in our house, it has to be” (Interview).

However, utility bills are not the only household bill that disabled people encounter and maintenance of the home emerged as a significant extra cost because it can involve activities that disabled people may have carried out under different circumstances but now have to pay for someone else to undertake on their behalf (Indecon, 2004; Smith et al, 2004).

Timothy: "I have to bring somebody in now to do the maintenance on my house, whereas before I'd do the whole lot myself like, you know, so with a disability, that costs you more as well, the maintenance of your house, to maintain a house" (FG).

Other ongoing household bills include extra grocery costs. In fact two-thirds of participants in Thompson, Lavery and Curtice (1990) reported spending extra on food. The explanation for such costs was associated with particular diets (ibid) and not being able to shop around like non-disabled people, this sentiment was echoed by research participants in Sheldon (2001) and particularly by Fiona in her interview. Fiona identified two reasons for these extra costs, firstly, the distance to the supermarket was so far that she would require her PA to accompany her, which is connected to the quantity

of PA hours that she has and which tasks have to be prioritised: going shopping cannot not take priority over personal care. As a consequence, Fiona shops online for her groceries with Tesco. This is the second reason that she cannot shop around, as there is a limited choice of stores offering online shopping in the Cork area, with only SuperValu offering online shopping at selected stores in Cork (SuperValu, 2011)

Fiona: "But overall it's fine, but it's just I don't have the choice that other people would have" (Interview).

A lack of choice was also evident in the data concerning additional medical costs, particularly when these costs were connected to government cutbacks, among other reasons, which I will now turn to.

4.5 Medical Costs: "There are always some items you have to buy"

Disabled people can experience additional costs of living arising from impairment related medical costs (Smith et al, 2004; Thompson, Lavery, Curtice, 1990). In Ireland, a majority of disabled people are Medical Card holders (Quin, 2003), reflected in the majority of participants. Consequently, additional medical costs were twofold for the research participants, first, items that are not covered by the

Medical Card, for example, Don pays €50 per month for micro-enemas and for John, chiropody sessions cost him €45 every three weeks. Second, items once available through the Medical Card and have been removed due to cutbacks in the HSE budget (Department of Finance, 2009; 2010). However, some disabled people still have to purchase such items, for example Eleanor pays €30 and Don pays €50 a month for incontinence sheets.

However, the participants relayed to me that the reasons that they were given for the end of free provision of incontinence sheets was due to a 'perceived' health and safety risk with their usage, not because of budgetary constraints. Moreover, there have been clearly defined cutbacks, which have added to the extra costs of living for some disabled people (DFI, 2009), for example, the addition of a charge of 50 cent per item on each prescription for Medical Card holders in Budget 2010 (Department of Finance, 2009). In John's case it adds an expense of €7 to his monthly bills.

The Medical Card system (see chapter one) serves as a disincentive to taking up full time employment as exceeding the income threshold means that disabled people can loose out on the benefits associated with it, thereby increasing additional costs of living and forming a poverty trap (OECD, 2008). Both, Susan and Colette, in particular,

described their experiences of this predicament potently:

Colette: “If I got a full time job, my welfare would be taken away, but I’d lose my Medical Card as well, now we’re hit with that as well because I’d love a full time job but then you’re worried like, if you lose your Medical Card you’re screwed” (Interview).

Possession of a Medical Card also determines access to assistive technology and as that is a capital cost (Thompson, Lavery, Curtice, 1990) I will discuss it in chapter five, however, the maintenance of such equipment is an ongoing cost (Large, 1991), which is discussed next.

4.6 Assistive Technology Maintenance: “We have to pay for the service ourselves”

Some disabled people make use of a selection of assistive technology in their daily lives and is an essential element of independent living (Hasler, 2003). However, equipment needs to be serviced and repaired and can create additional costs of living for disabled people (Large, 1991; Thompson, Lavery, Curtice, 1990). The additional cost of maintaining assistive technology was

discussed by only one member of the focus group, Maura, who opined that if a disabled person purchases a piece of equipment, then the HSE will not service it. This transpired to be a significant issue for all of the interview informants. Whereby, the cost that would ensue from maintaining a piece of equipment privately, either deterred some of the informants from buying a piece of equipment, or proved a large ongoing cost. John and Colette have such an experience with their ceiling hoist:

Colette: "To get it serviced is over €300 and they want payment up front before they come out and we have to pay that and then they had to put in a new motor there today, and that's another €200 and we'd just paid for a service, €500" (Interview).

Don, however, revealed some inconsistencies within the health service on this issue:

Don: "People...shouldn't be too hasty in assuming that the HSE won't look after it, because if you have a good relationship with your OT, I mean I have talked them into maintaining the equipment I have bought" (Interview).

This thread ran through the data, in particular, where the personality

of a person involved in service delivery determined the quality of service that some disabled people received (D'Eath et al, 2005), an issue that I will address in more detail in chapter five.

4.7 Conclusion

In this chapter I followed the definition of additional costs used in the existing literature by applying the two categories of costs to the data, ongoing and capital, I discussed how the first of these arose within the data and the impact that these costs have on independent living. The cumulative affect of these costs was best described by Susan who commented that “...it just adds up” (FG). Of course the story of the cumulative nature of additional costs is not complete without discussion of the capital costs incurred by disabled people, which I will treat of in the next chapter.

Chapter Five: “Extortionate”

5.1 Introduction

Like the previous chapter, here, I will present the findings of the data analysis that focused on the second broad categorisation of additional costs of living: capital costs, meaning expenditure on large and small items that are once-off purchases (Thompson, Lavery, Curtice, 1990; Tibble, 2005). Again, each cost is addressed

individually whilst being considered from the perspective of how these costs impact on independent living with particular attention given to the twelve needs of independent living (Hasler, 2003) where applicable and more generally to the wider meaning based on disabled people having choice and control over their lives, like in chapter four. The costs that the participants encountered were in relation to housing and adaptations, car adaptations and assistive technology, which I will address first.

5.2 Assistive Technology: “It was seen as a sort of luxury”

As I alluded to in chapter four, some disabled people require access to a wide range of assistive technology in order to fully engage in independent living (Hasler, 2003; Morris, 2003; Ratzka, 2003) and can be a source of significant extra costs (Berthoud, 1991; Harris, 2010; Indecon, 2004; Large; 1991). This projects’ participants were no different, examples of costs incurred included a ceiling hoist at €1,000 per meter (John and Colette); a hand remote for a ceiling hoist, €435 (John and Colette); a mobile hoist €3,500 (Don); calf and heel pad, €200 each (Don) and a wheelchair, €5,000 (Colette).

As I discussed in chapter one, the point of access for assistive technology for most disabled people in Ireland is through the HSE via Medical Card entitlement (NDA, 2003). However, the availability of

such equipment can be determined first, by budgetary constraints and second, by medical staff recommendations like occupational therapists (Indecon, 2004). According to some of the interview informants the decision of the public health nurse, physiotherapist, occupational therapist (NDA, 2003) to supply assistive technology can be determined by which priority the health service gives to a particular impairment and reflects the inequalities that disabled people in Ireland experience when interacting with the health system (D'Eath et al, 2005). John and Colette, for example are placed on different levels of 'priority', with John on a higher level, this impacts on what supports are given to each of them, thereby creating higher costs of living for Colette when she has had to buy equipment that John would get for free.

John: "The HSE will step in and give me as much support as I need, whereas Colette wouldn't be at that stage she's kind of mid way up and she finds it hard to get support with things.....people are treated differently because of the range of their health" (Interview).

This scenario contorts an established link in the previous literature between severity of impairment and higher additional costs of living (Indecon, 2004; Martin and White, 1988; Thompson, Lavery and

Curtice, 1990), however in this case it is also linked to the inequalities in healthcare delivery (D'Eath et al, 2005).

Consequently, a 'Catch 22' situation developed for some of the research participants when seeking such equipment from the health service, in particular, when gaining approval for equipment is difficult and may take a long time to receive (Indecon, 2004). This resulted in some informants purchasing the equipment privately (Rabiee, Glendinning, 2010) thereby incurring large capital costs (Indecon, 2004) from already stretched incomes, or, the most undermining outcome for independent living: going without. The latter was an experience also reflected in the National Disability Survey (CSO, 2010).

For example, Don, having been refused equipment and frustrated by the health service, a common occurrence reported in UK studies (French, Swain, 2006), gave up accessing assistive technology, in particular wheelchairs, from the health service and imports his equipment from the US, using websites like 'sportaid.com', or the UK. For instance, his expenditure amounted to €3,000 on his last wheelchair, but as he pointed out, it would have cost him substantially more had he bought it in Ireland: one hundred percent more. The only concession to these costs is a VAT refund on assistive technology from the Revenue Commissioners (Revenue,

2011).

Furthermore, the costs of assistive technology prompted all of the interview informants to discuss what they see as a monopoly and a lack of competition in the assistive technology market. This problem is not restricted to Ireland however and Ratzka (2003) described a situation in Sweden that is similar to experiences of the informants: where many disabled people also access such products through medical ‘professionals’ who obviously are not the end-user of the product. As a result, consumer preferences for assistive technology do not reach the product developers, who in other product markets would listen to consumer demands: instead finances and ‘professional’ intervention dictate supplier responses (Ratzka, 2003). This also extends to the ‘specialist’ medical aura around such equipment as wheelchairs (Woods, Watson, 2004) which creates substantial costs of living for disabled people and forms a barrier to independent living (Harris, 2010).

Fiona: “The disability industry is so specialised that they can have as much price as they want you know.....anyone can get a new bed, just a cheap old thing in Argos, whereas with me it’s not the same..” (Interview).

Additional capital costs of living for disabled people do not end at assistive technology but also extend to adaptations to the home (Frisch, 2001; Large, 1991) which is the next additional cost that arose.

5.3 House Adaptations: “I’d build a house to my own specifications”

“A suitable place to live” (Hasler, 2003: unpagged), that is affordable, adapted to meet the needs of disabled people or at the very least will be financed to do so, is one of the key elements that makes independent living possible (Salvage, Zarb, 1995; Barnes, 2006). Irish building regulations such as Part M of the Building Control Act, 2007 state that houses only have to be ‘visitable’ and not ‘livable’ by disabled people (Browne, 2007) therefore further adaptations are required to make houses livable. In addition, disabled people in Ireland have no legal right to adaptations, thus some disabled people must depend on the public funding available (Assist Ireland, 2011). Funding is accessed through Housing Adaptation Grants (see chapter one), which are available through local authorities, the HSE or through voluntary organisations (CSO, 2010). However, previous research has indicated that less than ten percent of the 264,600 disabled people, in the National Disability Survey (NDS), had received such a grant (ibid), a situation that could indicate that

people are financing their own adaptations. This issue affected the research participants in differing ways. For example, Timothy, who acquired his impairment in his adult years, had to adapt the home he lived in with his family but the grant did not cover all of it, an experience mirrored in previous research (Browne, 2007).

Timothy: "I had a three bedroom house, which was adequate, but now I have to live downstairs, I had no bedroom downstairs or toilet. I had to put in a bathroom and a bedroom downstairs, so that cost, you know, the grant would fall short of it so you had to cover the other half of it yourself. About another €20,000 or €25,000 to pay for all of it." (FG).

In relation to the interview informants, John and Colette live in a private home that they built and designed themselves. However, both Don and Fiona live in local authority properties that were purpose built, but to differing degrees. Such properties are the source of housing for some disabled people because of "disabled people's lack of economic power" (Morris, 1993: 136), the background to which I discussed in chapter one. Ergo, some disabled people cannot purchase a house privately (Browne, 2007; French, Swain, 2006), or have to turn to local authority housing because it is more likely to be adapted (Morris, 1993; NDA, 2005).

Fiona witnessed this situation: she only found one privately owned apartment in Cork with a fully accessible bathroom that she could rent in the past. The apartment was not only more expensive, but the nature of its accessibility did not extend to the external doors which were so heavy and difficult to open, that they forced her spend excessive amounts of time indoors. Moreover, Don described that he is in “*real danger of isolation*” (Interview) as a result of a lack of a social life which he says has a lot to do with his current level of income but also because, he:

“Can’t get out of the house, there is nowhere to go, the built environment around here is just not suitable” (Don, Interview).

An experience reiterated by thirty percent of disabled people in the NDS (CSO, 2010). Second, the housing estate is in “*a really rough area*” (Don, Interview) rife with anti-social behaviour. To conclude, a house can be perfectly adapted on the inside, whether at high personal cost or not, but if there is no consideration given to locating it in an accessible environment, both physically and socially, then the value of a lone adapted house is indeed questionable in terms of its ability to facilitate successful independent living (Dunn, 1990; French, Swain, 2006). Nevertheless, some disabled people can by-pass the inadequacies of their immediate built environment

through car ownership (ibid), which is the next capital cost that emerged in the data.

5.4 Car Adaptations: “I can’t just go on ‘carzone.ie’, you know”

For some disabled people access to a car was found, in a UK study, to be the only source of accessible, convenient and secure transport, a view also reflected in the non-disabled population (Wilson, 2003). As popular a choice as car ownership is, disabled people in Ireland are less likely to own a car than non-disabled people (NDA, 2005) and even if disabled people do have access to a car, over 20% of respondents in this category in the National Disability Survey (CSO, 2010) cited the main reason for not driving the car was its need for adaptations. Such adaptations are a source of extra expenditure for disabled people as “specially adapted items cost more than its standard equivalent” (NDA, 2004b: 111). For example, wheelchair lifts can range between €3,000 and €7,000 and electric clutches can range between €1,500 and €3,500 (ibid). Fiona describes her perception of this additional capital expense vividly:

Fiona: “It’s not the actual vehicle that costs, it’s the adaptations that cost the most, and life would be so much easier if I was able to invest in a car for myself, but the only thing stopping me at the moment is the cost and the extortionate expense, you know, if it

wasn't any more expensive than what another person would spend for a car you know then I wouldn't mind it..." (Interview).

In chapter one I outlined grants such as the Motorised Transport Grant and the Disabled Driver or Passenger's Scheme (NDA, 2004b) that are available for disabled people in Ireland. However, there seems to be some contradictions within the grants, even though they were generally seen in a positive light in the focus group discussion. For example, Timothy highlighted the fact that there is a difference in the level of discount available to disabled drivers when compared to a disabled passenger, as the latter receives a bigger deduction than the disabled driver.

Timothy: "You get a percentage of the VAT and VRT back on the vehicle... if the car is over €24,000, you get the maximum back which would be €9,500 and if we say it was a family member buying the car for you.....they'd get a maximum of €15,500 back on VRT, which is good, the vehicle thing is very good" (FG).

However, the additional costs of financing and adapting car have a net result of decreasing choice as a consumer (NDA, 2004b), as Fiona describes:

Fiona: “If I was able to drive that would mean so much more independence, I could drive into town or I could drive anywhere.... I can’t just go on www.carzone.ie you know and buy a car like anyone can...” (Interview).

Furthermore, these costs serve to deprive disabled people of “the right to spontaneous action” (NDA, 2004b: 137) a theme that emerged within the data on more than one occasion, with Fiona illustrating her lack of her own transport as resulting in “*any spontaneity*” being “*out the window*” (*Interview*). In short, there certainly are implications for these additional costs for independent living because, for some disabled people they prevent getting “where you need to be” (Hasler, 2003, unpagged).

5.5 Conclusion

“That’s what independent living is, life” (John, Interview). Throughout this chapter I discussed how life is affected for disabled people who experience the additional capital costs of living by presenting the themes that arose within the focus group and individual interviews from the standpoint of independent living. However, the manner in which some participants fund these capital costs, through loans for example, served to convert these costs into ongoing costs of living

which severely impedes access to an 'adequate income' (Hasler, 2003):

Don: "I have zero disposable income at the end of every week, my loans to the Credit Union are €50 so that already brings it down to €140" (Interview).

Getting by on €140 weekly can have severe implications and reinforces Large's first law of extra costs: "if you don't have the income you can't pay for the expense, and if you can't pay for the expense, the cost is deprivation" (1991, p. 111). The next chapter will discuss what kinds of solutions to these costs are favourable from the perspective of the disabled people who participated in the research.

Chapter Six: Solutions?

6.1 Introduction

The issue of solutions to the additional living costs of disabled people has been explored in the past by much larger scale studies, with mixed results (Martin, White, 1988; Thompson, Lavery, Curtice, 1990; Indecon, 2004). Therefore, given the limitations of a small-scale study, the focus throughout this research has been on the

phrase: 'from the perspective of disabled people'. The issue of a potential solution was put to both the focus group and interview participants and generated different quantities and depth of data due to changes in the research process, as outlined in chapter three. As a result, the data that is discussed here is largely sourced from the individual interviews and secondary data. The main themes under four main headings are: a 'cost of disability' payment, change in philosophy within 'disability' services, legislative changes and direct payments, which I will address first.

6.2 Direct Payments: "I'd definitely be truly independent"

Direct payments, as outlined in chapter two, are potentially one aspect of a solution to the additional costs of living of disabled people in Ireland, because, at the very least, they place the control over some expenditure in their hands (Evans, 2002). Additionally, direct payments would empower Irish disabled people as consumers of assistive technology, as they would have the choice to find the most cost-efficient products to meet their own needs (Ratzka, 2003) and perhaps decrease additional costs. Support for direct payments was reflected by all of the interview informants in the research and is consistent with the opinions of disabled people in previous Irish research (Nolan, Regan, 2003). Colette explained why she and John would support direct payments:

Colette: "So yeah we would be in favour of direct payments because that would give you huge control, because having a PA is great but it's still controlled by who ever pays them, so you are independent but only to a certain extent" (Interview).

However, the focus group data revealed less absolute positive reactions to the issue of direct payments than the individual interviews, with two participants expressing concerns over potential abuse of a system of direct payments by some people:

Maura: "If I was an alcoholic now or an addict of any sort where would my direct payments go? You wouldn't give them to me?"

Susan: No, no, a person would have to be assessed and interviewed and so on.

Maura: And who would do the assessment? Because I think direct payments are open to abuse.

Timothy: I think they are too" (FG).

This exchange underlines the need for suitable structures to be put in place for those who wish to use direct payments (Egan, 2010) that would allay concerns and facilitate people with all impairments. However, as it stands, there is neither a direct payments structure

nor a legal entitlement (see chapter two) to one in Ireland (Egan, 2008), but the experience of other countries like the UK (Pearson et al, 2005) is there to be learned from. However, there is evidence that the Home Care Package Scheme-HCPS (Department of Health and Children, 2009), which was established in 2006 to provide care in the home for older people via cash grants to buy support services in the home, was unofficially extended to some disabled people (Egan, 2008) and there are some pilot projects underway (Cunningham, Mallon, 2009).

For instance, “2 Go Direct” (Egan, 2010), is a case study of two disabled people who succeeded in negotiating a direct payment from the HSE for PA hours. Recommendations of what form a direct payments scheme could take in Ireland did emerge from these case studies as well as from the Independent Living Conference (CIL, 2007). The latter outlined criteria for a successful direct payment policy, which would alleviate the concerns of some disabled people around the implementation of direct payments (Egan, 2008). Among the criteria was the need for a succinct definition of what a PA means and does; that direct payments should include some of the associated overhead costs and that any model of direct payments should have choice and control at its core (ibid). Of course choice and control mean nothing if there is no legislative right to it and it is

the changes to facilitate this right that are discussed next.

6.3 Legislation: *Not* “Another bloody consultation group”

Over the years there have been umpteen consultation groups by the Irish state with disabled people, purportedly with the aim of implementing a social model perspective on legislation and services (NDA, 2003). Nevertheless, despite Don’s and other disabled people’s participation in such consultation groups Irish ‘disability’ legislation (see chapter one) is still not rights based and there is certainly no right to independent living (ANED, 2009). In fact, Don illustrated that past governments regarded a completely rights based legislation as being like a: “*contravention of the constitution because it would make disabled people special citizens above other people*” (Don, Interview). An opinion echoed in Toolan, 2003.

Furthermore, the current emphasis on the availability of monetary resources underpinning ‘disability’ legislation, creates service provision that is unregulated, fragmented (Power, 2010) and underfunded (ANED, 2009), with the effect that Ireland is not meeting the standards set out by Article 19 (b) of the UN Convention on the Rights of Persons with Disabilities (ANED, 2009). Disappointingly, Ireland has signed the Convention but it has yet to ratify it (UN, 2011). Moreover, in order to do so, the Irish state must adjust the

current Ward of Court system which clashes with Article 12.2 of the Convention (ANED, 2009) which states that: “parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life” (UN, 2006: 9). As it stands, a person with learning difficulties can be judged as not having the ‘capacity’ to make any decision in their lives and be made ward of the court (ANED, 2009). This is due to change with the awaited enactment of the Mental Health Capacity Bill, 2008, whereby instead of the courts making sweeping judgements on capacity, they would operate on an issue-by-issue basis (Inclusion Ireland, 2003). Obviously this has major ramifications for people with learning difficulties, independent living and access to direct payments in the future (Nolan, Regan, 2003).

In support of the aims of the Convention, Fiona also expressed the importance for the Irish state to adopt a fully rights based legislation. In particular to the right to have a personal assistant, which would at least guarantee the supply of support services for disabled people, thereby preventing personal income being spent on PAs or losing opportunities for paid work because of limited PA hours:

Fiona: “I think legislation has to move from a resources based to a rights based legislation so that, you know, a person with a

disability should have a right to a personal assistant whatever the economic state of the country is...” (Interview).

This view substantiates three of the criteria for direct payments developed by the Independent Living Conference (CIL, 2007), which stressed the importance of enshrining the right to a PA in legislation regardless of the resources of the state or, the means of the individual (Egan, 2008). However, other ways to alleviate the additional costs of living of disabled people like a cost of disability payment were also discussed.

6.4 Cost of Disability Payment: “A pipe dream”

A ‘cost of disability’ payment was first recommended by the Commission for the Status of Disabilities in 1996 and since has been endorsed by the NDA (Indecon, 2004). The proposed payment would cover the extra daily living expenses of disabled people, similar to the Disability Living Allowance in the UK (Hyde, 2000), perhaps with an element to purchase support services and would be scaled to match level of impairment (Indecon, 2004). It would be based on ‘need’, not on age or employment status (Gannon, Nolan, 2005) as it would be intended “to facilitate participation” (Indecon, 2004 unpagged), not to alleviate poverty.

I posed the question to participants of a specific state payment to meet the additional costs of living of disabled people with particular reference to the Indecon report recommendations for a staggered 'cost of disability' payment of €10, €20 and €40 per week depending on level of 'need'. The reaction to this proposed solution, by one member of the focus group was less than positive: "*It's better than nothing*" (Maura, FG). The latter was the extent of direct comment on the issue as a designated payment was seen as unrealistic given Ireland's current economic situation. Don had similar views when he described it as a "*pipe dream*" (Interview) in the current economic climate but he did comment that it could be worth fighting for in the future.

In contrast, Fiona was in favour of such a payment on top of her existing benefits, however, much like the direct payments issue, her enthusiasm was counterbalanced with words of warning about the potential abuse of the welfare system. When John and Colette were asked what they thought, Colette suggested her own solution in the form of a fund for independent living, however no direct discussion of the potential of a 'cost of disability' payment ensued. Therefore, the data analysis does not expose a consensus on this as a potential solution to the additional costs of living of disabled people.

Nonetheless, a consensus did emerge among interview informants that existing benefits were not adequate due to their ongoing and capital extra costs of living. It is because the current 'disability' welfare payments do not meet the extra costs of living of disabled people (McManus, 2003), that Irish disability organisations have been campaigning for the introduction of a 'cost of disability' payment for years (DFI, 2008; 2009). To-date there has been no progress made in introducing the payment (DFI, 2010) and it seems less and less likely due to the threat of more budgetary cuts, not to mention that the government has already cut 'disability' payments and services in general (Department of Finance, 2010). Perhaps a more attainable solution to extra costs of living could be to change the philosophy underlying the delivery of certain services that disabled people access, this theme arose *in vivo* during analysis and is addressed next.

6.5 Philosophy: "I had to sign under 'patient' even though I'm not sick"

In chapter one I outlined the nature of Irish state 'disability' policies and services. Within the literature a typology of words emerged, be they concerning health services, social welfare or 'disability' policy. Words like 'fragmented' (OECD, 2008), 'ad hoc' (Power, 2010), 'inconsistent' (Department of Health and Children, 2009) and 'discretionary' (McManus, 2003) are used frequently, which gives an

indication of some of the problems that occur within service provision in Ireland. The focus group participants discussed the existing system of state services extensively. What became apparent, in the analysis, is that the way in which some state services are delivered can inadvertently create additional costs of living for some disabled people. I discussed aspects of this issue in the previous two chapters where I outlined how some of the inconsistencies in the health service led to some disabled people experiencing more extra costs than others. For example, how insufficient personal assistant hours can force some disabled people on a limited income to buy PA hours themselves. Also, how being turned down for approval due to funding limitations, or enforced “*paternalism*” (Don, Interview) in relation to assistive technology, caused some of the informants in the research to incur the cost of the equipment themselves.

Therefore, a solution to some of the additional costs could be deduced from the data in terms of a change in the way health services are delivered beginning with a fundamental philosophical change within the ‘disability’ services:

Fiona: “It should be about the social model rather than the health model like a person with a disability isn’t sick, they have a disability, it’s totally different...” (Interview).

Fiona cited her experience of signing her home help contract with the health service in which she was referred to as the 'patient' as an example of this philosophy. Colette and Don made similar recommendations in their interviews. Such a change in philosophy could also encompass the provision of assistive technology, thereby bringing to an end the perception within the health service that this equipment is a "luxury" (*Fiona, Interview; Don, Interview*) for disabled people.

In chapter five, I discussed the perceived monopoly that the suppliers in the 'disability' industry have in the market in Ireland. Intervention by the government (Seelman, 2005) in that sector to encourage the mainstreaming of 'disability' products was suggested by Fiona, who went on to point out that Argos (Argos, 2011) are now offering affordable assistive technology, which is a step towards the mainstreaming of 'disability' products which can avoid "unnecessary financial outlay" (Harris, 2010: 428) for disabled people.

6.6 Conclusion

In this chapter, I discussed themes that emerged in the data analysis that could offer potential solutions to the problem of additional costs of living like, direct payments, new legislation, a cost of disability

payment and philosophical changes in service delivery. Some potential solutions were induced and some deduced, from the data of the focus group and the interviews, with the latter providing some in-depth opinions as to what is preferred by the research participants. What emerged was that no one was suggesting a huge increase in social welfare payments; that a cost of disability payment was the only solution and the views expressed were certainly not: “... *that people just want to be given money and that’ll sort of cheer them up a bit...*” (Don, Interview). The data really pointed to direct payments, a change in philosophical outlook in ‘disability’ services, reinforced by solid rights based legislation as the starting point to any resolution of additional costs of living.

Chapter 7: Overview

At the outset of this dissertation I explained that this research project was conducted on a background of severe economic recession in Ireland (Bergin et al 2011). As with any recession in a capitalist economy, disabled people are one of the first marginalised groups to feel its negative effects (Russell, 2002) even though they would have been unlikely to benefit from an economic boom in the first place (Carpenter, 2009). In the introductory chapter, I outlined the extent

to which disabled people in Ireland did *not* benefit from 'Celtic Tiger' and described how years of 'not benefiting' have culminated in extensive statistical illustrations of social exclusion. It was in this context that the Cork CIL chose this topic for research, in an attempt to use the research as a lobbying tool to prevent further erosion of the already precarious position of disabled people in Irish society (Dolan, 2010).

This action situates this research project within the philosophical and methodological approach of emancipatory disability research (Mercer, 2004), which I discussed in chapter three. Critically, it could be said of the findings in this research, that nothing was totally new, however, what was new, in the Irish context and also made this research worth doing, was that this research was conducted through the lens of the social model of disability of which there is a dearth of such research in Ireland (O'Connor, 2005). I found it frustrating to read reports that were supposedly committed to the social model, whilst endorsing a 'biopsychosocial' model, with undertones of the individual model of disability throughout. I would say that from this experience there needs to be more done, on this topic and on the issues that arose within the research, because there were so many points to make originating from the empirical data that I did not have the scope to include.

Furthermore, an organisation of disabled people wanted a study done on this topic and as they controlled the research, this is central to the emancipatory research principles underpinning this research project (Mercer, 2004). Hence, throughout the research process I attempted to adhere to those principles to the best of my ability, although, I cannot say whether this research was a successful attempt at the latter for several reasons. First, the research process is not yet finished, there is still feedback to be obtained from participants about the findings and there is no guarantee that they will agree with them (Barnes, 1992b). Second, a report has yet to be written and disseminated by the CIL. Third, the research can only be judged as being so following completion, (Oliver, 1997) and certainly not by me, a non-disabled researcher, as “empowerment/emancipation is not in the gift of the researcher” (Mercer, 2002: unpagged) in any case. Therefore, this research must join the other attempts in emancipatory disability research with its many ‘disclaimers’ (Mercer, 2002: unpagged). Even so, I prefer to adopt Barnes and Sheldon’s view about doing such research, that is: “if we aren’t, then what’s the point in doing it?” (2007: 15).

In the ‘doing of it’, this research was based on three research questions. The aim of the first question was to gain an indication of

the nature of the additional living costs of disabled people living in Cork and was combined with the second question, the objective of which was to conceptualise how these costs undermined independent living. These questions were addressed via the secondary data, explored in chapter two specifically and throughout the analysis chapters, as well as through the analysis of the empirical qualitative data generated through one focus group with six participants and individual interviews with four interviewees. However, this was not the original research design, as I described in chapter three, it changed substantially during the research process. In hindsight, the original design was possibly over ambitious for the scale of the study and if I were to do the research again for the CIL I would focus on a qualitative design from the beginning.

The findings contained in chapters four and five, confirmed what the previous literature on the topic described: that some disabled people incur very high levels of ongoing and capital extra costs of living. For example, some disabled people experienced extra costs associated with; personal assistance when engaging in social activities and when subsidising PA hours with savings; extra transport costs in relation to taxis and cars; extra household bills like heating bills due to impairment and social exclusion; home maintenance costs were extra for disabled people who had to pay for someone to maintain

their home; also some disabled people had higher grocery bills because of not enough PA hours and a lack of choice in online stores. Some disabled people also experience extra medical related costs particularly when essential items are *not*, covered by the Medical Card. Participants in the research also had extra expenditure in relation to maintenance of assistive technology, an expense that non-disabled people do not have. In relation to capital costs, the research found that some disabled people accrue substantial costs in relation to assistive technology, specifically when items are refused by the health service and are priced as 'special' items isolated from normal market rules. Also, disabled people can accumulate substantial costs for housing adaptations when grants do not cover all of the costs. These extra costs extended to the cost of car adaptations, which are a considerable extra expense. The conclusion in relation to how these costs undermine independent living lies in the fact that all of these costs, in some way, severely curtailed the choice and control that disabled people have in their lives. This was certainly found to be no different for the participants of this research.

Finally, the third research question sought to forge some solutions to these additional costs of living from the perspective of disabled people. Chapter six addressed this research question and found that

the disabled people in the research considered direct payments, facilitated by legislative changes, reinforced by philosophical changes underlying service delivery to be at the core of a potential resolution to the extra costs of living incurred by disabled people in Ireland.

Therefore, the primary recommendation to emerge from this study is that these preferences for a resolution of costs should be implemented, they make economic sense in this recessionary climate as the positive cost/benefits of independent living to the state is well proven (Zarb and Nadash, 1994) and a change of attitude costs nothing.

Bibliography

Abberley, P. 1992: Counting Us Out: A Discussion of the OPCS Disability Surveys. *Disability and Society*, 7 (2), 139-155.

ANED, 2009: ***Country report on the implementation of policies supporting independent living for disabled people: Ireland.***
Galway: National University of Ireland, Galway.

Argos, 2011: ***Mobility Aids Webpage.***

http://www.argos.ie/static/Browse/ID72/14418351/c_1/1|category_roo t|Health+and+personal+care|14418350/c_2/2|cat_14418350|Mobility +aids|14418351.htm), Accessed 30 July, 2011.

Assist Ireland, 2011: **Homepage.**

(www.assistireland.ie/eng/Information/), Accessed 1 August, 2011.

Barbour, R. 2007: **Doing Focus Groups.** London: Sage

Barnes, C. 1992a: **Disability and Employment.** BCODP.

(<http://www.leeds.ac.uk/disability-studies/archiveuk/archframe.htm>),

Accessed 10 August, 2011.

Barnes, C. 1992b: Qualitative Research: Valuable or Irrelevant?

Disability and Society, 7 (2), 115-124.

Barnes, C. 2001: **'Emancipatory' Disability Research: project or process?** Glasgow, Public Lecture at City Chambers.

(<http://www.leeds.ac.uk/disabilitystudies/archiveuk/Barnes/glasgow%20lecture.pdf>), Accessed 19 October 2010.

Barnes, C. 2006: **Independent Futures: policies practices and the illusion of inclusion.** Presentation for European Network for

Independent Living. (<http://www.leeds.ac.uk/disability-studies/archiveuk/archframe.htm>), Accessed 11 November, 2010.

Barnes, C. 2007: '**Direct Payments' for Personal Assistants for Disabled People: a key to independent living?** Dublin, Centre for Independent Living Conference.

(<http://www.leeds.ac.uk/disabilitystudies/archiveuk/Barnes/Dublin%20-%20direct%20payments%20%202.pdf>), Accessed 11 November, 2010.

Barnes, C. 2008: An Ethical Agenda in Disability Research: rhetoric or reality? In Mertens, D. M. and Ginsberg P. E. (eds.) 2008: **The Handbook of Social Research Ethics**. London: Sage, 458 – 473.

Barnes, C. and Mercer, G. 2004: Theorising and Researching Disability from a Social Model Perspective. In Barnes, C. and Mercer, G. (eds.), **Implementing the Social Model of Disability: Theory and Research**. Leeds: The Disability Press, 1-17.

Barnes, C. and Sheldon, A. 2007: 'Emancipatory' Disability Research and Special Educational Needs. In Florian, L. (ed.), **The Sage Handbook of Special Education**. London: Sage, 233-246.

Beadle-Brown, J. and Kozma, A. 2007: **Deinstitutionalisation and**

community living – outcomes and costs: report of a European Study Volume 3: Country Reports. Canterbury: Tizard Centre, University of Kent.

Bergin, A., Fitz Gerald, J., Kearney, I. and O’Sullivan, C. 2011: The Irish Fiscal Crisis. ***National Institute Economic Review***, 217 (1), 47-59.

Berthoud, R. 1991: Meeting the Costs of Disability. In Dalley, G. (ed.), ***Disability and Social Policy***. London: Policy Studies Institute, 64-100.

British Sociological Association, 2002: ***Statement of Ethical Practice***. Durham, BSA.
(<http://www.britsoc.co.uk/equality/Statement+Ethical+Practice.htm>),
Accessed 20 November, 2010.

Browne, M. 2007: ***The Right Living Space-Housing and Accommodation Needs of People with Disabilities***. Dublin: Citizen Information Board and Disability Federation of Ireland.

Burke-Johnson, R. and Onwuegbuzie, A. J. 2004: Mixed Methods Research: A Research Paradigm Whose Time Has Come.

Educational Researcher, 33 (7), 14-26.

Carpenter, M. 2009: The capabilities approach and critical social policy: Lessons from the majority world? ***Critical Social Policy***, 29 (3), 351-373.

CIL, 2007: ***Conference Report Independent Living 2007***. Dublin: Centre for Independent Living.
(<http://www.dublincil.org/Documents/Conference%20Final%20report.pdf>), Accessed, 5 August, 2011.

Citizens Information Board, 2011: ***Homepage***.
(www.citizensinformation.ie), Accessed 31 January, 2011.

CSO, 2007: ***Equality in Ireland***. Dublin: Stationery Office.

CSO, 2008: ***National Disability Survey First Results***. Dublin: Stationery Office.

CSO, 2010: ***National Disability Survey Volume 2***. Dublin: Stationery Office.

Cullinane, J., Gannon, B. and Lyons, S. 2008: ***Estimating the Economic Cost of Disability in Ireland***. Dublin: ESRI.

Cunningham, N. and Mallon, K. 2009: ***Direct Payments: A Model of Independent Living for Persons with Intellectual Disabilities***. Dublin, National Disability Authority.
 ([http://www.nda.ie/Website/NDA/CntMgmtNew.nsf/DCC524B4546ADB3080256C700071B049/C60FC2E1F2A530068025768E003F108E/\\$File/directpayments_amodelofindependentlivingforpersonswithintellectual%20disabilities.htm](http://www.nda.ie/Website/NDA/CntMgmtNew.nsf/DCC524B4546ADB3080256C700071B049/C60FC2E1F2A530068025768E003F108E/$File/directpayments_amodelofindependentlivingforpersonswithintellectual%20disabilities.htm)), Accessed 16 July, 2011.

Danieli, A. and Woodhams, C. 2005: Emancipatory Research Methodology and Disability: A Critique. ***International Journal of Social Research Methodology***, 8 (4), 281-296.

Davis, K. 1990: ***A Social Barriers Model of Disability Theory into Practice: The Emergence of the Seven Needs***. Paper prepared for the DCDP. (<http://www.leeds.ac.uk/disability-studies/archiveuk/archframe.htm>), Accessed 14 December, 2010.

D'Eath, M., Sixsmith, J., Cannon, R. and Kelly, L. 2005: ***The Experience of People with Disabilities in Accessing Health Services in Ireland: Do Inequalities Exist?*** Galway, National University of Ireland for the National Disability Authority.
 (http://www.nuigalway.ie/health_promotion/documents/J_Sixsmith/20

[05_nda_healthinequalities.pdf](#)), Accessed 25 July, 2011.

DeJong, G. 1985: ***Economics and Independent Living***. Kansas: University of Kansas.

Department of Finance, 2008: ***Summary of 2009 Budget Measures -Policy Changes***. Dublin: Stationery Office.
(<http://budget.gov.ie/budgets/2008/2008.aspx>), Accessed 7 March, 2011.

Department of Finance, 2009: ***Summary of 2010 Budget Measures -Policy Changes***. Dublin: Stationery Office.
(<http://budget.gov.ie/budgets/2010/2010.aspx>), Accessed 7 March, 2011.

Department of Finance, 2010: ***Summary of 2011 Budget Measures -Policy Changes***. Dublin: Stationery Office.
(<http://budget.gov.ie/budgets/2011/2011.aspx>), Accessed 7 March, 2011.

Department of Health and Children, 2009: ***Evaluation of Home Care Packages***. Dublin: Stationery Office.

Department of Justice and Equality, 2009: ***Towards 2016 Strategic Document- National Disability Strategy Vision, Mission and Strategic Objectives.*** Dublin: Stationery Office.

Department of Social Protection, 2011: ***Homepage.***

(<http://www.welfare.ie/EN/Pages/default.aspx>), Accessed 31

January, 2011.

DeWispalaere, J. and Walsh, J. 2007: Disability Rights in Ireland: Chronicle of a Missed Opportunity. ***Irish Political Studies***, 22 (4), 517-534.

DFI, 2008: ***Pre- Budget Submission 2009.*** Dublin, Disability Federation of Ireland. (<http://www.disability-federation.ie/index.php?uniqueID=31>), Accessed 31 January, 2011.

DFI, 2009: ***2010 Pre-Budget Submission.*** Dublin, Disability Federation of Ireland. (<http://www.disability-federation.ie/index.php?uniqueID=226>), Accessed 31 January, 2011.

DFI, 2010: ***Pre- Budget Submission 2011.*** Dublin, Disability Federation of Ireland. (<http://www.disability-federation.ie/index.php?uniqueID=10159>), Accessed 7 December,

2010.

Disability Resource Centre, 2010: ***The Cost of Disability***. Auckland: Disability Resource Centre Inc.

Dolan, J. 2010: ***Recession - Reasons to Progress the National Disability Strategy***. Dublin: Disability Federation of Ireland.

Dunn, P. A. 1990: The Impact of the Housing Environment Upon the Ability of Disabled People to Live Independently. ***Disability, Handicap and Society***, 5 (1), 37-52.

Egan, D. 2008: ***Issues Concerning Direct Payments in the Republic of Ireland***. Dublin: The Person Centre.

(<http://www.dublincil.org/Documents/DP%20Report.pdf>), Accessed 2 August, 2011.

Egan, D. 2010: ***2 Go Direct***. Dublin: Centre for Independent Living. (<http://www.independentliving.org/files/2GoDirect.pdf>), Accessed 11 November, 2010.

Evans, J. 2002: ***How Disabled People are Excluded from Independent Living***. Madrid, Conference On European Disabled

People. (<http://www.leeds.ac.uk/disability-studies/archiveuk/archframe.htm>), Accessed 6 July, 2011.

Evans, J. 2003: ***Independent Living and Direct Payments in Europe***. Ipswich, Rethink Disability Annual Conference. (<http://www.leeds.ac.uk/disability-studies/archiveuk/archframe.htm>), Accessed 6 July, 2011.

French, S. and Swain, J. 2006: ***Housing: The Users' Perspective***. Leeds, University of Leeds. (<http://www.leeds.ac.uk/disability-studies/archiveuk/swain/housing%20chapter.pdf>), Accessed 18 August, 2011.

Frisch, J. 2001: ***Towards a Disability Allowance Offsetting the Costs of Disability: An Analysis***. Willawarrin: Physical Disability Australia.

Gannon, B. and Nolan, B. 2005: ***The Dynamics of Disability and Social Inclusion in Ireland***. Dublin: National Disability Authority and The Equality Authority.

Gannon, B. and Nolan, B. 2010: Disability and Social Inclusion in Ireland. In Bond, L. McGinnity and F. Russell, H. (eds), ***Making Equality Count: Irish and International Research Measuring***

Equality and Discrimination. Dublin: Liffey Press, 158-174.

Gibbs, G. 2007: ***Analyzing Qualitative Data.*** London: Sage.

Good, A. 2003: The Mixed Economy of Welfare and Disability. In
Quin, S. Redmond, B. (eds), ***Disability and Social Policy in
Ireland.*** Dublin: University College Dublin Press, 139-154.

Harris, J. 2010: The Use, Role and Application of Advanced
Technology in the Lives of Disabled People in the UK. ***Disability
and Society***, 25 (4), 427-439.

Hasler, F. 2003: ***Philosophy of Independent Living.*** Sweden,
Independent Living Institute.
(www.independentliving.org/docs6/hasler2003.html), Accessed 20
February, 2011.

HSE, 2011: ***Health Service Executive Homepage.***
(<http://www.hse.ie/eng/>), Accessed 31 January, 2011.

Hurstfield, J., Parashar, U. and Schofield, K. 2007: ***The Costs and
Benefits of Independent Living.*** Leeds: Corporate Document
Services for Department of Work and Pensions.

Hyde, M. 2000: From Welfare to Work? Social Policy for Disabled People of Working Age in the United Kingdom in the 1990s.

Disability and Society, 15 (2), 327-341.

Inclusion Ireland, 2003: ***Who Decides & How? People with Intellectual Disabilities - Legal Capacity & Decision Making.***

Dublin: Inclusion Ireland.

Indecon, 2004: ***Cost of Disability Research Project.*** Dublin: National Disability Authority.

Jolly, D. 2009: ***Research Paper on Community Living and the Support of Independent Living: Costs and Benefits.*** Working paper prepared for the European Network on Independent Living.

(<http://www.leeds.ac.uk/disability-studies/archiveuk/jolly/Research%20paper%20Community%20Living%20and%20the%20support%20of%20IL%20cost%20and%20benefits.pdf>), Accessed 11 November, 2010.

Kitchin, R., Shirlow, P. and Shuttleworth, I. 1998: On the Margins: disabled people's experience of employment in Donegal, West Ireland. ***Disability and Society***, 13 (5), 785-806.

Large, 1991: Paying for the Additional Costs of Disability. In Dalley, G. (ed), ***Disability and Social Policy***. London: Policy Studies Institute, 101-119.

Martin, J. and White, A. 1988: ***OPCS Report 2, The Financial Circumstances of Disabled Adults in Private Households***. London: HMSO.

McGettrick, G. 1994: ***Nothing About Us Without Us: Evaluation of the INCARE Personal Assistance Service Programme***. Dublin: Centre for Independent Living.

McGettrick, G. 2003: Access and Independent Living. In Quin, S. and Redmond, B. (eds), ***Disability and Social Policy in Ireland***. Dublin: University College Dublin Press, 68-82.

McManus, A. 2003: Social Security and Disability. In Quin, S. and Redmond, B. (eds), ***Disability and Social Policy in Ireland***. Dublin: University College Dublin Press, 57-67.

Mercer, G. 2002: Re-viewing Disability Research. In Barnes, C., Oliver, M. and Barton, L. (eds), ***Disability Studies Today***. Cambridge: Polity Press, 228 - 249.

Mercer, G. 2004: From Critique to Practice: emancipatory disability research. In Barnes, C. and Mercer, G. (eds), ***Implementing the Social Model of Disability: Theory and Research***. Leeds: The Disability Press, 118-137.

Morris, J. 1993: Housing, independent living and physically disabled people. In Swain, J. Finkelstein, V., French, S. and Oliver, M. (eds), ***Disabling Barriers- Enabling Environments***. London: Sage.

Morris, J. 1999: ***The Meaning of Independent Living in the 3rd Millennium***. Glasgow, Talk at University of Glasgow Centre for Disability Research. (<http://www.leeds.ac.uk/disability-studies/archiveuk/morris/The%20meaning%20of%20independent%20living%20in%20the%20new%20millenium.pdf>), Accessed 11 November, 2010.

Morris, J. 2003: ***Barriers to Independent Living: A scoping paper prepared for the Disability Rights Commission***. Manchester: Disability Rights Commission.

NDA, 2003: ***Towards Best Practice in Provision of Health Services for People with Disabilities in Ireland***. Dublin: National

Disability Authority.

NDA, 2004a: ***Survey on Social Participation and Disability.***

Dublin: National Disability Authority.

(<http://www.nda.ie/cntmgmtnew.nsf/0/9F11837D4C632B62802570660054EC11?OpenDocument>), Accessed 1 August, 2011.

NDA, 2004b: ***Towards Best Practice in Provision of Transport Services for People with Disabilities in Ireland.*** Dublin: National Disability Authority.

NDA, 2005: ***How far towards equality? Measuring how equally people with disabilities are included in Irish society.*** Dublin: National Disability Authority.

NDA, 2010: ***A Review of International Outcome Measures in Disability Service Provision: A Contemporary Developments in Disability Services Paper.*** Dublin: National Disability Authority.

NESC, 2009: ***Well-being Matters: A Social Report for Ireland Volume 2.*** Dublin: National Economic and Social Council.

Nolan, A. and Regan, C. 2003: ***Direct Payments Schemes for***

People with Disabilities. Bray: Bray Partnership.

O'Connor, M. C. 2005: ***The Research Role of the NDA.*** Dublin, National Disability Authority.

([http://www.nda.ie/website/nda/cntmgmtnew.nsf/0/87418679FAE58B0E80256F02004753E9/\\$File/4Open.htm](http://www.nda.ie/website/nda/cntmgmtnew.nsf/0/87418679FAE58B0E80256F02004753E9/$File/4Open.htm)), Accessed 22 November, 2010.

OECD, 2008: ***Sickness, Disability and Work: Breaking the Barriers, Vol. 3: Denmark, Finland, Ireland and The Netherlands.*** Paris: OECD Publications.

Oliver, M. 1992: Changing the Social Relations of Research Production. ***Disability & Society***, 7 (4), 101-114.

Oliver, M. 1996: ***Understanding Disability: From Theory to Practice.*** Hampshire: Palgrave.

Oliver, M. 1997: Emancipatory Research: Realistic Goal or Impossible Dream? In Barnes, C. and Mercer, G. (eds.), ***Doing Disability Research.*** Leeds: The Disability Press, 15-3.

Overlien, C., Aronsson, K. and Hyden, M. 2005: The Focus Group

Interview as an In-depth Method? Young Women Talking About Sexuality. ***International Journal of Social Research Methodology***, 8 (4), 331-344.

Pearson, C., Barnes, C., Jolly, D., Mercer, G., Priestley, M. and Riddell, S. 2005: Personal assistance policy in the UK: What's the Problem with Direct Payments? ***Disability Studies Quarterly***, 25 (1), unpagged.

Power, A. 2010: ***Individualised Resource Allocation Systems: Models & Lessons for Ireland***. Galway: Centre for Disability Law and Policy, National University of Ireland Galway.

Pridmore, A. 2006: ***Disability Activism, Independent Living and Direct Payments***. Leeds, Independent Living and Direct Payments, The National Picture Conference. (<http://www.leeds.ac.uk/disability-studies/archiveuk/pridmore/direct%20payments%20conference%20paper%2011.pdf>), Accessed 11 November, 2010.

Priestley, M. 1997: Who's Research? A personal audit. In Barnes, C. and Mercer, G. (eds.), ***Doing Disability Research***. Leeds: The Disability Press, 88-107.

Punch, K. F. 2005: ***Introduction to Social Research: Quantitative***

and Qualitative Approaches (2nd edn.). London: Sage.

Quin, S. 2003: Health Services and Disability. In Quin, S. and Redmond, B. (eds), **Disability and Social Policy in Ireland**. Dublin: University College Dublin Press, 83-98.

Rabiee, P. and Glendinning, C. 2010: Choice: what, when and why? Exploring the importance of choice to disabled people. **Disability and Society**, 25 (7), 827-839.

Ratzka, A. 2003: **From patient to customer: Direct payments for assistive technology for disabled people's self-determination**.

Sweden, Independent Living Institute.

(www.independentliving.org/docs6/ratzka200308b.html),

Revenue, 2011: **Revenue Commissioners Homepage**.

(www.revenue.ie), Accessed 31 January, 2011.

Russell, M. 2002: What Disability Civil Rights Cannot Do: employment and political economy. **Disability & Society**, 17 (2), 117-135.

Salvage, A. and Zarb, G. 1995: **Measuring Disablement in Society-**

Working Paper 2, Gaining Access: Disabled People and the Physical Environment. Economic and Social Research Council.

(<http://www.leeds.ac.uk/disability-studies/archiveuk/Salvage/meas%20work%20paper%202.pdf>),

Accessed 2 August, 2011.

Seelman, K.D. 2005: Universal Design and Orphan Technology:

Do We Need Both? *Disability Studies Quarterly*, 25 (3) unpagued.

Seymour, J. and Garbutt, R. 1998: '**Do we all get a PhD?**'

Attempting Emancipatory Research Relating to Disability in an

Academic Environment. Edinburgh, British Sociological

Association Conference. ([http://www.leeds.ac.uk/disability-](http://www.leeds.ac.uk/disability-studies/archiveuk/garbutt/Do%20we%20all%20get%20a%20PhD%202.pdf)

[studies/archiveuk/garbutt/Do%20we%20all%20get%20a%20PhD%202.pdf](http://www.leeds.ac.uk/disability-studies/archiveuk/garbutt/Do%20we%20all%20get%20a%20PhD%202.pdf)), Accessed 19 October, 2010.

Sheldon, A. 2001: **Disabled People and Communication Systems in the Twenty First Century.** PhD Thesis, Leeds: University of Leeds.

Silverman, D. 2006: **Interpreting Qualitative Data (3rd edn.).**

London: Sage.

Simkins, J. 1978: ***The Value of Independent Living***. London: Spinal Injuries Association.

Smith, N., Middleton, S., Ashton-Brooks, K. Cox, L., Dobson, B., and Reith, L. 2004: ***Disabled people's costs of living- More than you would think***. York: Joseph Rowntree Foundation.

Smithson, J. 2000: Using and analysing focus groups: limitations and possibilities. ***International Journal of Social Research Methodology***, 3 (2), 103-119.

Social Research Association, 2002: ***Ethical Guidelines***. London, SRA. (<http://www.the-sra.org.uk/documents/pdfs/ethics02.pdf>), Accessed 25 November, 2010.

Stapelton, D., Protik, A. and Stone, C. 2008: ***Review of international evidence on the cost of disability***. London: HMSO.

Stone, E. and Priestley, M. 1996: Parasites, pawns and partners: disability research and the role of non-disabled researchers. ***British Journal of Sociology***, 47 (4), 699-716.

SuperValu, 2011: ***Homepage***. (<http://shop.supervalu.ie>), Accessed

20 August, 2011.

Thompson, P., Buckle, J. and Lavery, M. 1988: ***Not the OPCS Survey: Being Disabled Costs More Than They Said.*** London: The Disablement Income Group.

Thompson, P., Lavery, M. and Curtice, J. 1990: ***Short Changed by Disability.*** London: The Disablement Income Group.

Tibble, M. 2005: ***Review of existing research on the extra costs of disability.*** Leeds: Corporate Document Services for Department of Work and Pensions.

Tisato, P. 1997: Travel Affordability For People With Disabilities. ***Urban Policy and Research***, 15(3), 175-187.

Toolan, D. 2003: An emerging rights perspective for disabled people in Ireland: an activist's view. In Quin, S. and Redmond, B. (eds), ***Disability and Social Policy in Ireland.*** Dublin: University College Dublin Press, 171-181.

UN, 2006: ***United Nations Convention on the Rights of Persons with Disabilities.*** New York: UN.

http://www.un.org/disabilities/documents/convention/convention_acc

[essible_pdf.pdf](#)), Accessed 5 September, 2011.

UN, 2011: ***United Nations Enable- Convention and Optional Protocol Signatures and Ratifications Webpage.***

(<http://www.un.org/disabilities/countries.asp?navid=12&pid=166>),

Accessed 5 August, 2011.

UPIAS, 1976: ***Fundamental Principles of Disability.*** London:
Union of the Physically Impaired Against Segregation.

Wiles, R., Crow, G., Heath, S. and Vikki, C. 2008: The Management of Confidentiality and Anonymity in Social Research. ***International Journal of Social Research Methodology***, 11 (5), 417-428.

Wilson, L.M. 2003: ***An Overview of the Literature on Disability and Transport.*** UK: Disability Rights Commission.

Woods, B. and Watson, N. 2004: A Glimpse at the Social and Technological History of Wheelchairs. ***International Journal of Therapy and Rehabilitation***, 11 (9), 407-410.

Zaidi, A, and Burchardt, T. 2003: ***Comparing incomes when needs differ: Equivalisation for the extra costs of disability in the UK.***

London: CASE.

Zarb, G. 1992: On the Road to Damascus: First Steps towards Changing the Relations of Disability Research Production. *Disability & Society*, 7 (2), 125-138.

Zarb, G. 2003: *The Economics of Independent Living*. Sweden, Independent Living Institute.

(<http://www.independentliving.org/docs6/zarb2003.html>), Accessed, 20 February, 2011.

Zarb, G. and Nadash, P. 1994: *Cashing in on Independence*. Derbyshire: British Council of Organisations of Disabled People.

Zarb, G. and Oliver, M. 1993: *Ageing with a Disability: What do they expect after all these years?* London: University of Greenwich.

Appendix 1

Focus Group Information Sheet and Consent Form

a. Information Sheet:

Project title: An Investigation into the Additional Living Costs of Disabled People: Implications for Independent Living in Cork, Ireland.

Aims of the project:

1. To gain an indication of the additional costs of living of disabled people living in Cork. This research is under the guidance of an organisation of disabled people. It is based on the social model of disability which views disability as resulting from the

social and economic barriers that disabled people experience in society.

2. To gain an insight into how these extra costs of living impact on key aspects of independent living.
3. To come up with some ideas about how these costs could be resolved and as a result, prompt further debate on the issue.
4. Finally, to produce a report to be disseminated by the Cork CIL as they wish. One possible use is as a lobbying tool that could be aimed at a new government in order to ensure that these issues remain on the political agenda.

The research questions:

This project is attempting to answer three core questions:

1. What are the additional living costs incurred by disabled people in Cork?

Taking the additional costs of living to mean:

“...Additional costs associated with needs related to a person’s impairment and associated experience of disability.” (Disability Resource Centre, 2010: 27).

2. How do these additional living costs undermine independent living?

Taking the meaning of independent living to be:

“All disabled people having the same choice, control and freedom as any citizen -at home, at work, and as a member of the community”
(Morris, 2003: 4).

3. What could a solution to these living costs look like?

The objective is to seek the opinions of disabled people on what form a solution to these extra costs of living could take.

The research process:

The research will use two main methods to gather information or data: the focus group, followed by a questionnaire, followed by a focus group, this means that this is a mixed-methods research project. The findings will be available in September.

The research blog:

A research blog is being developed to prompt some online debate, if anyone would like to contribute, this is the address to go to, and it's at early stages yet so posts would be welcome. Just contact the researcher on the blog email to add posts or comment on the blog directly: <http://extracosts.blogspot.com/>

For any queries/comments contact: Carol O'Sullivan 086 374**** or cjcos@me.com

Consent form for participants of Focus Group One

Project Title: An Investigation into the additional living costs of disabled people: Implications for independent living in Cork, Ireland.

Carol O’Sullivan of the University of Leeds is conducting MA research, in conjunction with the Cork Centre for Independent Living on the extra costs of living experienced by disabled people and how these costs impact on the different aspects of independent living, with a view to identifying solutions to this issue. Your participation in the study would be greatly appreciated. As a participant in this focus group you will be asked to discuss your knowledge and experience of these issues. The researcher will be able to look at this data and draw conclusions that will be used to help improve the questionnaire that will be sent to more participants. A report of the findings will be written for the Cork CIL as well as for the purposes of a dissertation.

We hope that this research is beneficial to people in the future, we cannot say if there is a direct benefit to you now. There are no anticipated risks to you in the study, emotionally, socially or physically. Your participation is voluntary and you are free to

withdraw from the research at any time. No one in the group is obliged to answer any questions they do not want to.

The Focus group discussion is estimated to last for up to 1.5 hours, and will be audio-recorded. The reason for recording the discussion is so that the researcher can ensure that no information is overlooked. The recording will only be listened to by the researcher and will be stored as securely as possible on a password-protected computer.

The information given is confidential. Only the researcher will have access to the information and any findings will not contain your name, or any information that could reveal your identity. As a participant in the group you are entitled to a copy of the transcripts before they are used in the research to read, comment on and change if you feel you would like to.

If you have any more concerns about the research, or your rights as a participant, please do not hesitate to ask any questions during the group. After the focus group discussion is over, the researcher, Carol O'Sullivan, can be contacted on 086 374**** or cjcos@me.com, with any more concerns or questions you may have.

I understand that I will be participating in the research entitled “An Investigation into the Additional Living Costs of Disabled People: Implications for Independent Living in Cork, Ireland”. I have read and understood the above information and have been made aware of my rights as a participant.

I have been informed that the focus group discussion is going to be audio-recorded, and I understand the purpose of the research. I am aware that I can contact the researcher with any questions or concerns that I may have.

I also understand that my participation is voluntary and I can withdraw any time without giving any reason.

I give my consent to participate in this research.

Signed _____

Date _____

Please include your contact details here if you would like to receive a copy of the transcripts:

Name:

Address:

Appendix 2

Focus Group Topic Guide 14/04/2011

Vignette: Taken from Chapter 6 of Thompson, Lavery and Curtice (1990). Prices are in euro, adjusted to today's values using the average earnings rate from www.measuringworth.com

Linda Rice is 58 and lives with her husband in a house they are buying with a mortgage. Her husband is an accountant and Linda is self-employed, breeding Cavalier King Charles spaniels. Linda has a medium level of personal assistance need.

She spends €47 a week on private domestic help and €23 a week for

gardening and odd jobs. Chemist items and unprescribed medications cost €4.80 a week and she eats whole foods without additives (a diet recommended to her) which adds a further €36 to her food bill.

Over €2400 has been spent on the purchase of equipment for the house including a special combination of microwave oven, a washing machine and a freezer.

Linda says she is “managing quite well”. Total household income is €1071 per week with ongoing extra costs of living at €119 a week, totaling 11%. However, there is no benefit income in this household. Clare Bell is 38 years of age she is a wheelchair user and has a high level of personal assistance need.

Research Question One

1. In general do people feel that they have extra costs of living?

Prompts:

Are large chunks of income spent on these items?

Is it possible to save for a rainy day?

Are there items that people have to forego spending on?

Is managing money an issue?

2. What kinds of items cost the most? Once off items like:

Prompts:

Capital costs like car/house adaptations.

Did anyone avail of the Disabled Passenger/Driver Scheme or the Mobility Transport Grant?

House adaptations and assistive technology.

3. How about on going daily costs? What items cost the most?

Prompts:

Personal assistance, medicines, clothes, laundry, food- special diet, fuel/heating, electricity, transport and travel, wear and tear.

4. Are there any items that you would spend more money on if you could?

Prompts:

Personal assistance, additional services from the HSE, transport, public/ private, heat/electricity, house adaptations, social activities

5. How about going on holidays, are holidays something that are the first to be sacrificed because of money has to be spent elsewhere?

6. Does anybody think that disabled people have to forego spending on certain items as a result of extra costs of living?

7. Do people think that worrying about bills and debts in general is common in the disabled community because of these extra costs?

Research Question Two

8. Do people think that the concept of Independent Living is understood by the government, its services and society in general?

9. What does independent living mean for this group?

Prompts:

Is it about, choice mainly, control, rights, personal assistance, a decent income?

10. Do people feel that finances have an affect on independent living?

11. Of the elements of independent living as defined by the independent living movement like...SEE PROMPTS...does the additional costs of living affect these elements?

Prompts:

Personal assistance, transport, assistive technology, adapted

housing, equal opportunities for employment.

Research Question Three

12. What do people think would be an appropriate solution to the extra costs of living?

13. Are present state benefits adequate to meet extra costs?

Prompts:

Increased state benefits across the board for anyone receiving a disability related payment; a specific cost of disability payment: means tested/not? Indecon suggested €10 low need, €20 medium need, €40 per week high need; direct payments to be managed by the person receiving the payment to be spent on services as needed. Tax credits; would changes in: Legislation, society make a difference?

Appendix 3

Transcript: Focus Group 14/04/2011

All names of participants have been changed any personal information has been removed and has been replaced by the following symbol: *****.

[Discussed the project, read out consent form and gained consent]

1. **Moderator:** Ok, I suppose the first thing I would like to do is
2. read a story or vignette that I have, that I took from an
3. existing piece research on the additional costs of living and I
4. am going to read it to see if anybody has any comments on
5. it, and I will ask some questions after that. This story is taken

6. from a UK study done in the 1990's.
7. Linda Rice is 58 and lives with her husband in a house they
8. are buying with a mortgage. Her husband is an accountant
9. and Linda is self-employed, breeding Cavalier King Charles
10. spaniels. Linda has a medium level of personal
11. assistance need. She spends €47 a week on private
12. domestic help and €23 a week for gardening and odd
13. jobs. Chemist items and unprescribed medications cost
14. €4.80 a week and she eats
15. whole foods without additives (a diet recommended to
16. her) which adds a further €36 to her food bill.
17. Over €2400 has been spent on the purchase of
18. equipment for the house including a special combination
19. of microwave oven, a washing machine and a freezer.
20. Linda says she is "managing quite well". Total household
21. income is €1071 per week with ongoing extra costs of
22. living at €119 a week, totaling 11%. However, there is no
23. benefit income in this household.
24. **Moderator:** From that story would that be a common
25. experience of the lower level of extra costs of living?
26. **Susan:** Most disabled people I know would have a
27. Medical Card so their main medical bills would be met by
28. that, but there are always some items you have to buy

29. that are not necessarily on the Medical Card, em, and
30. then in terms of my own situation I suppose my biggest
31. extra expense would have been that I would always have
32. had to rent accommodation with two bedrooms. I'm a
33. single person but because I would have personal
34. assistants staying overnight I always had to make sure
35. that I could provide accommodation for them as well so
36. having a bigger accommodation means bigger heating
37. bills and so on as well. (...) Yeah that would be my
38. experience.

39. **Maura:** I am fortunate to have my own house (.)
40. but the added costs in private accommodation is house
41. insurance and security. And security bills are huge.
42. And I see that as a real priority, safety and security and
43. (..) like immediately I put safety and security as a priority
44. my list and maintenance to the security company (.) and
45. then if you call them out it's €90 (..) and then when I got
46. sick I was in London and I've an upstairs and I wanted a
47. chairlift to be put in and they could not install it for six
48. months so my brothers got it and put it in privately and the
49. maintenance officer, he wouldn't cover it as it was put in
50. privately but luckily I have a friend an engineer and he
51. maintains it. So now the HSE (..) even I have PA's and

52. HSE home helps. The home help (..) I had visitors
53. coming, only for the PA's with independent living (..) they
54. wouldn't make up (..) home helps are told by the HSE just
55. to do the clients bed and not any other room. So my
56. friends were coming and they were advised not
57. to do it. (...) So I feel the HSE, the independent living (..) the
58. *** is better than the HSE.

59. **Moderator:** So is that because the HSE have a different
60. concept of what independent living means?

61. **Maura:** (xxxxxxx)-

62. **Susan:** (overlapping) I think what Maura means is that
63. with home helps, it's very (..) their job description is very
64. prescribed, it's very much what you can and can't do
65. and the whole idea behind personal assistance would be
66. is whatever the person needs you to do in that time, so for
67. example, if you are getting a PA for an hour, that hour
68. could be spent doing a mixture of personal care,
69. domestic duties, (..) or community activities, (..) whereas
70. I know a lot of, quite a few disabled people, because
71. they would have a limited number of PA hours, or home
72. help hours even, that they have to pay for someone to
73. come in and clean the house maybe once a week-

74. **Maura:** (overlapping) Yeah, I did that at the beginning.

75. **Susan:** Yeah, and I know people (..) that because the
76. home help service, they are only allowed to kind of (..)
77. in some cases they are only allowed to do personal care
78. if they are allowed to do some domestic duties it's only
79. where the person is resident, so there could be a four
80. bedroom house and they might only be allowed to,
81. change the sheets in the persons bedroom and if there
82. was rooms downstairs and the disabled
83. person was predominantly in the kitchen this would be
84. the room that they could (...) actually clean. And okay,
85. you might think that that's fair enough if the other rooms
86. are not being used, but you know, you're going to be
87. going in and out of all the rooms, and there is going to be
88. may be dust, so it can be an extra expense.

89. **Moderator:** So is that an extra cost as well in terms of
90. getting-

91. **Maura:** (overlapping) It's not because I have a PA.

92. **Susan:** It can be for a lot of people.

93. **Maura:** It could be for lots of people that wouldn't have a
94. PA or enough hours.

95. **Susan:** That woman (..) you read out her case study, she
96. had to pay people for domestic duties and gardening and
97. they are things that practically speaking if someone didn't

98. have a disability they would do it themselves, gardening
99. in particular.

100. **Moderator:** Yeah, exactly. So how does (..) if the HSE
101. gives a certain amount of funding towards personal
102. assistants or home help, what about the rest of the time,
103. what do people do, are there extra costs involved in that
104. regard?

105. **Timothy:** Well I'd say if you were living on your own
106. there would be, whereas the likes of me I'm lucky, I'm at
107. home with my family. So I have a PA twice a week and I
108. have home help coming to me as well. But what Susan
109. was saying there while ago, if I was going anywhere,
110. away for the weekend or anything I'd have to ask the
111. home help to come with me or something and I'd have to
112. pay for them, you know, and I'd have to pay for the room
113. and the whole lot, pay for their transport, stuff like that
114. you know?

115. **Susan:** Yeah, that's a huge expense. Even for people
116. who are working (..) you know the average person might
117. go on holidays maybe at least three or four times a year
118. now, you know, weekends away and stuff. But for a
119. disabled person it could be every two, three years by the
120. time you save up to cover the other persons

121. accommodation, flight and so on.

122. **Timothy:** Yes, it's tough. I have to have heating as well

123. so, my heating bills are extra because I have the heating

124. on all the time in my house, with what I have, come

125. summer now all right it's grand you know (..) in the winter

126. time I have to have the heating on an awful lot, with what I

127. have you know, you have a big heating bill then you

128. know, so you have to think you have to pay double the

129. amount because if you have someone in to help you, you

130. don't expect them to pay, so you have to pay for them as

131. well.

132. **Susan:** It's not even going on holidays it's-

133. **Timothy:** (overlapping) it's going anywhere.

134. **Susan:** going out on a Tuesday night or something-

135. **Timothy:** (overlapping) it could be going anywhere, that's

136. right.

137. **Moderator:** And as a result would that be the main

138. ongoing cost? Because when you are looking at costs

139. there are capital costs, like housing adaptations, or cars-

140. **Timothy:** (xxxxxxx) when I was putting an extension on

141. to my house, a bedroom downstairs and a bathroom and

142. stuff, so I got a grant towards it, but I had to pay the rest

143. then myself so you have to come up with the money

144. to pay the rest yourself-
145. **Susan:** (overlapping) sometimes people were getting
146. into debt, you know get a loan out-
147. **Timothy:** (overlapping) that said you'd have to borrow to
148. do it you know. I had a three bedroom house, which was
149. adequate, but now I have to live downstairs, I had
150. no bedroom downstairs or toilet. I had to put in a
151. bathroom and a bedroom downstairs, so that cost
152. you know, the grant would fall short of it so you had
153. to cover the other half of it yourself. About another
154. €20,000 or €25,000 to pay for all of it.
155. **Moderator:** That's a lot of money.
156. **Timothy:** And to do that you had to get a loan.
157. **Moderator:** Does the current economic situation now (..)
158. has that affected what it would be like to get a loan as the
159. banks don't seem to be loaning any money?
160. **Timothy:** That's it yeah.
161. **Susan:** You have to be employed et cetera, et cetera.
162. **Moderator:** They say they are doing it but they are not
163. really.
164. **Susan:** Because I live alone with PA's, when I did get a
165. mortgage, when I was looking for a place I knew I had
166. to get a place with more than one bedroom, obviously

167. left to my own devices, I'd be happy to rent, or to buy
168. a one bedroom apartment, but instead I had to get
169. a three bedroom place (..) which is obviously a bigger
170. outgoing if I didn't have PA's.
171. **Moderator:** As a result do people feel like that there is
172. income left after the extra costs, is there a big chunk of
173. income gone?
174. **Timothy:** If there is anything left, it's very little, you know,
175. because of what you have to pay out.
176. **Susan:** I think with the cutbacks, or the reduction of
177. social welfare rates this year, I mean, how much was
178. was the Disability Allowance reduced by?
179. **Maura:** 7 euro-
180. **Timothy:** (overlapping) 8 euros
181. **Susan:** Like that could have been what you'd pay a
182. cleaner or someone to come in once a week to do cash-
183. in-hand work and stuff.
184. **Maura:** Also, now I need a new chairlift, I got it second
185. hand, the HSE don't do it anymore, and then you need to
186. maintain it yourself afterwards-
187. **Susan:** (overlapping) It's costly.
188. **Maura:** That would be because I would only have
189. someone to do it, and I know I couldn't live independently

190. without my family. I could not do it.
191. **Moderator:** So do you think family's pick up the extra..?
192. **Timothy:** Oh yeah, an awful lot-
193. **Maura:** (overlapping) yes.
194. **Timothy:** I'd be lost without my family, my sons and
195. daughters, they are very good to me. Because I need
196. help getting into the car, taking away the wheelchair and-
197. **Susan:** (overlapping) It's filling in those gaps when you
198. don't have a PA.
199. **Timothy:** Yeah.
200. **Moderator:** And if that time was quantified, in terms
201. of extra cost, that would be quite a lot.
202. **Susan:** Even in something like CIL we provide services
203. or PA hours or small amount of PA hours to individuals
204. and maybe they get one session a week to go into town,
205. to go shopping or to go to the cinema or something. Like
206. I was just thinking about this yesterday, that there is a 20
207. Yr old person who attends the training centre down in
208. ***** on a Saturday, he'd have a disability, a mild
209. learning disability as well as a physical disability and (..)
210. his PA and himself used to go into town on a Saturday
211. and one day last year the father rang me to say that he
212. was concerned, the receipts were coming back. Now, the

213. son who'd have a mild learning disability and (.) they
214. might give their son maybe €15 or €20 for the couple of
215. hours (.) but the receipts were coming back and the son
216. might be getting, you know, coca cola, but the PA was
217. getting three course meals and that kind of thing.

218. **Timothy:** Yeah.

219. **Susan:** And that's, you know, (..) maybe some people
220. just assume (.) I was talking to someone in the office
221. about this yesterday (..) I know that, I think in England
222. the Independent Living Fund, that people get money for
223. non-pay costs (.) a PA, their meals and stuff would be
224. covered but obviously not in Ireland. Like that PA was
225. Irish, and that was taking advantage really.

226. **Timothy:** It was, yeah, it totally was.

227. **Susan:** He's a young adult but he does have a learning
228. disability, he could be taken advantage of.

229. **Moderator:** Certainly if someone is getting a coke and
230. someone else is getting a dinner!

231. **Susan:** Yeah, it's totally wrong.

232. **Maura:** Like I feel, with independent living, we have great
233. rights but also responsibilities.

234. **Susan:** Yeah exactly.

235. **Maura:** And I think that that responsibility is forgotten

236. sometimes.
237. **Susan:** Yes (....) Eleanor could you think of any extra
238. costs that would apply to yourself, like transport or (..)?
239. **Eleanor:** Em, with me it's mostly medical.
240. **Susan:** What are things that are not covered by the
241. Medical Card?
242. **Eleanor:** Like incontinence sheets, they would be €60
243. so that's, €30 a month for incontinence sheets, they were
244. usually covered.
245. **Susan:** In the past by the medical card.
246. **Moderator:** Since when has that changed, is that a
247. recent change?
248. **Eleanor:** Yeah, since the recession.
249. **Susan:** I was talking to the Public Health nurse and
250. she was saying it wasn't actually a financial decision,
251. whether it's true or not, she was saying that research
252. showed that incontinence sheets could make, say,
253. pressure sores worse, you know, so it was actually
254. on that ground that (.) but I don't know if that's true
255. or not.
256. **Eleanor:** What were the grounds?
257. **Susan:** That they weren't good for skin basically, that
258. they could make pressure sores worse (...) But, I don't

259. know, I was talking to my Public Health Nurse there and
260. because I used buy them myself all the time but now they
261. are giving them to me.
262. **Eleanor:** They are giving them to you?
263. **Susan:** Yeah, I was buying them for years.
264. **Eleanor:** I was the opposite I got them for free?
265. **Susan:** Yeah, I was buying them now you are (..)
266. yeah, I know what you are saying
267. **Eleanor:** The incontinence sheets I have to (..) buy now,
268. they're the only things I have to buy but still it's costly.
269. **Moderator:** It's a lot of money.
270. **Eleanor:** And (..) the doctor, my neurologist said that
271. I have to go on certain vitamins and they are not even
272. covered, so (..) they're €10 every time.
273. **Moderator:** And how often would that be? Once a month
274. or..?
275. **Eleanor:** One lot is once a month and the other is twice a
276. month.
277. **Moderator:** Do you think that there is inconsistencies
278. within the HSE on things like that or? (..) is it hard to
279. know what you're entitled to?
280. **Susan:** Yeah, because last year I went to visit a couple
281. and the husband has **** (..) his wife (..) because

282. at the time I had a problem with my ankle and her
283. husband had as well and she showed me that his foot
284. was in a very good support system. And she shocked me
285. because she actually had to buy that because it used to
286. be on the Medical Card and it's not now. And (..) this
287. couple wouldn't have a spare cent.

288. **Adrian:** I took my prescription in the other day (..) and I
289. didn't query it at all (..) I should have done (.) and I took
290. my prescription in and they gave me what was on
291. prescription, but then they charged me €5-

292. **Susan:** (overlapping) 50 cent per prescription.

293. **Adrian:** I don't know what that was all about-

294. **Timothy:** (overlapping) 50 cent per item.

295. **Eleanor:** 50 cent per item.

296. **Timothy:** If you have 5 different items, do you know, you
297. pay 50 cent on each one. Like I pay €4.50 every month
298. now (.) €4.50 for my prescription because I've 9 items on
299. my prescription, 9 different medicines (..) so I pay 50
300. cent for each one, that's a new thing that came out last
301. year.

302. **Adrian:** I didn't even know about it.

303. **Timothy:** Yeah.

304. **Susan:** That's true I had forgotten about that yeah.

305. **Timothy:** There are all these small costs.
306. **Susan:** But, they all kind of add up.
307. **Moderator:** They add up, yeah.
308. **Adrian:** Yeah, definitely.
309. **Moderator:** So that means things like, managing money
310. becomes an issue in terms of savings? Actually having a
311. rainy day fund?
312. **Maura:** Yes, for me it's doing without luxuries, like make
313. up or a present for my birthday now would be money for a
314. taxi. Put it into a taxi account.
315. **Moderator:** And I suppose that brings us on to transport.
316. What are the extra costs in relation to transport?
317. **Maura:** But then you know (.) if I was well I would have a
318. car, I'd have to pay an enormous amount on insurance
319. (...) because I know a friend and they have to pay an
320. enormous amount on insurance.
321. **Susan:** I thought there was a ruling that it was
322. discrimination (.) that women could get cheaper
323. insurance.
324. **Moderator:** Yeah they are starting that now.
325. **Timothy:** Yeah it has to be equal now between the men
326. and the women (..) because young fellas were being
327. discriminated against on insurance.

328. **Susan:** I suppose there was a reason behind that
329. discrimination.
330. **Timothy:** I don't know (..) I don't know about that now.
331. **Susan:** But you know I mean, they were driving fast,
332. recklessly and all that-
333. (laughter)
334. **Timothy:** Yeah that's only the young fellas alright (.)
335. would be driving fast I agree with that (...) But if you get
336. the Medical Card you get a bus pass and stuff like that. A
337. lot of disabled people have bus passes so they can use
338. the bus themselves for free, you know, or the train or
339. whatever (..) well like that now if there is someone coming
340. with you, your PA and stuff, you don't expect your PA to
341. pay for it you know, so you pay for your PA.
342. **Adrian:** Is that a companion pass?
343. **Timothy:** Well my wife is on my one you see, I must get it
344. changed to a companion pass alright (..) whereas if I had
345. a companion pass, say my PA now, he'd be able to go
346. with me-
347. **Susan:** (overlapping) would go with you yeah.
348. **Timothy:** Or my home help or whatever. My home help is
349. very good to me, I have a fantastic home help, he's as
350. good as a PA you know.

351. **Susan:** Because I work (...) I don't have a companion
352. pass but like I go up home, up the country to visit my
353. parents and I'm bringing a PA so I'm buying two tickets
354. which is €100.
355. **Timothy:** I think that is a disgrace (.) when you are
356. disabled you should be entitled to that whether you are
357. working or not-
358. **Susan:** (overlapping) I wouldn't mind (.) well I'd be happy
359. to (..) maybe not the companion pass but-
360. **Timothy:** (overlapping) just a pass for yourself-
361. **Susan:** (overlapping) just a pass or a pass for the PA
362. and I'd pay for myself.
363. **Timothy:** That's a disgrace (.) I didn't realise that until
364. Susan told me that one day, that if you're working they
365. don't give you bus pass, which is a disgrace really.
366. **Susan:** I mean train travel is expensive now and I'm
367. paying double, I mean it's not fair to ask the PA to pay
368. because she's traveling and I've asked her to travel.
369. **Timothy:** That's it yeah.
370. **Adrian:** What's the criteria for the companion pass?
371. **Susan:** Well-
372. **Adrian:** (overlapping) I mean to get a companion pass
373. you have to be married or something?

374. **Susan:** No, no because I was never married (..) it would
375. be like-
376. **Timothy:** (overlapping) No, normally single people would
377. get a travel pass and they'd get a companion pass so-
378. **Susan:** (overlapping) so that a family member and PA
379. would go with them-
380. **Timothy:** (overlapping) so that they would go with them
381. for free you know.
382. **Susan:** If you are on the train (.) you are not going to be
383. able to go up to where they sell the food and stuff so
384. your PA would go with you, or you need to use the
385. bathroom, your PA would be with you. It doesn't have to
386. be a family member.
387. **Timothy:** It's just that when I got mine I put down the
388. wife's name on it, but I must get it changed to a
389. companion pass.
390. **Adrian:** (xxxx) (xxxx) so you can go with your wife.
391. **Timothy:** That's it yeah.
392. **Moderator:** So is public transport accessible?
393. **Maura:** Some of the buses are not wheelchair accessible
394. **Susan:** Most of them are to be fair.
395. **Maura:** The train is good now, the train is good-
396. **Timothy:** (overlapping) The train is fantastic. The train is

397. very good, but I don't know about buses because I have a
398. car myself so.
399. **Susan:** But then you see it depends on where you live if
400. you are near a bus stop (.) now I am but because I don't
401. have my own transport (.) I do shell out on taxis a lot (.)
402. like since I came back to work in mid January (.) I was in
403. a different chair because (.) I just had to be in a different
404. chair and I was paying taxis twice a day to go to work and
405. back again (.) another thing is that I don't even live that
406. far away now that I'm back in this chair I'd walk home you
407. know (.) but then I suppose if you had your own transport
408. you'd have to pay for-
409. **Timothy:** (overlapping) Petrol.
410. **Susan:** Petrol and diesel-
411. **Timothy:** (overlapping) That's it yeah.
412. **Moderator:** I know that there is a Disabled Driver or
413. Passenger Scheme or the Mobility Transport Grant
414. has anybody availed of that?
415. **Timothy:** You get a percentage of the VAT and VRT back
416. on the vehicle, it depends how much the vehicle is on the
417. money you get back if the car is over €24,000 (.) you get
418. the maximum back which would be €9,500 (..) and if we
419. say it was a family member buying the car for you, do

420. you know, if you were a passenger there with a driver
421. they'd get a maximum of €15,500 back on VRT (.) which
422. is good, the vehicle thing is very good.
423. **Moderator:** That is good isn't it.
424. **Timothy:** That is good, I must say like that that is good (.)
425. but I think it should be the driver that gets the €15,000
426. rather than the passenger, you know.
427. **Susan:** I suppose it's whoever is paying for the car.
428. **Timothy:** Yeah but whoever is paying for the car should
429. get the tax (.) I think it's stupid like that (.) say if I
430. nominated you as my driver and you as the person who
431. was going to be driving the car for me and stuff like that
432. and I put your name on the vehicle, well then
433. you're buying the car for me but I'll get €15,500 off the car
434. if the car is over €24,000 (.) but if I'm buying it in my own
435. name I'll only get €9,500 off it.
436. **Susan:** Why's that?
437. **Timothy:** I don't know. It's crazy (.) That's why I think it's
438. all wrong, if I'm buying it for myself I should get the
439. €15,500 but if I'm giving you the money to buy it and I'm
440. the passenger and your driving for me you get €15,500
441. off it.
442. **Susan:** I doesn't make sense at all.

443. **Timothy:** Yeah (.) it should be the opposite way around
444. (..) as well as that then because I'm buying a car for
445. myself you get free road tax up to a maximum of 2000cc,
446. right, but if you're buying it for me and your name is on it
447. (.) you can get any size engine you want (.) you can get a
448. big four litre car and you still don't have to pay tax on it.
449. It's crazy isn't it?
450. **Susan:** It's open to exploitation. Because that's why-
451. **Timothy:** (overlapping) see that's what a lot of people are
452. doing.
453. **Susan:** They are bringing in new regulations now
454. because(.) you know the wheelchair sticker you see in the
455. front of the car, that can be (..) we see that all the time
456. because we have a wheelchair space out the front-
457. **Timothy:** (overlapping) Oh that drives me crazy.
458. **Susan:** It could be someone who bought it, their mother
459. is in a nursing home and they bought the car in her name
460. (.) to get the car, to get all the VRT back, em-
461. **Timothy:** (overlapping) To get the sticker (.) then they use
462. it themselves to go shopping.
463. **Susan:** And then once a month they might go down to
464. visit the...
465. **Timothy:** It's a disgrace. I often park (..) I parked one day

466. in SuperValu, I got mad, I went to Super Value, ***** ***
467. and it was raining and there was a one (..) at
468. the time when I was able to walk with the two legs (.) and
469. this girl pulled in and she went into the disabled parking
470. zone which meant that I had to go over and park
471. somewhere else and I wasn't using the wheelchair at the
472. time I had the crutches (.) and when I went over I had a
473. look and she had no sticker on and she came out of the
474. chemist and I said do you realise that I had to park over
475. there because of you because you have no sticker on
476. your car (mimicking voice) 'I know' says she, that's what
477. you get, 'I was only two minutes, that's all, going into the
478. chemist' (.) I said that doesn't matter says I, I still had to
479. park over there because of your selfishness-
480. **Susan:** (overlapping) At least you said it to her.
481. **Timothy:** (mimicking voice) 'Oh my sister died', I mean
482. what does she expect me to do, I don't care if your sister
483. died, says I, you parked there and you shouldn't have
484. parked there. (mimicking voice) 'I'm very sorry', but they
485. all do it.
486. **Susan:** No it annoys me, it really annoys me.
487. **Timothy:** It drives me crazy.
488. **Moderator:** You see it a lot, I saw it the other day.

489. **Susan:** Also because you don't have to be in a
490. wheelchair obviously to get that (.) a lot of people are
491. getting it because they had a particular issue, maybe a
492. heart issue or something and then they'd say to the doctor
493. to get a letter saying that they were getting very tired
494. (xxxx)
495. (traffic noise).
496. **Timothy:** That annoys me.
497. **Susan:** That's going to be put out.
498. **Timothy:** Because what they do then is they say they
499. can't walk far, so they get a sticker, right, they get the
500. sticker and what do they do they spend the next two
501. hours walking all over the shopping centre (.) and still and
502. all they can't walk that far. It drives me crazy. Because I'd
503. have to park somewhere else then (..) you need plenty
504. of room to get in the wheelchair and to get out of the car.
505. **Susan:** Eleanor, because you live alone with PA's, I know
506. that you don't have them 24/7, but do you ever find that
507. you have to buy extra tea, bread (..) I mean do PA's ever
508. eat in your house?
509. **Eleanor:** They'd have the odd cup of coffee or the odd
510. slice of toast.
511. **Susan:** Ah yes, I suppose that's not much.

512. **Eleanor:** Not on a regular basis (...)
513. **Susan:** Eleanor lives independently but the PAs would
514. come at night and go away in the morning.
515. **Moderator:** So on food, does the accessibility of
516. shopping centres or Town mean that food ends up costing
517. you more?
518. **Susan:** If it's not near, I mean I live ***** so I
519. can come down to Dunnes Stores (..) but we have a local
520. shop too and em, there is a huge price differential and
521. you need a mobilised chair okay, but there could be
522. someone, a person in an ordinary wheelchair (...) actually
523. I know somebody who lives in the same estate as me, he
524. had a ***** a couple of years ago, he recovered really
525. well, he's only in his ***** but for him, he uses the local
526. shop virtually all the time because it's too far for him to
527. walk down to ***** and a taxi would be expensive for
528. him.
529. **Moderator:** Yes and a local shop is always extra.
530. **Timothy:** Yeah, well I'm lucky because I'm not very far
531. away from ***** and ***** and stuff like that, I'm lucky
532. where I am in *****.
533. **Susan:** Adrian can you think of anything where that it
534. would impact on your life (..) because you are living alone

535. with PAs (..) would it be mainly (..) would you have any
536. kind of things from the chemist that your doctor would
537. recommend that is not covered by the Medical Card?
538. **Adrian:** No (xxx)-
539. **Susan:** (overlapping) I have to say-
540. **Adrian:** (overlapping) There was some tablets from the
541. health side of it, but there are a lot of things made that
542. you can't claim on the Medical Card, because they are
543. not covered by the Medical Card-
544. **Susan:** (overlapping) you mean the more holistic
545. therapies.
546. **Adrian:** Yeah, they are not covered by it yet they are a
547. lot better for you than what is being prescribed.
548. **Susan:** Yeah and would that be particular foods that are
549. good for your condition and so on?
550. **Adrian:** That's right yeah (..) there are a lot of things that
551. come in to it like, the supermarket and-
552. **Susan:** (overlapping) and some people have the internet
553. now I suppose and people can kind of do a lot more
554. research about the particular condition and diet is usually
555. one answer, not the cure, but to improve your quality of
556. life.
557. **Adrian:** This is it, because I had to see a dietician

558. because I lost a lot of weight, but I mean (...) I forget the
559. name of the (...) medicine but it's not covered by the
560. Medical Card, you get it in the health shop (..) I just don't
561. understand why you can't get the healthy option that is
562. doing you better.

563. **Susan:** That's why (..) they took St. John's Wort off the
564. market, it was good for depression, you can get a
565. prescription for it but you can't buy it in health food shops

566. **Moderator:** Yeah they are taking more off the market
567. now that would be blood pressure related etc.

568. **Timothy:** It's all politics really.

569. **Susan:** Yeah, money.

570. **Adrian:** Just going back to what you were saying about
571. the stickers in the car (..) about the parking (..) I've noticed
572. that when I've been going down to ***** for some
573. physio and that, that some of the roads are so
574. inaccessible to get off (..) you know the way people park
575. if they park on the pavement then I can't go down the
576. small slip because of the way the car is parked-

577. **Timothy:** (overlapping) That's it yeah.

578. **Adrian:** Somebody told me like, to take a camera, take a
579. photograph and send it in (..) and they just send out the
580. fine then, if it's right you get the registration of the car.

581. **Susan:** Oh good I must try that because every time I go
 582. home there is a car parked at the end of the footpath
 583. before you get onto ***** *****. -
584. **Timothy:** (overlapping) I know the one you are talking
 585. about (.) the ramps (..) blocking the ramp is it?
586. **Susan:** Yeah, I just go on the main road then because
 587. there is no point in-
588. **Timothy:** (overlapping) Like even where I work up
 589. in ***** , up to the ***** ***** , for the computer
 590. course, there's a (..) they've made a special kind of lane,
 591. do you know, to go from the step out onto the road and for
 592. wheelchairs and stuff and at the end of it there is a yellow
 593. box, with box lines so that no car is supposed to park
 594. there (..) and most of the time the guy that is bringing me
 595. into the ***** ***** has to go way down because
 596. there's cars blocking the ramp you know (..) they just don't
 597. think you know (..) they just park there (.) it's put there for
 598. reason like (.) all these kinds of things.
599. **Adrian:** Before I was in this wheelchair I had a scooter
 600. before, so that was easy, you could go out on the road
 601. and everything. Now that I've got the wheelchair I find it
 602. more harder (..) like I think I've got to go to a certain place
 603. and rest assured, especially the ***** ***** (..) they

604. just park in anyway they like on the pavement, it's just the
605. accessibility (..) many a time I've just had to out on the
606. road in the wheelchair find a driveway I can get up and
607. in.

608. **Susan:** Adrian when you're on the scooter can a scooter
609. go on the main road or the pavement?

610. **Adrian:** Well, I don't know, there are no real laws about
611. the scooter (..) but eh (.) the scooter was a lot better than
612. this because this (..) I find this a lot harder (.) because
613. people are totally oblivious to people in wheelchairs (..)
614. and such. But scooters are not a taxable vehicle.

615. **Susan:** Just getting back to the whole area of diet I mean
616. most people with a disability (..) there would be certain
617. foods that would be good for them (..) lets say that
618. disabled people would need a lot of protein for healing
619. for skin issues.

620. **Timothy:** Yeah

621. **Susan:** Em, calcium if you are sitting down in a
622. wheelchair all the time (.) the bones could be a bit fragile
623. so lots of calcium and again those are things you get in
624. the (..) health food shop.

625. **Moderator:** So lets say a dietician recommends
626. something does that ever come under what is covered by

627. the Medical Card?

628. **Timothy:** No. There are those drinks, what are those

629. drinks?

630. **Susan:** Ensure or Cubetin.

631. **Timothy:** Cubetin and stuff like that, they come on the

632. Medical Card alright (..) when I was in hospital, the

633. dietician would come in and she'd tell you, you should do

634. this and do that (..) and I know the Cubetin (.) you used to

635. get that in the chemist, other than that you'd have to buy

636. the other stuff you know.

637. **Moderator:** It's a kind of tonic is it?

638. **Timothy:** It's-

639. **Susan:** (overlapping) It's like the old fashioned Complian.

640. **Moderator:** Oh yeah.

641. **Timothy:** Something like an Actimel, a drink like that you

642. know.

643. **Susan:** There's high protein-

644. **Timothy:** (overlapping) They are very high protein food.

645. **Susan:** You can also use a food replacement-

646. **Timothy:** (overlapping) Yeah if you don't eat that (..) if you

647. aren't eating that much you know (..) like when I was in

648. hospital I usen't eat the food in there, it was so (..) like

649. I used to be on that dietician stuff and she'd be telling you

650. then to get special breads and em (..) there was honey
651. special honey that was very good for me.
652. **Susan:** Manuka honey yeah.
653. **Timothy:** Yeah Manuka (..) but Manuka honey is (..) a
654. small jar was about 40 odd euros, you know (..) it's grand
655. to say get it but at the time I couldn't afford it (..) now I'm
656. lucky I'm on a ** *****, you know, and so I could
657. afford that stuff now you know (..) but on the normal
658. (..) I'm on a disability pension (..) you just couldn't
659. afford to get the stuff they are telling you to get you know.
660. **Moderator:** In terms of equipment, does the HSE cover
661. it? If there is anything extra living aids that people would
662. need is there a budget for it?
663. **Susan:** Well environmental controls (..) Maura was it you
664. who mentioned that some things are covered by the
665. County Council.
666. **Maura:** Yeah a chairlift is not covered by the County
667. Council
668. **Susan:** Yeah I think it's kind of based on a UK model
669. (..) because I know someone who used to work in
670. the housing authority in England (..) and if somebody
671. if they were a PA user if they were moving into new
672. accommodation, the accommodation would be fitted with

673. environmental controls so that, you know, the individual
674. could go in and turn on the television independently and
675. open the curtains, close the door, (.) and that way, that
676. might reduce the number of hours, the PA hours that
677. were allocated.

678. **Moderator:** Yeah.

679. **Susan:** It makes sense but (..) we have a very different
680. system here, but (..) the City Council which actually fund
681. the environmental controls but obviously, there is (..) a
682. huge waiting list and so on, (.) because I met with
683. someone who works in the Council there last year and (..)
684. How did you get on in the end Anne, you had to get
685. environmental controls?

686. **Anne:** I had to pay half and the housing organisation paid
687. the other half.

688. **Susan:** Okay (.) because Anne lives in an apartment that
689. was built by a particular housing association so basically
690. they paid-

691. **Moderator:** (overlapping) So they paid half.

692. **Susan:** So the City Council didn't pay anything.

693. **Moderator:** Oh right!

694. **Susan:** So basically only if she was willing to go on a
695. waiting list for three or four years (.) you see the thing is

696. that Anne lives alone and she needed it now.
697. **Anne:** Yeah, because I couldn't get in and out of the
698. house myself without it.
699. **Moderator:** So those extra costs aren't covered unless
700. you are willing to wait.
701. **Susan:** It was the doors you got done?
702. **Anne:** Yeah just the front door.
703. **Moderator:** Is that an automatic door?
704. **Anne:** Yes.
705. **Moderator:** I'm just thinking here of some on-going costs,
706. things like (.) we've looked at fuel and diet, what about
707. wear and tear, in terms of, your house, even extra
708. clothes, wear and tear on those items, has it ever become
709. an issue for people?
710. **Susan:** Well if you use a motorised wheelchair inside
711. your house, chances are doors will have scratches on
712. them.
713. **Timothy:** That's right.
714. **Susan:** Yeah.
715. **Timothy:** You would be bumping into this and that
716. because of the wheelchair.
717. **Susan:** It's impossible not to do it.
718. **Timothy:** I'd be scraping off doors and you'd be

719. damaging the walls, like I got the walls painted and next

720. thing, boom I'm after scrapping the walls and stuff-

721. **Susan:** (overlapping) Yeah but like you can't see what's

722. behind you-

723. **Timothy:** (overlapping) you can't no.

724. **Susan:** And you can't estimate the distance between the

725. wall and you (.) or if you're not in a custom built house

726. designed for a wheelchair user, sometimes, going in and

727. going around corners and doors is a bit tight you know-

728. **Timothy:** (overlapping) Yeah.

729. **Susan:** You are damaging walls (..) it might be only paint

730. and plaster, but if you've got a very strong chair you

731. could actually do more structural damage, but more

732. expensive damage I suppose you know.

733. **Adrian:** I'd just moved (..) into a bungalow and when I

734. moved in it looked really nice but the wheelchair has

735. done so much damage to the walls with turning and

736. everything and I just got this wheelchair as well (..) and I

737. had to wait a head rest off the (..)

738. **Susan:** From the wheelchair company?

739. **Adrian:** It was the HSE, from ***** (.) and it just

740. wasn't meant for this wheelchair and every time I was

741. going around I was scratching the walls and everything.

742. They're only scratches (.) but it's furniture that's upsetting
743. me and getting out the backdoor (..) I mean they're
744. supposed to be accessible housing and I really don't
745. think they are at all.
746. **Susan:** Yeah, because I was saying that to Eleanor (..)
747. **Timothy:** Wheelchairs are getting so big now.
748. **Susan:** Yeah, exactly (..) but one ** ***** ** ***
749. have just been offered a two bedroom apartment in
750. a new development in ***** ***** and I'm really
751. impressed with it (..) he's not a wheelchair user yet
752. but he will be eventually (.) because when you go in the
753. main door it's almost like a semi-circle, you know, a shape
754. to the hall, because most halls go straight, there is two
755. bedrooms to one side and then you've got another door
756. then for the shower or bathroom and then you've got
757. another door for the kitchen living area (.) so it's very
758. clever think because it's not a straight hall like most
759. people would have (.) it's a kind of semi-circle.
760. **Moderator:** Plenty of room for turning.
761. **Susan:** Yeah maneuvering, exactly, I have to say fair
762. play, City Hall have done it properly this time, they really
763. made an effort (..) because I've got a straight hall and
764. when I go down into my bedroom (.) it's not that tight but

765. sometimes I make scratches.
766. **Adrian:** It's like all these properties (.) you were just
767. talking about ***** ***** and the ones (..) I don't know
768. if you know them but, the *****?
769. **Susan:** Yeah, I haven't seen them or been them but..
770. **Adrian:** But like to come out of the front door (.) and
771. things like that you have to turn to get out the front door,
772. like I'm always catching this-
773. **Susan:** What do you mean you have to turn, I don't
774. understand.
775. **Adrian:** Well, the way it is it's not like it's straight, to get
776. out the front door you have, open the front door then start
777. maneuvering to turn and to get out the front door.
778. **Susan:** That sounds a bit daft alright yeah.
779. **Adrian:** It is.
780. **Susan:** That's kind of disappointing because (..) that's a
781. relatively new development and it seemed like there were
782. good people involved in the design (.) and I knew one
783. person who works down there and he was kind of
784. disappointed when it was done, because the regional
785. architect's plans were very good but they try and
786. cram more humans into space (..) How do you find them
787. or you're not in the new..?

788. **Eleanor:** I'm in the *****.

789. **Susan:** That's there a good bit isn't it? That's not part of

790. where Adrian is living?

791. **Eleanor:** No.

792. **Timothy:** And before now I could paint and paint the

793. house and stuff like that (.) and fix stuff like that, whereas

794. now can't do it (.) so then you have to bring people in and

795. pay people decorate your house, whereas I would do it

796. before myself, you know. Now you have to pay someone

797. to do it.

798. **Susan:** That's true, exactly (.) because I'd have to pay

799. people say to put down wooden floors or any of those

800. kind of DIY tasks (.) but if I didn't have a disability I could

801. have-

802. **Timothy:** (overlapping) Or just paint walls and stuff (.) all

803. these maintenance things around the house-

804. **Susan:** (overlapping) Maintenance of the house, yeah.

805. **Timothy:** I have to bring somebody in now to do the

806. maintenance on my house, whereas before I'd do the

807. whole lot myself like, you know (..) so with a disability, that

808. costs you more as well (.) the maintenance of your

809. house, to maintain a house.

810. **Susan:** When I moved in the house, there was a garden

811. out the back and I really liked the idea of having flowers

812. and stuff (.) I'm just lucky that my particular PA enjoys

813. that you know, but if she didn't (.) like if she was to leave

814. in the morning, and I wanted to maintain it, I'd have to pay

815. someone to come in every so often to come in, it's costly-

816. **Maura:** (overlapping) And cleaning.

817. **Susan:** Because she has potted plants and it adds up.

818. **Timothy:** Things that you took for granted before,

819. whereas now it would cost you, like Susan said (.) to get a

820. gardener in to plant stuff for you, you know, it would cost

821. you money now.

822. **Moderator:** They are very hidden costs.

823. **Timothy:** Yeah, exactly, hidden extras you know, they

824. wouldn't have been there before you know.

825. **Susan:** Even getting your outside windows cleaned

826. every so often-

827. **Timothy:** (overlapping) That's right yeah, you have to pay

828. someone.

829. **Susan:** Even the companion dog that must be an extra

830. cost, having any kind of pet does but-

831. **Eleanor:** (overlapping) Yeah.

832. **Susan:** It's a big dog so feeding it is going to cost,

833. making sure it gets its injections and all that kind of thing.

834. **Eleanor:** I went to the vet with her last week and there
835. was a booster vaccination and fleas, for fleas, and
836. worming and (.) €92.
837. **Susan:** You should get pet insurance definitely.
838. **Eleanor:** What?
839. **Susan:** Pet insurance.
840. **Eleanor:** I'll see, thankfully she doesn't go that often.
841. **Susan:** I know but she could have an accident.
842. **Eleanor:** Is that dear?
843. **Susan:** No, No, I thought Triona said no, if you shop
844. around.
845. **Eleanor:** Triona has two small dogs hasn't she?
846. **Susan:** Sorry to diverge (.) what's that company?
847. is it abc.com or 123.com? The insurance company.
848. **Moderator:** Yeah 123.ie is it?
849. **Susan:** Check that out because God forbid she got an
850. illness or got knocked down (.) because my Public Health
851. nurse, she said to me the other day that the vet ended up
852. costing 400 and something, she had to get an x-ray and
853. the vet was asking about pet insurance and she thought
854. she was kind of joking you know it gotten expensive now
855. to go to vets.
856. **Timothy:** A lot of people now actually have pet insurance

857. like common day things like paying the gas bill every

858. month.

859. **Susan:** I can't imagine it's that expensive so you should

860. check it out.

861. **Timothy:** You should look into that, I don't know what

862. price it is though.

863. **Susan:** Because your dog is almost like a substitute

864. personal assistant, the dog you have (.) that particular

865. dog is designed to do certain tasks for you as well you

866. know (.) it is allowing you to live independently, so there

867. are extra costs there with that (..) and again I know you

868. probably you love her and if you'll always have a reason

869. to have PAs 24/7 but if you did have more PA's you

870. maybe wouldn't have even considered getting her in the

871. first place (.) you know.

872. **Maura:** Can I say something about dental costs with the

873. cut backs.

874. **Susan:** It's only two fillings a year now, two trips.

875. **Maura:** I think so, yeah and one cleaning or is it two

876. cleanings per year.

877. **Susan:** I don't think they are doing any cleanings any

878. more, I think it's two trips.

879. **Moderator:** They cut it down didn't they.

880. **Susan:** I went recently and I didn't have to pay because it
881. was my first trip that year.
882. **Maura:** Yeah.
883. **Moderator:** Dental costs are unbelievable.
884. **Susan:** Well it's a big fear for me because (.) I do have
885. my Medical Card right but I obviously because I work full
886. time you are well over the eligibility income limit and every
887. other year I got away with it, not that I got away with it, but
888. you have to get a letter from your doctor and so on (..) but
889. if I lost my Medical Card I'd actually lose my right to have
890. personal assistants. Because you have to have a Medical
891. Card to actually (.) for any HSE funded service, from
892. having the Public Health nurse calling, medication, to
893. having PA's issued and so on (.) and it is concerning
894. because this year they've said already that they are
895. going to be tightening up the criteria for Medical Cards.
896. **Moderator:** Do things like that create a disincentive to
897. work? Is it a catch 22 situation?
898. **Susan:** Well with all the disabled people I know who
899. would have an opportunity to take up a place of work it
900. would be a worry (.) but I know if you work part-time you
901. can retain your Disability Allowance and your Invalidity
902. Pension (.) and so far I've been lucky.

903. **Moderator:** Does the fact that everything is associated
904. with the Medical Card, does that cause problems?
905. **Susan:** The medications that I'd have to pay for would be
906. the least of my worries.
907. **Moderator:** Is health insurance an option if Medical
908. Cards aren't?
909. **Susan:** I don't have it myself but I know a couple of
910. people with Bupa (..) with Bupa after a year or so (..) there
911. would be a particular period of time that they wouldn't pay
912. for any treatments that are related to your disability.
913. **Timothy:** VHI is five years
914. **Susan:** So for the first couple of years they will
915. treat you if it's not something to do with your disability?
916. **Timothy:** That's right yeah.
917. **Susan:** That's a long time.
918. **Timothy:** Like what Susan is saying there if you get
919. health insurance you're not covered anyway
920. by the health insurance for your particular illness for
921. the first five years and after that then they will cover you,
922. you know (..) so unless something else happens you in
923. the meantime (..) you're paying dead money, you know.
924. So I don't have health insurance either, I just rely on the
925. Medical Card simply because I'd have to wait five years

926. and it's so expensive in the first place (.) you wouldn't be
927. able to afford it, if you were just on Disability, you
928. wouldn't be able to afford it, that's the truth, it's very
929. expensive.

930. **Moderator:** And looking at any items that anybody would
931. like to spend more money on if you had it? (..) If you had
932. a lot of extra money where would it go? Would it go
933. towards more PA hours or things like transport or your
934. home, or...?

935. **Susan:** Yeah, transport, I'd love to get my own transport.

936. **Maura:** Yeah, transport (..) if I won the Lotto it would be a
937. car and a driver.

938. (laughter)

939. **Timothy:** With me I'd like to have someone on the
940. weekend.

941. **Moderator:** Is it very limited in terms of your PA's, do
942. they just decide you are getting X amount of hours..?

943. **Susan:** Well they look at the money that they have, then
944. they look all the people on the waiting list and they want
945. to be seen to give as many hours as (..) well to be seen to
946. take loads of people off the waiting list so (..) that can
947. determine small amounts of hours to people (..) so they
948. can give hours to more people.

949. **Timothy:** I'm kind of lucky now, I have a PA twice a week,
950. you know, and I think it's brilliant (.) before I got the PA
951. now, through CIL I was stuck in all the time, watching (..)
952. all I used to do was spend my time (..) the kids would be
953. at school and I'd just spend the day just watching TV you
954. know (.) but with the PA (..) I actually look forward to the
955. PA coming to get out like, you know? (.) and I hate the
956. weekend because if my young fella isn't doing sport or
957. playing a match or something your going nowhere as
958. such you know what I mean (..) that's why I'd like to be
959. able to get more on the weekend alright, but (.) that's the
960. drawbacks of it then (.) that's the way it is.
961. **Moderator:** If you were at home would there be extra
962. costs in relation to hobbies or extra heating usage, if you
963. are spending extra time at home?
964. **Timothy:** Well there is with me (..) the heating with me (.)
965. I'd have to have the heat on because the cold affects me
966. (.) I actually have the heating on an awful lot in my house,
967. you know, they'd be all going around sweating in my
968. house and I'd still be cold.
969. **Susan:** Any of the rest of ye find the same thing?
970. **Maura:** Just if I'm sitting down and not exercising I need
971. much more heat (.) I need the house more heated.

972. **Susan:** Because I have this blow heater, and I know a lot
973. people hate them, because one of the side-effects of my
974. disability is sometimes I'd be kind of dripping sweat and
975. it's not because I'm too hot (..) it's just an internal kind of
976. malfunction of the heating system so I'm sweating but I'm
977. not hot (..) it's my body telling me I've a pain somewhere
978. (..) so the blow heater makes me feel more comfortable
979. but they eat up electricity.
980. **Moderator:** No they're not efficient.
981. **Susan:** No and not environmentally friendly either.
982. **Adrian:** You know those portable heaters (..) they are like
983. a light as well, what are they called?
984. **Timothy:** Oh yeah, I know the ones, they are very
985. expensive.
986. **Adrian:** I live on my own and (..) I have a bedroom and a
987. bathroom and all these radiators and I can't keep going
988. to one room find it cold and put the rad on (..) I find that it
989. takes a long time for one radiator to heat the room up, so
990. think well (..) since I started cutting off the gas, I'd put
991. something else onto heat the (xxx) rather than put on the
992. heating to heat the bathroom and the bedroom(.) you
993. know I turn radiators off but-
994. **Timothy:** (overlapping) You can turn off the radiators as

995. well in the rooms that you're not using and then the other
996. radiators would heat up faster because the water doesn't
997. have to heat up as much, so you could be cost effective
998. that way.

999. **Susan:** I remember years ago I had Danish personal
1000.assistants, because in Denmark they are very advanced
1001.and they all have underfloor heating (.) so in the flat I'd
1002.be living in, they'd have their (.) they'd be wearing their t
1003.shirts and they'd have every possible heating thing
1004.turned on full blast, it used drive me nuts, because I'd be
1005.getting these horrendous heating bills.

1006.**Moderator:** Yeah, I lived with Americans and they loved
1007.to go around in their t-shirts.

1008.**Susan:** Yeah I remember one particular Danish person,
1009.she was very particular about (.) she wore a lot of white
1010.clothes (.) so she was very particular about her clothes
1011.(.)so she would wash each item separately in the
1012.washing machine and then-

1013.(overlapping) (laughter)

1014.**Susan:** Wash everything at the highest temperature, and
1015.my mother would turn it down and she'd turn it back up
1016.again.

1017.**Moderator:** She'd never heard of putting on a white wash

1018.then.

1019.**Adrian:** I just miss my open fire, that's what I'm pining for,

1020.I loved my open fire (.) my home help didn't though.

1021.**Moderator:** And what about this winter, I thought it was

1022.particularly long, what about the heating bills this year?

1023.**Timothy:** The gas bills were very high this year.

1024.**Susan:** Just thinking about last year (..) was it weather

1025.related (..) it was. Do you remember the ***** was

1026.without water for ages (.) and that neighbour I was talking

1027.about who lives in my estate and had the (.) you know he

1028.had the ***** and he had a good recovery, but he had

1029.(..) the local shop really took advantage of people who

1030.didn't have transport and they really inflated the prices of

1031.the big bottles of water (.) and he had no choice (.) it

1032.wasn't really fair.

1033.**Moderator:** Just looking at some other questions in

1034.relation to holidays (.) would holidays be sacrificed?

1035.**Susan:** Yeah holidays would be sacrificed or wait three to

1036.four years to (.) everybody loves to get away, I mean,

1037.everyone loves a change of scenery, it's great for your

1038.mental health and you know-

1039.**Maura:** (overlapping) You have to take somebody with

1040.you.

1041.**Susan:** You do yeah and that means you are paying for
1042.more (..) food, if you are going abroad then it just adds up
1043.and it's horrendous.

1044.**Moderator:** I think in the UK if you have a PA, you are
1045.entitled for a free room for the PA in the hotel.

1046.**Susan:** Yeah that's brilliant (.) and even in Sweden your
1047.PA doesn't pay for the flight I think the disabled person
1048.pays for the flight the PA doesn't, they recognise it as an
1049.extra cost (....) In some parts of the UK (.) I suppose it
1050.depends on what part of the UK-.

1051. **Timothy:** (overlapping) I couldn't see Ryanair doing that.

1052.**Susan:** But in some local authorities in the UK, people
1053.are accessing the Independent Living Fund (.) there is a
1054.fund there to fund (.) you know you can pay for that
1055. second ticket, that second person (....) and it's not just
1056.the flight, say if you are going for a week (.) depending on
1057.the relationship you have with your PA, like you might
1058.negotiate beforehand that you'd pay the flight but the
1059.PA would pay for all their own meals and drinks and
1060.stuff (.) but if you're not willing to do that then (.) that's
1061.another group of costs (..) Have you ever had that
1062.experience? Have you ever gone abroad or..?

1063.**Eleanor:** I went to Berlin, I went there for about four days

1064.**Susan:** And did you kind of negotiate before (..) was It a
1065.PA that you went with?

1066.**Eleanor:** I was with a PA and a friend (...) I couldn't have
1067. done it any other way.

1068.**Susan:** And tell me did you kind of negotiate beforehand
1069.with the PA what you'd cover and what she'd cover?

1070.**Eleanor:** Well we kind of did it separately because she
1071.would have been going on anyway.

1072.**Susan:** Oh perfect.

1073.**Eleanor:** So we just looked after ourselves and that was it
1074.then (..) but it was very cheap that way but-

1075.**Susan:** (overlapping) That was a stroke of luck that way
1076.that she was traveling on.

1077.**Eleanor:** Yeah, it wouldn't have been able to work out
1078.otherwise, it would have been too expensive (..) Like my
1079.brother got married there (..) last year or the year before
1080.and it was too expensive for me to go because he was
1081.getting married in America and it would've been too
1082.expensive I'd be paying up to €2000 alone (..) and that's
1083.just for flights-

1084.**Susan:** (overlapping) For flights.

1085.**Eleanor:** Traveling yeah (...) so I didn't go (..) so.

1086.**Moderator:** Weddings are costly anyway.

1087.**Susan:** Yeah, that's actually (..) I remember a good friend
1088.of mine who lives in England and she invited
1089.me to her wedding years ago (..) and I added it up I just
1090.realised it was going to be way too expensive (..) there
1091.was the flights and there was getting from London to
1092.where the wedding was going to be, then staying in the
1093.Bed and Breakfast, because you have to maybe hire two
1094.rooms, or a room with two beds and all the other costs
1095.also, whereas if it had been just me (...) you can't do
1096.things on the cheap sometimes (...) because it's
1097.backfired (.) I tried to book a holiday through the internet
1098.(.) a couple of years ago and as it turned out I didn't go in
1099.the end because my PA got sick but (..) even though I
1100.told him I was disabled I'd say the place wouldn't have
1101.been suitable, you know? So I don't think you can really
1102.trust those (..) a lot of people get cheap flights and cheap
1103.accommodation when they go on the internet,
1104.there are loads of different sites but when you have a
1105.disability you need to make sure that it's really genuinely
1106.accessible and not too far away or whatever (...) so then
1107.maybe you're missing out on bargains-

1108.**Moderator:** (overlapping) like package holidays.

1109.**Susan:** I mean I love travelling I would love to see (.) you

1110.know different parts of the world and even today on

1111.the Yahoo home page there was ten places you have to

1112.see before you die but like it's just so expensive, you

1113.know and I work full-time.

1114.**Moderator:** And a lot of the older cities have old quarters

1115.that aren't accessible.

1116.**Timothy:** Even if you are going away you have to be

1117.sure that you will get a PA to go with you, you know (.)

1118.you might say to your PA I'm going away for a week

1119.and I'll pay for you or whatever, they mightn't

1120. want to go away they might have their holidays booked

1121.somewhere else you know, so, even if you do have the

1122.money it doesn't necessarily mean you are going to go

1123.away you know.

1124.**Susan:** And then you might ask an organisation like CIL

1125.there are people on their books who want to go away but

1126.you don't know how you're going to get on with them you

1127.know-

1128.**Timothy:** (overlapping) Exactly, yeah.

1129.**Susan:** Because even if you go traveling with a friend

1130.everybody's got those disasters (..) of going with quite

1131.close friends but being cooped up 24/7 takes it's toll you

1132.know.

1133.**Timothy:** Yeah.

1134.**Susan:** For me that's the biggest thing that I can't (..)

1135.yeah I'd love to have transport but I think even

1136.more so than that I'd love to be able to (.) be in a position

1137.to go on holidays (.) because I'd know plenty of people

1138.who maybe three times a year they might go to even

1139.Belfast for a weekend (.) even just going to-

1140.**Timothy:** (overlapping) Belfast is lovely, I was up there

1141.last year with the home help.

1142.**Susan:** Even going in Ireland, like I went to *****

1143.last year and I booked an accessible apartment for four

1144.nights, you know (..) obviously I had to get extra

1145.bedrooms and the usual.

1146.**Timothy:** If I was going away for a week I don't expect the

1147.PA to pay for it because I want to go to that particular

1148.place.

1149.(Conversation from non-participant).

1150.**Susan:** Some people might not look at it like that, for

1151.some people it is just work and they get paid, which is

1152.fine if it's a person you get on well with, you know.

1153.**Moderator:** Going on holidays with someone is definitely

1154.a challenge, even close friends.

1155.**Timothy:** But you'd know from before that you'd get on

1156.with them you know (..) that's the thing about it (..) I've
1157.home help everyday, I'm haunted, the two of them are
1158.sound but if I (.) as Susan was saying there, if they didn't
1159.want to come away with me, there are organisations that
1160.you can get but you don't know who're going to get you
1161.know.

1162.**Susan:** It's awkward-

1163.**Timothy:** (overlapping) When you don't know them you
1164.know.

1165.**Susan:** And they want to do different things (.) but you're
1166.paying for it so they should do it the way you want to do
1167.it.

1168.**Timothy:** Well that's the way I look at it, if I'm paying for it
1169.(.) I'm going to see what I want to see, if I'm paying for
1170.them they are paid to come along with me and help me.

1171.**Susan:** Because I know in the past I've had PAs who,
1172.you know (..) for years before I was running the PA
1173.service, I used to advertise abroad and get, you know,
1174.Danish people, to come work with me and I'd get an au
1175. pair arrangement because in Denmark as a student you
1176.get extra points to go to university if you work abroad and
1177.you get another extra point if it's this kind of work (.) so
1178.for someone who might want to do physiotherapy or

1179.social work and they didn't have the necessary points in
1180.their Leaving Cert. so by coming here (..) so they were
1181.usually young people and they'd like going to the cinema,
1182.so usually we'd come to some sort of arrangement or
1183.compromise where (.) if it was a film I wanted to go an
1184.see and they had no interest, I'd cover the ticket and if it
1185.was another night and they'd be saying can we go and
1186.see such and such a thing, kind of won't be in the cinema
1187.much longer and I'd not be particularly interested but I'd
1188.go along and each of us would buy our own ticket (..) but
1189.it depends on the relationship you have with the person.

1190.**Moderator:** I suppose that brings us onto the next
1191.section, independent living itself and a general
1192.question would be (.) do you think the concept itself is
1193.understood by the services that are provided in terms of
1194.government services or is it a kind of version of it?

1195.**Susan:** Yeah there is a watered down version of it (.) like
1196.people only get a limited number of PA hours (.) Eleanor
1197.would be a good example of this, she'd have huge gaps
1198.in the day where she wouldn't have a service that means
1199.she's kind of stuck at home, she can't come and go as
1200.she pleases, it's only when the next person comes at
1201.eight o'clock at night or whatever, that she can actually

1202.come and go as she pleases (..) because independent
1203.living is about control and freedom of choice in your daily
1204.life but it's like the hours that you don't have a PA you are
1205.stuck inside and that's not really independent living (..)
1206.and obviously some people may only have the home help
1207.for maybe at intervals in the morning to get you up, come
1208.back at lunchtime and then seven o'clock at night put you
1209.to bed kind of thing and it's a very kind of limited life
1210.really I mean you are just down to the basics of eat, drink
1211. and go to bed or the toilet, you know it's not a very
1212.holistic lifestyle.

1213.**Moderator:** How do people feel that the extra costs affect
1214.independent living (..) the choice and control that you
1215.have over your life?

1216.**Susan:** If you don't have enough hours, then the hours
1217.you do have are (..) I suppose you have to prioritise
1218.certain tasks that need to get done and that can maybe
1219.be personal care, I suppose would be one (.) whereas if
1220.you had more (.) if you had enough hours then you know
1221.you might be able to go visit friends more often or you
1222.go for a drive or (..) maybe have a physio routine where
1223.our PAs might do exercises with you, but if you don't
1224.enough time then you might have to scrap that which

1225.might have long-term implications.

1226.**Moderator:** So it's a trade-off.

1227.**Susan:** Yeah because a lot of people would have (..) I

1228.know a woman whose physio recommended that she

1229.stand (.) use a standing frame twice a week (.) well she'd

1230.only have enough PA hours for (.) because she has to

1231.get other things done during the PA's time (.) so she has

1232.time for one session on a standing frame (.) so she'd be

1233.on the standing frame for maybe an hour or two.

1234.**Moderator:** And do you think people understand it in the

1235.non-disabled community, do you think there is enough

1236.understanding of independent living?

1237.**Susan:** I don't think so because (.) someone might have

1238.a neighbour who has PA's and every time they see them

1239.outside they'll maybe see them with a PA so they

1240.assume that they have the PA 24/7, not realising then

1241.that there is huge gaps.

1242.**Timothy:** They'll never understand it unless they're

1243.actually in the situation themselves-

1244.**Susan:** (overlapping) Or they have a family member in

1245.that situation .

1246.**Timothy:** Yeah, never you know, even like people in a

1247.wheelchair you don't know what it's like unless you

1248.actually go in there and say to them look sit in that

1249.wheelchair for so many days (..) it's only that kind of way

1250.that people realise, you know.

1251.**Susan:** I mean a lot of disabled people before they

1252.became disabled would never have given any thought to-

1253.**Timothy:** (overlapping) I mean I never did.

1254.**Susan:** What it was like (..) I mean not in a negative way

1255.but you just wouldn't be thinking about it (..) what do you

1256.think Anne?

1257.**Anne:** Like people think I have 24 hour care and I don't

1258.they assume when they see somebody with me that I've

1259.24-hour care and I don't.

1260.**Moderator:** So just to tie that into extra costs, would

1261.Personal Assistance be the number one area to spend

1262.extra money on?

1263.**Susan:** Yeah.

1264.**Timothy:** Yeah, it would cost you a fortune to get one all

1265.the time, to be hiring people to be with you all the time.

1266.**Susan:** I do know people who supplement their PA hours

1267.with (..) they might have a cash-in-hand arrangement with

1268.someone for a few hours a week or one night a week or

1269.something.

1270.**Moderator:** How about the housing situation, are

1271.accessible houses in short supply?

1272.**Susan:** None in the private sector unless someone with a

1273.disability custom builds their own accommodation (..) in

1274.the local authority housing it's only in the last couple of

1275.years that they are taking on board when they build a

1276.new estate they now have to (..) every new estate would

1277. have to have a certain number of unit's that would be for

1278.a disabled person (..) so actually in the last two years

1279.there's a reasonable amount of people who were actually

1280.offered a wheelchair accessible accommodation, which is

1281.good (..) when I wanted to get my own place, I went

1282.through the Affordable Housing Scheme to get a

1283.mortgage and they were building an estate quite near

1284.**** (.) a friend of mine told me about it and so it took me

1285.about a year and a half of writing to them because their

1286.initial response was you're one individual, therefore you'd

1287.be better off in a one bedroomed apartment (.) the three

1288.bedroomed houses are for families, you know, but it

1289.took letter after letter to explain to them that I'd always

1290.have a PA that is staying over night and because I'm not

1291.from Cork I'd have family members visiting and

1292.eventually they did agree to that but it was too late then

1293.for me to actually have any input (..) if they had agreed to

1294.it much earlier, I could have had discussions with the
1295.developer to make the place much more accessible than
1296.it actually is because the house was built by the time they
1297.allocated the housing (..) because it was built in 2004
1298.legislation states now that any new accommodation
1299.must be visitable by a wheelchair user, like a toilet
1300.downstairs, but it can be very small so they did install
1301.a shower but it's very very small and not really accessible.

1302.**Moderator:** And that kind of moves us on to what kind of
1303.solutions there are in terms of extra costs.

1304.**Timothy:** There's another thing as well, like if you own
1305.your own house and you have to adapt it, you will have to
1306.pay for the adaptations yourself but if you are living in a
1307.Council house the Council will pay to adapt the house
1308.(..) so if I was actually living in a Council house, they will
1309.actually do all of the modifications for me and it would
1310.cost me no money at all (..) because I'm living in a private
1311.house I have to do it myself (.) and they'll give me so
1312.much of it back.

1313.**Susan:** Because that *****I was talking about earlier,
1314.the ***** , where they had to buy a lot of
1315.items that they need and are not on the Medical Card
1316.(.) they bought their house years ago, they happen to

1317.have a mortgage but that means every little thing that

1318.goes wrong in the house they have to pay for it (.)

1319.obviously (.) any minor thing that goes wrong can add

1320.up to be quite expensive (.) you know.

1321.**Timothy:** That's right (.) one thing if you're disabled you're

1322.better off if you have rented accommodation from the

1323.Council rather than owning your own house because

1324.they'll actually do everything for you (.) they'll put on the

1325.extension on the house they'll put in a bedroom or

1326.whatever-

1327.**Maura:** (overlapping) and the insurance.

1328.**Timothy:** Because you own your own house and you're

1329.disabled you are penalised.

1330.**Susan:** Yeah, because a lot of people who have acquired

1331.their disability maybe in their forties or fifties, you know,

1332.they might've been working into their twenties and

1333.thirties and you know got a mortgage.

1334.**Moderator:** For example there has been talk of a cost of

1335.disability payment for a long time (..) what way would

1336.people like to see that delivered?

1337.**Timothy:** What's that?

1338.**Moderator:** Literally a specific payment to meet extra

1339.costs.

- 1340.**Susan:** Because visually impaired people get a (.)
- 1341.don't know the exact term (.) Blind person's pension, you
- 1342.get that irrespective of whether or not you are working (.)
- 1343.I know someone who is working full time and he also
- 1344.gets it (.) it's again like compensation for any costs that
- 1345.result because of the visual impairment, maybe you have
- 1346.to get taxis more often or whatever (..) and there should
- 1347.be an equivalent then for people with physical and
- 1348.sensory disabilities (..) because the living alone
- 1349.allowance, does that still exist? Is that just for older
- 1350.people or..?
- 1351.**Adrian:** 60's and older.
- 1352.**Maura:** I think-
- 1353.**Susan:** (overlapping) So it's for over 65's?
- 1354.**Maura:** No, I get it-
- 1355.**Susan:** (overlapping) Oh you actually get it?
- 1356.**Maura:** It's in with my Disability (..) it's paid by the
- 1357.Health Board .
- 1358.**Susan:** Ah okay (..) it's kind of like a cost of disability
- 1359.payment, it kind of compensates-
- 1360.**Eleanor:** (overlapping) it's only about €7 weekly.
- 1361.**Maura:** Yeah.
- 1362.**Susan:** Oh is it, I won't get too excited then (..) So I

1363.suppose (.) even though it's a very small sum, it's a

1364.recognition that you are on your own, you have no

1365.one to share costs with you.

1366.**Maura:** It adds up (.) when I was working in London (.)

1367.you can work there and get your disability money and if I

1368.acquire a disability I get my Disability regardless (..) not

1369.here.

1370.**Moderator:** And I suppose the fact that they cut it here..?

1371.**Maura:** The difference between here and England is that

1372.there was severe disability, medium and low.

1373.**Susan:** I suppose that goes back to the fact that an

1374.awful lot of disabled people (..) there is a huge rate

1375.of unemployment among disabled people and that (.)

1376.obviously leaves you more prone to living in poverty

1377.(.) you know (.) and there's a number of factors (.) you

1378.know a lack of work that people can do maybe if they

1379.have a physical disability (.) the fact that they need a PA

1380.in the workplace (.) because if I didn't have a

1381.PA in the workplace, I wouldn't be able to work or

1382.you might get a job but the transport costs might be

1383.prohibitive (.) because I remember years ago when you

1384.were working in (.) what was the name (.) in *****(.)

1385.your transport bill (.) before you had your van.

1386.**Eleanor:** Oh yeah ***.

1387.**Susan:** You were having to pay a lot in transport just to

1388.get to work.

1389.**Moderator:** Because previous Irish studies have come

1390.out with suggestions for payments per week and they

1391.had divided up the payments into levels of need and they

1392.had suggested, €10 low need, €20 for medium and €40

1393.for high levels of need, per week.

1394.**Susan:** How many years ago was that?

1395.**Moderator:** That was 2004. I suppose, how far would

1396.that money go, is the question. Is that realistic?

1397.**Maura:** Is that the Disability Allowance?

1398.**Susan:** As an extra payment I suppose.

1399.**Moderator:** As an extra payment, that wouldn't be means

1400.tested everybody would receive it. What would you think

1401.of that amount of money?

1402.**Maura:** But then how would people assess if you were

1403.severe medium or low, that's another problem.

1404.**Moderator:** €40 a week doesn't sound like

1405.a lot of money to me.

1406.**Maura:** It's better than nothing (..) and another thing, it's

1407.about responsibility again, I mean, if the HSE have no

1408.money they cannot pay and the expectations are huge

1409.like, I feel the Health Board cannot maintain financially,

1410.that's being real.

1411.**Susan:** One thing they are looking at, at the moment is

1412.(..) my PA got a letter in the post this morning from the

1413.Irish Wheelchair Association, you know (..) they're

1414.looking at premium rates on a Sunday and bank holidays.

1415.**Timothy:** Yeah.

1416.**Susan:** Now if they are entering into negotiations with

1417.SIPTU (..) because all the staff who work in HSE funded

1418.organisations get a 100% bonus if they work on a

1419.Sunday if you normally earn €13 an hour, you get €26 for

1420.a Sunday and a bank holiday (.) like, that's a significant

1421.amount of money (..) like if the premium was reduced

1422.to a 50% bonus you could deliver an awful lot of extra

1423.hours (..) because now organisations like CIL and IWA

1424.are going to have to compete with all these private

1425.commercial providers like ***** and other ones and

1426.they only pay about €9 an hour.

1427.**Maura:** They don't give good value.

1428.**Susan:** No and they don't give anything extra either.

1429.**Maura:** Quality yeah.

1430.**Timothy:** I wouldn't fancy going to one of those private

1431.firms because I think the people they employ wouldn't be

1432.as good you know (.) you wouldn't get the same attention
1433.off them.

1434.**Susan**: I was going to say the turnover of staff is huge
1435.(.) because the staff are just not treated well.

1436.**Moderator**: And are they the same service providers that
1437.would provide elderly care?

1438. **Susan**: It used to be just elderly care, but now it's gone
1439(..) they're targeting under-65 services as well and they
1440.charge maybe €20 an hour to the family but the PA would
1441.get maybe €9 an hour.

1442.**Timothy**: What you are better off doing yourself to be
1443.honest with you, what I would do anyway, I'd rather
1444.approach a PA that I knew-

1445.**Susan**: (overlapping) Cut out the middleman.

1446.**Timothy**: You know, cut out the middleman, exactly (.)
1447.and we say (.) instead of giving them €9 give them we say
1448.€14 or €15, you're still saving yourself €5 an hour but if
1449.you use an awful lot of hours it all adds up you know
1450.(.) I can't understand why more people aren't doing that
1451.you know, I'd rather than going directly to those people.

1452.**Susan**: Like a lot of families who have a disabled or older
1453.person in the family and never had any PA services so
1454.they are afraid to just go and put ads in the Echo and get

1455.a random (..) they wouldn't be as confident about it.

1456.**Timothy:** With a small bit of research on the computer

1457.and go and look at the centres that provide PA services (.)

1458.through the HSE and stuff like that.

1459.**Susan:** Yeah, like a small number of our PAs would be

1460.***** ** **** ** **** ***** (.) some

1461.we'd know about some we wouldn't.

1462.**Moderator:** And how do people feel about the idea of

1463.Direct Payments like they use in the UK?

1464.**Timothy:** There's talk about that alright.

1465.**Moderator:** Where you get the money and you buy the

1466.services yourself.

1467.**Susan:** I think it's fantastic, it wouldn't be everyone's cup

1468.of tea a lot of people they prefer to have the back up of

1469.an organisation.

1470.**Maura:** If I was an alcoholic now or an addict of any

1471.sort where would my direct payments go? You wouldn't

1472.give them to me?

1473.**Susan:** No, no, a person would have to be assessed and

1474.interviewed and so on.

1475.**Maura:** And who would do the assessment? Because I

1476.think direct payments are open to abuse.

1477.**Timothy:** I think they are too.

1478.**Susan:** Well I suppose everything is open to abuse, it
1479.seems to work well in the UK anyway.

1480.**Maura:** It's just the assessment would be very important.

1481.**Susan:** And I suppose if someone has a significant
1482.disability and they have a drink problem and they use
1483.all their money for drink and nobody is there to get
1484.them out of bed in the morning it's going to be quickly
1485.flagged to the HSE that this is not a suitable person.

1486.**Timothy:** Yeah, because you know yourself, there's some
1487.people if they were getting a payment every week to pay
1488.their PA, you know, you'd be afraid in case (.) like you
1489.were saying there, that they'd abuse it, you know,
1490.so look (mimicking voice) 'I'll give you twenty now
1491.and another twenty next week' you know, or whatever
1492.it may be, he's going to leave him short you know.

1493.(..) I don't mind the way it is at the moment.

1494.**Susan:** There's a pilot project in Dublin, there's two
1495.people who have direct payments and at the end of the
1496.year that'll be reviewed and if it's gone well then hopefully
1497.it could be rolled out to other (..) because it's not
1498.everyone's cup of tea (..) despite even if it's a great idea
1499.the money could be misused, some people wouldn't want
1500.the responsibility of recruiting their own staff.

1501.**Moderator:** Yeah, you are an employer.

1502.**Susan:** Yeah there are a lot of legal responsibilities as

1503.well.

1504.**Adrian:** I recently got a letter about help with my heating,

1505.that I get every year, what they said now is that they are

1506.not going pay into a private (..) into like a bank account

1507.anymore, they'll pay it direct to the gas board and that's

1508. what they said in the letter that it's not going to be sent

1509.to you anymore, they'll send it to where it's got to go and

1510.I think it's unfair.

1511.**Timothy:** Before I got the course I'm on now I was getting

1512.help with my heating because I need the heating so

1513.much and they were paying directly to the gas board, you

1514.know, I didn't mind it, I knew they were payments going in

1515.there.

1516.**Adrian:** I don't mind it but I just like to see where it's

1517.coming from, if they are saying that people are drinking it

1518.or whatever.

1519.**Timothy:** Yeah, well when I got my bill I could see what

1520.the government, the HSE were paying and I could see the

1521.payments I was making, it would be on the bill, what

1522.they were paying (..) now on the course I'm on at the

1523.moment I lost it, they cut me off you know (.) but it's

1524.grand like (.) because I need the heating an awful lot.

1525.**Moderator:** Well it's actually 4.30 now, so just to finish

1526.up. I want to thank everyone for coming. And if anybody

1527.has any questions or concerns about the research I've

1528.given my contact number and my email on the information

1529.leaflet and also relation to a copy of the transcripts, I'll

1530.take your names and addresses and I will send you a

1531.copy, so you can have a look at it before I use it in the

1532.research, to see if you are happy with what was said o

1533.you want to change anything.

[Recorder switched off]

Appendix 4

Interview Information Sheet and Consent Form

Project title: An Investigation into the Additional Living Costs of Disabled People: Implications for Independent Living in Cork, Ireland.

Aims of the project:

1. To gain an indication of the additional costs of living that disabled people experience.
2. To get an idea of how these extra costs of living impact on key parts of independent living.
3. To come up with some ideas about how these costs could be resolved and as a result, prompt further debate on the issue.
4. Finally, to produce a report to be published and distributed by

the Cork CIL. One possible use is as a lobbying tool that could be aimed at the new government in order to ensure that these issues remain on the political agenda.

The research questions:

This project is attempting to answer three main questions:

1. What are the additional living costs incurred by disabled people in Cork?

Taking the additional costs of living to mean:

“...Additional costs associated with needs related to a person’s impairment and associated experience of disability.” (Disability Resource Centre, 2010: 27).

2. How do these additional living costs undermine independent living?

Taking the meaning of independent living to be:

“..All disabled people having the same choice, control and freedom as any citizen -at home, at work, and as a member of the community” (Morris, 2003: 4).

3. What could a solution to these living costs look like?

The objective is to seek the opinions of disabled people on what form a solution to these extra costs of living could take.

The research process:

The research will use two main methods to gather information or data: the focus group and interviews. The findings will be available in September.

The research blog:

A blog about the research is being developed to get some online debate going, if anyone would like to contribute, this is the address to go to, <http://extracosts.blogspot.com/> its at early stages yet so posts would be welcome. Just contact the researcher on the blog email to add posts or comment on the blog directly.

For any queries/comments contact: Carol O'Sullivan 086 374**** or cjcos@me.com

Appendix 5

Interview Guide: (30/05/2011, 07/06/2011)

Research Question One

1. Could you tell me what is your experience of extra costs of living?

For example ongoing daily costs? Which forms the biggest additional cost for you?

Prompts:

Personal assistance- in the focus group the cost of sustaining a PA came up- like going on holidays, having to rent bigger

accommodation because of PA medicines- the new prescription

charge, items not met by MC, clothes, laundry, food- special diet-

items recommended by dietician for example; items not met by MC

fuel/heating- need to have the heating on a lot, electricity, transport

and travel, wear and tear- on house

2. Could you tell me what is your experience when it comes to things like doing an adaptation to your house or car or buying environmental controls?

Prompts:

Do you think people have to go into debt to do these things?

3. Are there any items that you would spend more money on if you could?

Prompts:

Personal assistance, additional informal services- gardener, painter, transport: public/ private, heat/electricity, house adaptations, social activities.

4. In your experience do you have to forego spending on certain items as a result of extra costs of living?

Prompts:

How about going on holidays, are holidays something that are the first to be sacrificed because of money has to be spent elsewhere?

How about social activities? Luxury items?

5. Do you think that worrying about bills and debts in general is

common in the disabled community because of these extra costs?

Prompts:

Is saving a possibility?

6. How have the cut backs affected you and your ability to manage financially?

Prompts:

Medical card- items that were once met by and now not, Disability

Allowances cut backs, any services?

Research Question Two

7. Could you tell me what independent living means for you?

Prompts:

Is it about, choice mainly, control, rights, personal assistance, a decent income, owning your own home, etc?

8. How do you feel that the additional costs of living affect independent living for you?

Of the elements of independent living as defined by the independent living movement like...SEE PROMPTS...does the additional costs of living affect these elements for you?

Prompts:

Personal assistance, transport, technical aids and equipment,

adapted housing- came up in focus group that people were better renting from council? Equal opportunities for employment

Research Question Three

Now I would like to ask you about the possible solutions to the extra costs of living in Ireland.

9. What do you think would be an appropriate solution to the extra costs of living?

Prompts:

Are present state benefits adequate to meet extra costs? -Increased state benefits across the board for anyone receiving a disability related payment. A specific cost of disability payment: means tested/not? Indecon suggested €10 low need, €20 medium need, €40 per week high need. Direct payments to be managed by the person receiving the payment to be spent on services as needed.

Tax credits. Would changes in: Legislation, Society make a difference?

Appendix 6

Transcript: Fiona, 30/05/2011

*The names of participants have been changed any personal information has been removed and has been replaced by the following symbol *****.*

R: Researcher

F: Fiona

[Discussed the project, read out consent form and gained consent]

1. R: To start off the research is based on three main
2. questions and the first is around the additional costs of
3. living the things that you find extra, daily living costs,
4. ongoing costs, for example, the things that came up in the
5. focus group, like maintaining a personal assistant, like

6. renting a bigger apartment to accommodate the personal
7. assistant.
8. F: Yeah, well that used to be the case when I was living
9. in an apartment before I got this house, (.) then I'd have
10. to have a two bedroom apartment for my personal
11. assistant to stay in, and the apartment would have to
12. be a top range apartment, a pretty modern one which
13. would be more expensive than an ordinary one that
14. anyone could move into, it was a lot more expensive
15. than another person my age in the same
16. circumstances that didn't have a disability that could
17. move into, like if I didn't have a disability I could move
18. into a house share situation which would be far less
19. money, but since I moved into this council house here
20. its kind of less of an issue now. Like I was given this
21. house, a two bed roomed house for the personal
22. assistant to stay in the other bedroom,
23. it's grand now, it's working out alright, but before
24. I moved in it was a huge cost, was renting and you
25. would get rent allowance but not for everything you
26. know, and it wasn't out of luxury I was renting the
27. apartment, it was out of necessity for want of a bigger
28. space.

29. R: And I suppose old places are not accessible.
30. F: Most apartments would be upstairs or they'd be too
31. small or the bathrooms (.) my biggest problem was
32. getting one with an accessible bathroom, and I found
33. this apartment which appears to be the only
34. apartment in Cork that I could find, before and since.
35. R: Go way!
36. F: I was very lucky to find it but still I had to pay
37. through the nose, it was very expensive because it
38. was a top range apartment like, yeah that was one
39. daily living expense that was very hard going, but
40. since I moved in here my living expenses, if I try to
41. think about what I would have to pay for as opposed
42. to a person with no disability, (..) like my personal
43. assistance hours are (.) provided by the *** so and I
44. get home help hours as well so I don't have much to
45. come out of my personal costs, but if I do want
46. anything extra because my hours only cover certain
47. amounts of time during the week so there is a lot of
48. time that isn't covered, for example, going out at night,
49. I'd have to pay for my PA's taxi and you know, if you
50. were going to the theatre or something like that, or the
51. cinema, I'd have to pay for my PA's cinema tickets, so

52. to do something like that, where one person would
53. only have to pay for themselves where if they wanted
54. to treat their friend grand but I kind of have to if I'm
55. bringing a PA.
56. R: I mean it's a working relationship as well.
57. F: Yeah, in fairness now I do have some PA's now
58. that we are friends more than anything else and we
59. have an understanding but that's evolved over years
60. and years of relationship, it's not an expectation, but,
61. that's only our personal situation, we've reached an
62. understanding, but if I've a PA coming that's doing
63. relief work while my usual PA's are on holidays, if we
64. need to go out or anything it's expected that I would
65. have to provide transport for that PA, so it's that kind
66. of small thing, but the PA's that I have at the moment
67. it's a different relationship, it's not as official as
68. someone else, but there have been times before now,
69. if I wasn't as personal with a PA that you'd
70. have to pay for the bus or the taxi or whatever, and
71. especially, it would apply now even if I'm close to the
72. PA's if we were going to go on holidays I would have
73. to pay for most if not all of the PA's costs.
74. R: That came up as well in the focus group that the

75. holiday was a big issue
76. F: Yeah, it's a huge issue, like I can't, I could never go
77. on holiday by myself I'd have to have someone
78. helping me, and someone, you know it's a big job to
79. help someone with a disability and they have to be
80. paid and no one else will do it except for the person
81. that they have assisting you know (.) so that's the
82. holiday, that would be a big obstacle for me going
83. away.
84. R: Would that then be sacrificed, does it happen then?
85. F: No I just, I don't go, it would be too expensive, it's
86. basically double what anyone else would have to pay,
87. double the flights, double the accommodation, now
88. there is a facility in the CIL that they could provide
89. extra hours if you wanted to go on holiday, but that
90. would only cover a few hours wage, salary, for the PA
91. while they are gone, but they are not going to pay for
92. accommodation. As well as that it depends on the PA
93. then, they expect to get a salary on top of that for the
94. hours working with you. So it all depends on the
95. relationship you have with the PA, but in general they
96. are the extra costs (...) with regard to daily living then,
97. transport costs are a major problem, I do

98. get the bus if it's anyway dry at all and that's free
99. travel and that's fine, but you know Irish weather.
100. R: It's definitely not reliable.
101. F: No, if you have to be somewhere, and you have to
102. be there, now you can get **** *,
103. but they need to be booked in advance, you can't just
104. ring them and say you need a taxi, so any spontaneity
105. you want is out the window with them and then what I
106. would need to do is book a taxi and in fairness now,
107. wheelchair taxis are fairly easy to come by now days,
108. well in my experience, but you are paying through the
109. nose again just to go in to town, you know.
110. R: Yeah
111. F: Or go down the road for an appointment or
112. something (.) when someone else could just walk
113. there, hop on the bus, drive even, so that's another
114. expensive, costly, daily thing if you know what I mean
115. (.) I'm trying to think of what else (..) I think that's really
116. it daily living wise in my personal experience you
117. know.
118. R: And the other things like, items related to the
119. Medical Card, things like prescription charges?
120. F: Well (.) no its hasn't, I'm on the Medical Card, and I

121. get my prescriptions for free, but there is an extra, for
122. every prescription you have to pay fifty cent now.
123. R: That's a new thing.
124. F: Yeah but it's not, you know, burdensome or
125. anything.
126. R: Yeah.
127. F: So I'm (.) because I'm on the Medical Card, you
128. know, a lot of my medication is for free and my
129. doctor's appointments are for free, so that way there's
130. no problem (.) but that's only because I'm on the
131. Medical Card.
132. R: And have you come across anything that was
133. covered by (..) say a dietician recommends
134. something, like an example that came up was that
135. someone was recommended Manuka honey.
136. F: Yeah
137. R: It's a bit cheaper now, I've seen it in Aldi, for €10
138. but at times it was very expensive about €40 or
139. something (.) is there anything like that that you've
140. come across? Like dietician saying you have to eat
141. certain foods or?
142. Something that wouldn't be covered by the medical
143. card.

144. F: No, not in my experience, now there would be a
145. need to do some exercise a lot to exercise my
146. muscles, and I do have an exercise machine that I got,
147. oh it's a good 15 years ago now that I got it, so I still
148. use it but it's fairly archaic now at this stage, it's
149. something that I would need and it's something that I
150. would be interested in getting again, but they are
151. easily a grand, you know, to get, and you are not
152. going to get a grant for that as it's not seen as a
153. necessity, as it's not going to stop me getting out of
154. bed in the morning, so, that is the only thing
155. I can think of that is not so much recommended to me
156. but, the one's now are better than 15 years ago,
157. the one of 15 years ago, it's old, it doesn't have the
158. same facilities as a new machine would have but the
159. new one is totally extortionate and the same with, you
160. know, with new equipment, like if I wanted to get a
161. new hoist, I can apply through the Health Board, but to
162. get the best hoist there is for example, you'd have to
163. pay a lot of money.
164. R: And how does that work then, they'd buy it for you?
165. F: Yeah, you'd apply to the HSE but you'd see they'd
166. only do it if you absolutely need it.

167. R: Yeah.

168. F: So now I have a great hoist at the moment and it's
169. brilliant, but a ceiling hoist would be much better
170. because it would maximise space more, and it would
171. mean more space for me to get around, but you have
172. to get reinforcements into the roof and all of that and
173. the HSE would never sanction that, especially when I
174. have one already, I'm happy with the one I have
175. already but you know I'd have to pay extortionate
176. money if I wanted to up grade you know, they are the
177. only things I can really think of, there's real necessities
178. that I've been advised to get and that I can't get
179. because of the cost, I'm pretty lucky that way, you
180. know, a new hoist and a new exercise machine are
181. things that I'd buy if I won the Lotto kind of thing you
182. know.

183. R: Right, yeah.

184. F: But it goes to show like that a basic thing that would
185. really improve my standard of living, that is not even a
186. luxury, would cost more than it would cost a person to
187. buy a car, even a house, a ceiling hoist would be
188. extortionate.

189. R: Really.

190. F: Yeah (.) an exercise machine you are looking at a
191. couple of thousand (.) so it's those kinds of things that
192. are really necessary and really important
193. to have in tip top shape and to have the best
194. available, but its the most expensive, and that's
195. because the whole area of disability, the disability
196. industry is so specialized that they can have as much
197. price as they want you know (.) or if I needed a new
198. bed, a profiling bed, the ones that go up and down,
199. that would be expensive as well, you know, anyone
200. can get a new bed, just a cheap old thing in Argos,
201. whereas with me it's not the same you know. But
202. again I have no problems with it, its grand,
203. but if it broke down in the morning, you know.

204. R: So what happens then, is it a case of, they decide
205. what to buy, or is there a compromise?

206. F: They are not going to give you a top of the range
207. ceiling hoist when they could give you a cheaper one
208. that is not a ceiling hoist but does kind of the same
209. thing, they wouldn't be thinking of something that
210. would be maximising space, you know, that'd be
211. better for you overall, they'd be looking at the price, of
212. course if you buy it yourself, I'd buy it myself if I had

213. the means you know (.) so yeah, you basically, they
214. won't give you anything if they deem that you don't
215. need it, you basically would have to have nothing,
216. you'd actually have to be sleeping on the floor before
217. they'd say you need a bed you know.
218. R: And is it harder, have things become harder in
219. terms of budget?
220. F: Yeah, I'm lucky now, that I haven't had to call the
221. HSE to get anything but I mean, this wheelchair for
222. now, for example, is five years old, and I would be
223. needing to look at getting a new one in the next
224. couple of years and it's more expensive, you are
225. looking at €10,000 to €15,000 (.) and the HSE, a reply
226. from the HSE, you'd be waiting forever for their
227. approval and again you'd have to be (.) you'd have to
228. have a really good excuse to get a new chair, it would
229. have to be falling apart on me you know, whereas
230. someone who has a car, if they want to upgrade it, like
231. you'd want to upgrade your phone, you know.
232. R: Yeah
233. F: Upgrading your wheelchair would be more
234. important you know, your body shape changes all the
235. time, you put on weight, you loose weight and after

236. five years you'd want to be reseated.
237. R: Its something you use everyday like.
238. F: Yeah it is, for that to be changed its a lot of
239. bureaucracy, and a lot of waiting and making
240. applications (.) you know anything you can't pay for
241. yourself you ask the HSE and maybe the Council, but
242. you have so much paperwork to fill out, it's hard like
243. you know. So it's those kinds of costs daily living wise.
244. R: And if you had to pay out a big chunk of money, if
245. whatever reason a person couldn't get the HSE to pay
246. out, like does debt become an issue? Like it came up
247. that people find it really hard to save any money?
248. F: Yeah I'm finding it hard, and I'm lucky that I'm not in
249. debt and I've never found myself on the verge of debt
250. or anything, but I'm finding it hard to save because
251. everything goes on, like I have my budget say, and I
252. have my extra costs that you can't budget for, like the
253. taxis now going into town, or you know if you want to
254. go to the cinema, buy tickets for your PA, it's that kind
255. of thing now that would be the extra costs.
256. R: Something else that came up was extra heating
257. costs, like do you need the heating on all year round.
258. F: Yeah, I suppose I would have more a need for

259. heating in the winter especially, but I do get my
260. heating paid for in my home care package, so or my
261. Household Benefits Package rather and that gives you
262. an allowance your fuel allowance, your gas allowance
263. and your electricity allowance, so it's not too bad
264. actually, it helps, it's not any different to anyone else
265. with a heating bill, its not any different, you just have
266. to be careful.
267. R: Yeah, and I mean this year was so cold.
268. F: Yeah it was awful during the winter, the snow and
269. the freezing over was unreal.
270. R: Yeah, I was going to a garage around here and it
271. was so icy.
272. F: Yeah, you'd be slipping everywhere so that was
273. cold alright but I'd be no different that way.
274. R: Other things that came up was wear and tear on
275. the house, when people's houses were not designed
276. in a totally accessible way, people's mobility aids were
277. scratching walls and things.
278. F: Yeah, there'd be a lot of scratching of walls alright
279. now. But if any equipment ever breaks down I'd ring
280. my OT and she would get on to ***** ** to
281. come out and fix it but the thing about it is, and they

282. would pay for it, the thing about it is you are waiting
283. forever if the HSE pay for it, but if you pay for it will
284. happen straight away but you can't because it's so
285. expensive, and again we are back to the whole (.)
286. wheelchair equipment is so specialised that you know,
287. it's a monopoly really between the couple of hundred
288. companies that do it, you know what I mean?
289. R: Yeah.
290. F: So (.) you would have to pay for more maintenance
291. of the house and it's not as easy to look after a house
292. when you have a person in a wheelchair living there,
293. because you have specialist equipment that can easily
294. breakdown, and it seems the more specialised it is, it
295. seems the more it wants to break down.
296. R: Yeah
297. F: But again I wouldn't have to incur those costs,
298. they'd be done through the HSE, but the downside of
299. that is that you have to wait until it's fixed because you
300. are not paying for it, so that would be my experience.
301. R: And something you've kind of touched on yourself,
302. any adaptations to the house or buying environmental
303. controls, is that something you'd have to pay for
304. yourself?

305. F: The City Council do give a grant of up to €5000 or
306. something for any adaptations you want to make to
307. the house but number one, the form is so complicated
308. and you have to bring in your own contractors and
309. their tax details, get a quote, send it in and then they
310. send you back stuff it's a long rigmarole of a thing
311. and even then, you know they have to stay within the
312. price range whereas if I won the Lotto in the morning
313. there's loads of stuff I'd get done you know and that
314. again is extra as any other person without a disability
315. wouldn't have that cost of getting environmental
316. controls or you know, like I'm managing okay without
317. them but eventually I will have to get them, you know
318. and that will incur, either a big long wait for approval
319. or, even if they do approve it you don't know how
320. much they are going to approve of it, you might have
321. to take care of the balance of that, so again it's all
322. extra costs.

323. R: And do you find having lived in private
324. accommodation, like someone was saying that you
325. are better off in Council accommodation, that you
326. have a direct link if something comes up, whereas if
327. you someone who lives in private accommodation he

328. got an extension but he had to pay a big chunk of it
329. himself.

330. F: Yeah (.) living in the Council is a lot better because
331. you have a direct but they are good landlords because
332. they'd have a lot of tenants with disabilities in the city
333. whereas a private landlord wouldn't have the same
334. understanding, like we had to make a couple of
335. alterations now in the apartment where I lived before,
336. just a couple of things like moving a table that was
337. attached to the wall, they were minor things, but you
338. had to ask them could you do it as it's not your house
339. and when I moved out I had to move everything back
340. so that I'd get my deposit back, but I didn't have to do
341. that kind of thing here, you know, it's my house so I
342. can do whatever. So yeah (.) I think Council houses
343. are better, they are more made to be tailored to your
344. needs (.) now I suppose this one in general could be
345. classed as wheelchair accessible, the low kitchen, but
346. it's not really.

347. R: Was it purpose built or?

348. F: It was more (.) it had a purpose built bathroom but
349. there was nothing else really, the switches aren't down
350. low, the counters aren't down low, it was more kind of

351. built generally for a person with a disability and I got it
352. (.) the bathroom is always the most important part and
353. that's fine and (.) everything else would need to be
354. upgraded, but I'd never get a grant, you know in an
355. ideal world now you'd get counters that would go up
356. and down at the flick of a switch and you could move
357. down the light switches so that I could hit them myself,
358. but the HSE would only pay for part of that I'd say, so
359. that's all extra then if I wanted all that.

360. R: So another question could concern items that you
361. would spend money on if you could on a daily basis,
362. like in relation to adaptations you spoke about that.

363. F: Yeah if I had more money I would totally adapt the
364. house. If I had more money again I'd get the best
365. equipment, if I had even more money than that again
366. I'd build my own house to my specifications, but in the
367. real world (.) like actually in the real world I'd get a
368. specially adapted car that you can drive in the chair
369. and drive from the chair, but again they are all very,
370. very expensive, up to, a brand new one with all the
371. required adaptations could be €50-60,000 (.) looking
372. at a second hand car would be €18-19,000, and they
373. do have a motorized grant but that only goes up to

374. €5000 so its not really a lot when you think about the
375. grand scheme of things, because if I was able to drive
376. that would mean so much more independence, I could
377. drive into town or I could drive anywhere, its not, I
378. can't just go on www.carzone.ie you know and buy a
379. car like anyone can, it's very expensive and it will take
380. along time to get it (xxx) so that would be another
381. cost, basic transport, even if I didn't want to drive
382. it myself it would cost a lot of money, so that would be
383. another thing that would be a real great improvement
384. in my life but I can't get it because of the cost.

385. R: Because I know they do the Disabled Driver's or
386. Passenger's grant, but you have to pay the money up
387. front and then get it back.

388. F: Yeah, and you do get the VAT back as well but
389. again you have to pay the money upfront and even
390. the motorised grant is only €5000, it's not a lot if you
391. were only getting a Ford Fiesta it would be brilliant, but I
392. would need an actual big, not a van as such, and it's
393. not the actual vehicle that costs it's the adaptations
394. that cost the most, and life would be so much easier if
395. I was able to invest in a car for myself, but the only
396. thing stopping me at the moment is the cost and the

397. extortionate expense, you know, if it wasn't any more
398. expensive than what another person would spend for
399. a car you know then I wouldn't mind it, it's a very high
400. cost.

401. R: Yeah I mean a car is a big outlay in general, but
402. like you said with €5000 you could get a good second
403. hand car you know.

404. F: Yeah, you can get second hand cars for nothing
405. you know. That's another thing that a hard to deal
406. with, you know, something that would make your life
407. so easy but you can't access it because of the cost of
408. it and the costs are so high because of the whole
409. monopoly thing of it you know.

410. R: It's a vicious circle.

411. F: Yeah a very vicious circle.

412. R: Something else that came up was in relation to the
413. holidays and forgoing extra costs, was something you
414. touched upon, like social activities, are they probably
415. the first to go?

416. F: Yeah, they are the first to go, like you need to have
417. your essential like getting up in the morning, being
418. able to eat, being able to have your personal care and be
419. able to get out of the house even for basic fresh air

420. you know if I want to go on a holiday, I can't because
421. I'm not just paying for myself, if I want to have an extra
422. night, and spend the night out on the town I can't
423. because I have to pay someone to do it (.) so that's,
424. so it's hard definitely costs are hard, like I said my
425. daily living isn't too bad except for the equipment I
426. have, the electricity and the 'phone bills and all that
427. they are not any different.
428. R: Something else that came up was in relation to
429. food, and someone had to buy food in a convenience
430. store, your local shop, because at the time, it was the
431. time of the ice, but in general it would have been too
432. expensive for this person to go into town in a taxi, so
433. instead they were buying their food in the local shop
434. which is usually more expensive than going to Aldi or
435. Tesco, but you are probably in a good location here
436. does that apply to you?
437. F: Yeah, I suppose but I would like to be able to have
438. a choice of shop, like Tesco is very good but Aldi or
439. SuperValu can sometimes be cheaper and I suppose
440. this would tie in with transport as well, as Tesco
441. wouldn't have a great variety in the stuff that I want
442. you know and then when you want to head out down

443. to SuperValu or Aldi and they are too far down
444. because number one, you can't bring the stuff home
445. with you yourself and number two because it's too far
446. away to go by yourself. Now I do, do it online with
447. Tesco, but you can't do it online with Aldi or
448. SuperValu, which is a bit of a nuisance, you know
449. because they do great deals and saving money that
450. way, I wouldn't be able to save money by going to a
451. cheaper supermarket, so I have to make do with
452. Tesco because it's the nearest, number one and
453. number two because it's the only online shopping
454. facility for groceries. But overall it's fine, but it's just I
455. don't have the choice that other people would have.
456. R: The local shop though is really expensive, I go to
457. Aldi myself.
458. F: Yeah like I would go to Aldi as well if I could but it's
459. just so far **** and it doesn't do online shopping but
460. I'm hoping that it's something that they'll do eventually
461. because it's getting that way with the internet and all
462. that.
463. R: They seem to be very kind of forward thinking
464. anyway, but they are very pared back on staff!
465. (laughter)

466. R: But (.) that would be your main issue on forgoing
467. things, and you mentioned that heating bills and that
468. worry wasn't an issue for you.

469. F: No, I do get the allowance and that's fine and even
470. if I didn't get the allowance I wouldn't have any greater
471. need than anyone else would so it wouldn't be any
472. extra cost when compared to anybody else, you know.

473. R: Yeah

474. F: But I have just to try and be as disciplined as I can.

475. R: And this is a new house and surely they put good
476. insulation into it.

477. F: Oh yeah, I mean I wouldn't have it on in the
478. Summer at all if I can get away with it, you know what
479. I mean.

480. R: And like older houses are not insulated (..) And are
481. you on a disability payment , are you
482. working?

483. F: Yeah I'm on a disability allowance once a week.

484. R: And how do you find that now with the cutbacks?

485. F: Oh, I lost, was it, €8 per week from those ones and
486. now as well, because the heating allowance, you don't
487. get that during the Summer months it's gone down a
488. little further but it's just a matter of budgeting and just

489. try to work around it you know, save money on some

490. things, spend less on others you know.

491. R: And you wonder are they going to do it again you

492. know.

493. F: Yeah, I was hoping they'd have a bit more optimism

494. now that the new government is in but I suppose there

495. is nothing they can do like, we need these tough

496. budgets but as long as they don't hit the frontline

497. services, you know, I think we can get through it, if

498. they don't cut the PA's because that would really be

499. the end of it then you know.

500. R: I don't know, that guy *****, I don't know if it

501. was a blunder, was saying that we'd need another

502. bailout next year!

503. F: Oh God. Another one!

504. R: So much for all those nice visits we had! (.) I

505. suppose that could lead us on to the concept of

506. independent living and the other research questions,

507. which is trying to tie in the extra costs and how they

508. impact directly on independent living for you. Even

509. though you discussed it anyway during

510. this. There is the independent living movement, and

511. then there's what it means for the individual, like what

512. it means for you?

513. F: Yeah, independent living basically is being able to
514. live a full life without your disability impeding that and
515. to have the same life goals, achievements and
516. satisfaction that any other person would and not
517. having anyone obstruct that, so for me that's living in a
518. house on my own without anyone looking down my
519. neck telling me what to do, I make my own decisions I
520. get to go out if I want to go out, if I want to stay in I
521. stay in, it's all my own decisions. Without anyone
522. saying that they know best, or it's for your own good or
523. whatever like that and that's what I'm doing, just living
524. your fullest life to the best of your ability.

525. R: Of the different elements of independent living, the
526. movement has identified 12 elements in total, like of
527. those, like personal assistance, transport, technical
528. aids and equipment, adapted housing, equal
529. opportunities for employment, like can you see the
530. additional costs affecting anyone of those in particular
531. for you?

532. F: Okay (..) well the first three definitely, the personal
533. assistance, transport and technical aids and
534. equipment, adapted housing, that's definitely an issue,

535. but it's not an issue for me now, if you came to me
536. three years ago it would have been an issue because
537. I was on the list for six years, in a very nice apartment,
538. but not that accessible, I couldn't go in and out as I
539. please because the doors were heavy, like that was a
540. lot of time spent on my own at that time because I
541. couldn't open the doors, but now that I'm renting from
542. the Council, it's much better, you know, because they
543. can build a house around your specific needs, and if
544. they don't they can adapt it if you
545. apply for, well, they can get you money to adapt it and
546. send the money, so for me it's not very relevant
547. anymore, but it's definitely very important to have
548. adapted housing. Equal opportunities for employment,
549. yeah that's very important as well, and my personal
550. experience of it was that I always got a good response
551. from people if I went for interviews or left my number
552. or anything, but I have heard of people being totally
553. overlooked or not thinking that they have no
554. favouritism towards them or anything (..) equal
555. opportunities for employment.
556. R: Like say for example (.) it came up in the focus
557. group, that somebody's transport costs were so

558. prohibitive that when they had the job, it actually
559. worked out, that how can you work, you're breaking
560. even, if that, and I suppose that's how the costs come
561. into it, that some costs, prevent you doing something
562. else.

563. F: Yeah, I suppose the sad fact about employment is
564. that there aren't equal employment, and it's not
565. because of people's maliciousness or anything it's just
566. because some buildings aren't accessible and there is
567. nothing you can do, the office might be too small, you
568. mightn't be physically be able to do as much as other
569. people and then because you can't do it you are not
570. taken on, there's no alternatives looked into,
571. employers want the easiest job, take you on, do the
572. work, go home, no more responsibilities after that (.)
573. yeah so all those five issues are important I think.

574. R: And you spoke already about transport being
575. affected by costs and the technical aids and
576. equipment, and personal assistance, there is only a
577. certain amount of hours available.

578. F: Yeah, yeah, there is only a certain amount of hours
579. and I've no social hours at all, all my hours are for
580. necessities, that's like cooking dinner, personal care,

581. going to bed, getting up after that then I have to make

582. my own fun, you know.

583. R: Yeah

584. F: And that's kind of (.) there are additional costs on to

585. that.

586. R: Yeah, like paying for someone to go with you.

587. F: Yeah.

588. R: The next research question relates to the solutions

589. for the extra costs of living, like have you thought

590. before about what you'd like to see happen?

591. F: I'd like to see, I suppose, to try to put an ending to

592. the monopoly of wheelchair supplies, like if it wasn't so

593. specialised then it wouldn't be so expensive, they

594. should make things mainstream, available for people

595. with disabilities (.) like I myself now, for example, like

596. the hoist, my bed, my commode, you know, those

597. kinds of things are very expensive and I have them

598. and I'm lucky and they work perfectly, but I think if

599. they break down there should be more of them,

600. maybe a priority thing.

601. R: So treating it like it's not a luxury item.

602. F: Yeah, it's an item that needs to be fixed, like if you

603. ring someone to come out and fix your washing

604. machine and you are paying them yourself they are
605. going to come out straight away, whereas the if the
606. hoist breaks down and the HSE is paying it they take
607. their time, whereas if you pay for it directly, they'll be
608. out straightaway, you know, and (.) no, like if I want to
609. get a new wheelchair it shouldn't be as expensive as
610. ten cars, you know, because it's a specialised thing, it
611. should be more mainstream, there should be more
612. companies making good sturdy wheelchairs and more
613. companies making more aids and equipment, now I
614. think they are, like I think Argos now have brought in
615. aids and appliances, now a very small selection on
616. one page, okay the didn't have that a few years ago,
617. like they have something now like a rain jacket for a
618. person in a wheelchair that would go over the
619. wheelchair and you could only get that before in
620. special equipment shops, whereas now you can
621. get it in Argos and you can get wheelchairs in Argos,
622. now obviously they're not specialized wheelchairs and
623. they're only push, but at least it's a wheelchair if you
624. were really stuck and you can get it in Argos, so its
625. things like that, that I think they should be more
626. mainstreamed.

627. R: That's very interesting.

628. F: And (.) the idea of the car as well to get adaptations

629. for a car alone could be €15,000 in itself, depending

630. on what you need, so I might need a joystick for

631. example, to steer the wheel, but the joystick has so

632. much wiring and everything that it could cost an extra

633. €15,000 on to what you are already paying and again I

634. think it comes down to mainstreaming the industry, not

635. having it so specialized and not having it so that they

636. can hike up the price and no one can do anything

637. because they don't have any competitors, that's my

638. view on it anyway.

639. R: And like do you think things like the state benefits

640. are adequate?

641. F: For me personally, I mean I'm living comfortably, I

642. don't have a life of luxury and I do go over my budget

643. and I do have to save money sometimes and I'm not

644. able to put in a lot of savings or even as close as I

645. would like but its keeping my head well above water,

646. not anywhere near going under, and think that's all I

647. need and I'm grateful for that, so for me personally I

648. would agree that it's adequate, but obviously I

649. wouldn't say no if they increased it, because it has

650. gone down in the last couple of budgets so it would be
651. nice to have it up again where it used to be.
652. R: At least definitely maintain it and not cut it again.
653. F: Definitely maintain it (.) No, I mean I say I'm
654. comfortable, but I am just breaking even if you will, I'm
655. not getting into the minus or the red or anything, I'm
656. breaking even, but I don't have much extra for luxuries
657. then you know, there's not a lot for savings, if I want to
658. save for a holiday, put aside the fact that I have to pay
659. for the PA but just for arguments sake I wanted to
660. save for a holiday, I can't do it on what I'm getting at
661. the moment because it all has to go into the
662. maintenance of the house and groceries and Disability
663. Allowance is now cut down (.) and anything extra then
664. you have to really note it down because it could have
665. a big effect, you know at the end of the week you want
666. to go out for a couple of drinks or order in a pizza, you
667. know.
668. R: Oh yeah.
669. F: I'd never have enough where that would slot
670. perfectly into the budget, it would always be extra, so
671. (.) yeah.
672. R: There was a report done in 2004 for the National

673. Disability Authority and in the report they suggested
674. (...) they used a couple of methods to calculate
675. people's extra costs and at the end of it they came up
676. with a suggestion that people would get €10, €20 or
677. €40 a week payment for extra cost only, not means
678. tested, depending on their level of need, what would
679. you think of that?
680. F: So that would be in addition to your Disability
681. Allowance?
682. R: Yeah
683. F: Yeah, I would agree with that, that would definitely
684. be a big help and it wouldn't have to be a lot of
685. money, like I said an extra forty euro a week would
686. be plenty, just for that extra bit, because the budget
687. that I organise for myself would be the income from
688. the Disability Allowance and I have very little left over
689. at the end of the week for anything nice, you know I
690. wouldn't be able to go over to ***** now or
691. anything and treat myself to a nice top or a bit of make
692. up, without it going over budget, you know.
693. R: Yeah.
694. F: And then you've over spent and you are trying the
695. next week to build that back up and you have to forgo

696. more things.

697. R: And anything like cosmetics are expensive.

698. F: Yeah they are expensive, yeah (..) so it would be

699. nice to have even a nominal amount you know (.) that

700. you could maybe even put aside every week and let it

701. save up to a certain amount and then you could do

702. something with it then (.) or if they (.) I know they'd be

703. worried about abuse then but if they could just make it

704. for people who are already on the Disability Allowance

705. and any new applicants would have to pass very

706. stringent requirements to get this payment every

707. week, I mean there are ways and means of doing it

708. and making it fair for everyone.

709. R: Oh there are.

710. F: Yeah I'd definitely be in favour of that.

711. R: It was interesting in the focus group because a lot

712. of comparisons came up between the UK and Ireland,

713. I suppose the fact that the course I'm doing is based

714. there and they seem to be far ahead on a lot of issues

715. and comparisons came up, like the fact that they have

716. direct payments. How would you feel about that?

717. F: I would be in favour of that, like I do have hours and

718. all that but they are dictated in a way by the

719. authorities, the HSE through ***, and the HSE has it's
720. home helps, I mean you get your hours but you have
721. to use them in a specific way and you have to ask
722. permission if you want to do something different with
723. them you know so they are not at your own disposal
724. so to speak and I would definitely, I would feel more
725. independent having my own hours, to hire the people I
726. want for the hours that I want and to be able to
727. change them around without having to ask permission
728. or go to anybody about it, because they'd
729. be my responsibility, so I'd definitely, definitely be
730. truly be independent then that's the way to do it (.)
731. because with independent living there is responsibility
732. with it as well, you can't have one without the other
733. really.

734. R: There are things like, tax credits, you know if
735. people were working, at least it would go towards
736. some costs, like the transport costs we were talking
737. about earlier that would counteract that (.) how about
738. issues around legislation, would you have thoughts on
739. that, like you were saying like the employer not really
740. making much effort to adapting the office.

741. F: Like they wouldn't adapt the office because it's an

742. expense for them, but I know FAS have grants now for
743. adapting an office now so that's good, and I think the
744. human perception of people with disabilities is
745. evolving I think, like you'd go into an interview and
746. you'd know straight away they don't want to hire you,
747. whereas now it's kind of, there's no problem like, it's
748. only my experience of it, but my personal experience
749. of it might be totally different, but my experience of it is
750. that people's attitudes is less of a problem than the
751. actual work involved, the structure of an organization
752. the actual physical building (.) you know, like a person,
753. like say an employer would take someone on no
754. problem if they could do the work but if they can't, like
755. I wouldn't be able to do filing for example, in big filing
756. cabinets or reach up to a high shelf so if the employer
757. was willing to work around that and see that you could
758. contribute in other ways, like I think that's coming
759. along, like I don't think (.) well I haven't experienced
760. actual discrimination because of your disability, if there
761. is going to be a reluctance it would be about the
762. trouble and the cost of doing up a, or reorganizing an
763. office, say if the office is too small or whatever, but I
764. don't think it's discrimination for discrimination's sake,

765. you know what I mean so I think people's attitudes
766. have definitely changed, but they need to change a bit
767. more and they need to be more
768. proactive, you know, like I went to a job interview once
769. and it was with the civil service and they were very
770. positive, they were like, anything now that you need
771. for this job it would be done, we'd have the facilities for
772. you and they were very encouraging and that was
773. only at the interview stage, like if more employers
774. adopted that attitude you know, like and said there are
775. FAS grants out there and we'll look into whatever
776. grants are available so don't be worrying about that
777. aspect of it so long as you can do what's on your job
778. description we'll help you as much as we can (.) I
779. think it's going towards that way, ten years ago getting
780. a job was a lot harder than it is today I think (.) so with
781. regard to legislation (..) I think legislation has to move
782. from a resources based to a rights based legislation
783. so that you know, a person with a disability should
784. have a right to a personal assistant whatever the
785. economic state of the country is (.) like everyone has a
786. right to (..) to basic rights, a right to
787. property, a right to employment, a right to leave the

788. country, constitutional rights so to speak, or rights
789. irrespective of what the government can and cannot
790. afford, whereas disability rights, like rights to live
791. independently, rights to a personal assistant, they can
792. be taken if the government wants to cut the budget
793. tomorrow there's no one to stop them, now there is an
794. EU directive for a person with a disability, now Ireland
795. have signed it but they haven't ratified it yet and if they
796. do ratify that I think it would be a big step forward and
797. also a change the legislation to like I said to a rights
798. based legislation so that it's an absolute right for a
799. person with a disability who has the mental capacity to
800. do what other people can then they should have every
801. right to have the assistance to do that, irrespective of
802. money (.) as well as that they should move away from
803. a health model, that disability is seen as kind of (.) it's
804. kind of run by the HSE, whereas it should be run by
805. maybe the Department of Social Protection and more
806. about social inclusion and lifestyle than more about
807. health, you know.

808. R: The social model.

809. F: Yeah it should be about the social model rather
810. than the health model like a person with a disability

811. isn't sick, they have a disability, it's totally different, so
812. that needs, I'd say another ten years will tell an awful
813. lot, for example the home help system run by the
814. HSE, I know it did start off for elderly people and sick
815. people and people who were terminally ill, but it's
816. moved on now to people with disabilities and it's even
817. moved to children in a lot of cases, but the person is
818. still seen as a patient, so when I had to sign my home
819. help agreement when I got my home help a few years
820. ago I had to sign under patient even though I'm not
821. sick, so it's that kind of attitude that really needs to be
822. updated

823. R: Yeah, and I suppose that's where you can see the
824. understanding, or lack thereof of the concept of
825. independent living within the ***, regarding home
826. helps, it's a different way of looking at it.

827. F: Yeah, it's not independent living, you know really
828. (..) in that respect, with regard to society, again, they
829. have to get away from the idea that disabled people
830. are kind of ill and not capable of working, they think
831. that, I find a lot of people assume, if I met them on the
832. street, they would assume that I'm in a day centre or
833. I'm doing arts and crafts.

834. R: Really?

835. F: Yeah, like I was asked that once by someone like,
836. oh and you go to a day centre and they didn't even
837. know anything about me and I had to tell them I
838. actually went to college and I work or whatever, like
839. people's perceptions of the person with a disability is
840. that they've gone to a special school, they go to a day
841. centre now, they might do a job, they might do a job,
842. an easy job like behind a till or something, they never
843. assume, they assume the worst of you on the basis of
844. what people used to believe, like that has to evolve,
845. but I think ten years, even five years will tell a lot, but
846. there is still a long way to go, it's not even part of they
847. what.

848. R: Yeah, even judging from the type of research that is
849. done here you know I think it's like 5% of the research
850. that is done on disability in Ireland is social model
851. based, showing the emphasis, and there is very little
852. about Ireland you know.

853. F: Yeah, and I think there should be more information
854. for people with disabilities you know, like if I wanted to
855. book a hotel and look up about accessibility they'd
856. have general information about accessibility not

857. specifics, like I'd need, like I wouldn't need a
858. specialized bed but I'd need a bed that goes off the
859. ground to let the hoist go underneath it, I'd need to
860. see pictures of the bathroom, not that, you know that
861. it's accessible, like when they say it's accessible that
862. there's a lift or when they say it's accessible there's a
863. bar beside the toilet.
864. R: Yeah you'd see that.
865. F: Yeah, so people have a lot of misconceptions and I
866. think there needs to be more information, like,
867. available again in the mainstream instead of having to
868. look up specialist websites and specialist blogs you
869. know.
870. R: Yeah, like it should be universal design, like a
871. house for life, because you never know, everyone
872. gets older and no one knows the future.
873. F: Yeah, like someone can have an accident, nobody
874. knows (.) and people seem not to prepare themselves
875. for that you know, even though it happens everyday,
876. people get ill, it has nothing to with disability.
877. R: Yeah and the lifecycle.
878. F: Yeah, people get old and I suppose people don't
879. want to think about that and when it happens you are

880. really stuck you know, you should prepare (.) so (...)

881. yeah.

882. R: I think we have touched on everything and I

883. suppose that's coming to the end and we are gone

884. over the hour, that's great, thank you very much.

885. F: Thanks, I'm glad I could help.

[Recorder switched off, discussed transcribing, sending a copy to participants home and thanked participant]

Appendix 7

Transcript: John and Colette, 30/05/2011

*The names of participants have been changed any personal information has been removed and has been replaced by the following symbol: *****.*

R: Researcher

J: John

C: Colette

[Discussed the project, read out consent form and gained consent]

1. R: Like I was saying in the information sheet, the research
2. is divided into three main questions and I suppose the first
3. one is related to the extra costs directly and what kind of
4. costs would you experience, some examples of issues
5. that came up in the focus group were things like, ongoing

6. costs, for example, things that are not covered by the
7. Medical Card or things that a dietician might recommend
8. to somebody, or maintenance of a PA, like paying for the
9. PA when going to the cinema or (..) what would your
10. experience of those kinds of costs be?

11. J: It's funny you should mention the cinema there
12. and the personal assistants and going out, because
13. disabled people who have PA's they have that cost
14. factor, you know, you budget for two people if you're
15. going anywhere and a lot of businesses, like cinemas
16. they're not very accommodating when it comes to
17. having an attendant, they don't give you a
18. reduced rate particularly in the cinema now or in
19. entertainment they class it as the other person is
20. there to enjoy it, they don't recognize that the person
21. is actually doing their job and may actually hate the
22. film.

23. R: Yeah

24. J: They're attending you and it's a chore to them, but
25. that would be one considerable cost on a social level
26. and obviously when you're out with your PA you can't
27. really go and have a bite to eat without at least
28. offering somebody a cup of coffee, you just, as

29. humans we're not designed just to, you know, sit
30. there and ignore people, it's tricky you know, I find (.)
31. that in my relationship with Colette that the
32. two of us would go out together and we'd have
33. somebody with us and you're trying to invite that
34. person to be part of the circle rather than create ill
35. feeling and send that person away (.) now we would
36. on occasion say, you sit here and have a cup of
37. coffee we're going to go off and do the weeks
38. shopping and that's good because it gives us our
39. independence and separation, but like I said in the
40. entertainment side of things you are paying for extra
41. person and sometimes two, because if Colette
42. needed to bring an attendant, that's two extra people
43. (.) so we go to the cinema and you're paying €9 for a
44. ticket each, that's €18 by two.
45. R: €36 to go to the cinema and it's not a cheap thing
46. anyway.
47. J: And then the film turns out to be rubbish!
48. R: Yeah!
49. J: And you've just blown €36 away (..) another big
50. factor for me is electricity, electricity is really
51. expensive and we don't get a lot of coverage for it

52. because our heating is mostly storage electric (.) our
53. heating bills the fuel allowance would not cover our
54. heating bills in the winter, because of my
55. particular disability I have to maintain quite a warm
56. temperature so it's just a case of, I have to there's no
57. way around it, but our bills are very high in the winter.

58. R: I know that there is a Household Benefits
59. Package, I don't know, but does that apply to
60. yourselves or ?

61. J: It does but it's only (.) it's very small, very, very
62. small and now that the recession has hit like a lot to
63. that stuff is clawed back and reduced significantly, so
64. I mean it's household costs that kill us, because not
65. only do we have to provide electricity for ourselves
66. but I have live in carer's 24 hours a day, now they're
67. on (.) they're working for the ***** company it's a
68. community care project, but they're here in the house
69. all the time and we don't get expenses from the
70. HSE to pay for the electricity that they would use,
71. and what electricity they would use, you'd be
72. surprised, kettles and toasters, laptops, you know,
73. it's just extra it's not astronomical but it does impact
74. and push the bills up a bit but it's a necessity.

75. R: And that was an interesting part of the focus
76. group, was that those extra costs, something that I
77. had not come across in the literature before, which is
78. good to highlight, and something that came up as
79. well was comparisons with the UK and the way the
80. hotel would recognize the PA and give the room for
81. free.

82. J: Yeah, say if myself and Colette wanted to take a
83. holiday, I have to bring two carers with me, Colette
84. has to bring one, so (.) five of us heading off and you
85. find out the room only takes two people so you end
86. up with three rooms I order to accommodate that you
87. have to put the girls in one room and the boys in
88. another and we are a couple.

89. R: Yeah, that's not the holiday you would set out to
90. have like.

91. J: It actually doubles the price, plus the airline
92. tickets, there's no reduction, it's quite savage you
93. know, that's why a lot of people just don't go on sun
94. holidays unless they are able to manage a lot of their
95. own care, like in my situation now, the last time I
96. went on a sun holiday was when I only
97. needed one assistant and that one assistant was

98. kind of working between three people, it's just that I

99. needed someone to give me a hand to get up and

100. get out, as simple as that, now it's a different

101. story

102. R: I mean five flights, that's a huge cost, huge.

103. J: Yeah, there's no subsidy there (.) I spent a bit of

104. time in Germany a couple of years back, there

105. around '99 and I was talking to some of the German

106. people with disabilities and they told me that the

107. German government gives an allowance every year

108. to a person with a disability to encourage them to

109. take a holiday, it's not like respite where you get a

110. certain fund and they said you actually have to

111. take this money and book a holiday, then you have to

112. send a receipt back to say that you were going on a

113. holiday and that you're attendant was paid for,

114. it has to do with mental health and the understanding

115. that the stress that people are under, so it's good for

116. the health.

117. R: Oh yeah, everyone needs a change of scenery.

118. J: It reduces medical bills because if you feel good

119. that you've had a nice holiday, you're less stressed,

120. you don't get sick as often, it all kicks into one, so I

121. thought that was intriguing.
122. R: It is isn't it (.) because here, I suppose that's
123. where the medical model emphasis comes in, you
124. know, having the respite care, because that's not for
125. the person, that's for the carer isn't it?
126. J: Because it's all done like that, you have to fight for
127. your respite care, it's all medical labelled, you don't
128. actually feel like the holiday is your own, it's almost
129. like a forced upon situation, just to give the carer a
130. break, it's very clinical, it's very (.) minimal, people
131. out there probably think (mimicking voice) 'ah sure
132. the disabled are well looked after, they get
133. their respites' but it's a very minimal amount, respite,
134. you know, for what, you know the supposed cost
135. these days, I'll give you an example of how the
136. medical thing can push up prices (.) last week (.) we
137. have a hoist in the house and it has a hand remote
138. and the hand remote started acting up,
139. so I rang the company that manufacture the hand
140. remote and I asked him what the trade price for what
141. the remote would be and he said seventy sterling but
142. that's before it goes to trade, that's factory price, it's
143. not available to the public, the trade price was £200

144. from the factory to the supplier and the price from the
145. supplier to me, I was quoted €435 for a plastic
146. remote, that has no wiring in it, it's just the
147. air tubes that just, it's just bubbles that you press,
148. cheap as chalk to produce and they just mark it up
149. because it's a medical device.
150. R: Actually that came up with the last person I
151. interviewed, the way the equipment is sold and
152. produced as something that's specialized medical
153. equipment not something that's-
154. J: (overlapping) It becomes something extra.
155. R: Yeah
156. J: I'm not sure if it's something that other people
157. have spoken about (.) even booking taxis around
158. Cork (.) it's, the price is ridiculous, even for me to get
159. from here to Patrick's street and book a wheelchair
160. taxi, if they're available of course, the taxi arrives, the
161. meter is on, taxi driver is taking out the ramps,
162. complaining about taking out the ramps,
163. immediately you feel uneasy because the person,
164. they make you feel like you are a real pain in the ass,
165. that adds to a day out or going into town with friends
166. or whatever, you are being pushed up a ramp and

167. you are trying to tell the guy it's a power chair, you
168. don't push it (.) but they shove you in and they're
169. complaining that the chair is too big and how am I
170. supposed to clamp it down, do you want a belt, do
171. you need a belt, you'll be grand without a
172. belt and all this kind of thing, and you are looking at
173. the meter and it's at 25, you're kind of thinking to
174. yourself-
175. R: (overlapping) So they put the meter on the minute
176. they arrive!
177. J: Yeah, they are moaning away about how long it
178. took to get in the taxi when they come out and they
179. say (mimicking voice) 'oh I could get six fares for this'
180. and by the time you get into town it's €37 one-way.
181. R: €37!
182. J: Yeah and then he drops you off in Merchant's
183. Quay or wherever and says (mimicking voice) 'oh I'm
184. mad busy today, mad busy' and you pay the price
185. and you can moan about it all you want but they are
186. the only way you can get home and then they go
187. (mimicking voice) 'will we come back for you', so
188. you're thinking-
189. R: (overlapping) I have to endure your whinging!

190. J: Yeah, (mimicking voice) 'I'd better pick you up at
191. four because I'm the only one on today' and you look
192. over your shoulder at the car park across by the bus
193. station and they're all standing there with their
194. newspapers folded telling jokes and stories, six or
195. seven wheelchair taxis parked up, do you know what
196. I mean-
197. R: (overlapping) I can't believe it!
198. J: You are penalized because of the fact that you
199. have a disability, you know you are charged extra
200. straight away (.) it's not a very nice feeling.
201. R: €37 to go to town and you are relatively near town
202. here.
203. J: And my wife uses a wheelchair and that's two of
204. us, you know, eventually it was costing the two of us
205. so much to get around that we were tired of taking
206. turns on the bus (.) if we wanted to go anywhere on
207. public bus, it's great that they are accessible I'm not
208. knocking that at all, but myself and Colette would
209. have to travel separately, so I'd go on the first bus
210. and Colette would have to wait for the next bus, or
211. vice versa, I don't always go first, yeah, you just wait.
212. R: There is not enough room on the wheelchair

213. section on the bus is there?

214. J: No, you are not allowed park on the aisle, it's too

215. dangerous (.) but yeah, eventually we had to fund

216. our own bus, which we did eventually, but even

217. saying that we have to fund that bus to keep it

218. running, the insurance, it's ridiculously expensive, to

219. allow us the carers to drive, not all of them can, only

220. a certain few would have a license to drive it.

221. R: Is that a B license or something?

222. J: Yeah it's like an 8 seater.

223. R: So they have to have that license.

224. J: And be over the age of 30, I think that's part of it,

225. which is awkward, so it means that we can go out

226. together, so the family can drive it and the carers that

227. can, but we've got fuel costs, the mobility allowance

228. goes toward that, cover the loan that we needed to

229. take out to pay for it.

230. R: I'm still quite shocked at the €37 to go to town.

231. J: Yeah and that is only one of many and that's a

232. little cost because there are so many others, the

233. heating is the biggest.

234. R: The heating would be the biggest?

235. J: Our heating comes to around €500 in the winter.

236. R: For a two month period.
237. J: Yeah, for two months.
238. R: And they are storage heaters.
239. J: They are storage heaters as well, but we have (.)
240. the house would be (.) I have quite a bad chest
241. complaint, it's just, I have to stay warm, if I don't I get
242. very ill and I end up in hospital and then if I'm in
243. hospital I contract other illnesses, it's a vicious circle,
244. so it's warm, almost tropical in our house it has to be.
245. R: Something else came up in relation to PA's was
246. having to rent or buy bigger accommodation to
247. accommodate a PA.
248. J: Yeah
249. R: Was that your experience, having to get bigger
250. accommodation?
251. J: Maybe in the early days, when Colette and
252. myself were renting, we never had a live in person
253. though, but it was awkward we'd be bumping into
254. each other and quite a lot of time we'd (.) one of us
255. would leave the apartment and go and do tasks for
256. the week while the other assistant was in
257. the house helping you, just you'd all be falling over
258. each other because was quite a tight space, then we

259. built our own place in ****, we were married in *****

260. and things just fell into place for us, everything was

261. just moving at the right time, I was working, Colette

262. was working, so.

263. R: Yeah, would it be your experience that the new

264. prescription charge was an issue.

265. J: To be honest I only experienced that recently (..)

266. that's something that came up recently in the

267. pharmacy, I started getting billed for filling out a

268. prescription, like I fill out a prescription about three

269. times a week, so that's €1.50 okay it's not

270. astronomical, it's still an additional cost, €7 a month.

271. R: And has anything ever come up in terms of

272. something being covered and then not being covered

273. by the Medical Card?

274. J: Yeah (xxxxx) (xxxxxx)

275. R: Because that came up about items being covered

276. and then not covered or even inconsistencies, like

277. someone getting something and someone else not

278. getting it.

279. J: No, I haven't really experienced that, but Colette

280. does, because of my type of disability, I suppose it's

281. top of the pyramid as far as back up and support

282. goes, I suppose my life span is quite short and I'm at
283. the peak now of (.) you know as healthy as I can be
284. and the HSE will step in and give me as much
285. support as I need, whereas Colette wouldn't be at
286. that stage she's kind of mid way up and she
287. finds it hard to get support with things, it's more
288. difficult, she has to fight harder and you know to be
289. honest it's hard on a relationship, if I say oh I need a
290. new cushion, the OT's come running in straight away
291. without question and if Colette asks for something
292. new for her chair there's a million questions that
293. you've got to go through first, why do you need that?,
294. what's wrong with the one you' have?, didn't we do
295. that there last year?, you know, the OT's have to do
296. their job and go back to their manager's, but the
297. bottom-line is that it's down to funding and people are
298. treated differently because of the range of their
299. health.

300. R: Something else that ties in too, that came up was
301. about items that are recommended to them by a
302. dietician some thing like expensive vitamins, like food
303. wise or diet wise.

304. J: Yeah, something that's (.) it's a personal issue, but

305. it is a cost factor is the chiropodist, because carer's
306. aren't allowed to cut toenails, that's one of the rules,
307. it's a big underlined no, for carers, it's an insurance
308. thing, feet are very (.) it's a very serious issue, even
309. for people (xxxx) so you have to go to a chiropodist
310. which can be awkward because they are not
311. always accessible, they are usually in small offices
312. with narrow doors, so if you get a house call from
313. one, you are going to pay through the nose to get
314. your nails cut every month or every three weeks,
315. yeah it can be up to €45.
316. R: That's expensive.
317. J: Yeah
318. R: And I suppose someone who doesn't know how to
319. do it then can cause problems.
320. J: Yeah and then you end up going to the chiropodist
321. or a nail specialist, it can be tricky (.) is that the kind
322. of thing you're looking for.
323. R: Yeah, definitely, I just have some lists of things
324. that came up before and actually one thing was wear
325. and tear on the house, like, you know, like somebody
326. had said they had lived places that weren't fully
327. accessible and they ended up with loads of scratches

328. on the paintwork and things, then having to pay

329. someone to come in?

330. J: You do (..) I've two thoughts on that, yes you have

331. to, you know there's wear and tear and that becomes

332. par for the course with power chairs, especially, and

333. if you've got a push chair you're going to bump into

334. things, the cost of getting painters, buying paint and

335. cleaning up the house, like that is a factor as well,

336. but I find, and maybe that's because we've got our

337. own place now (.) I actually like being able to pay for

338. it myself because I know it's my house, like if it's

339. something else like it's nice to put my stamp, when

340. I say my stamp I mean our stamp on it, okay we're

341. paying for paint but it's nice to pick choose the

342. colour, okay it costs but it costs everybody.

343. R: Yeah

344. J: We feel like we're (..) my wife would kill me for

345. saying this, like a normal couple and it's not grant

346. funded and it's not (..) although we could use the

347. money and put it elsewhere, that's not the issue (..)

348. that's my second thought.

349. R: True, it is nice to have control over your life and

350. not have to wait for someone else.

351. J: Like we had an issue, like our washing machine
352. broke down the other day and our washing machine
353. is essential, for towels and things like that and we
354. end up getting a new one (.) when we moved in
355. originally we got a package from the social welfare
356. officer, they gave us a cooker and a fridge
357. and washing machine and we got a present of a
358. dryer, but the washing machine broke down and you
359. have to re-apply again and it takes months (.)
360. imagine you're left then without a washing machine
361. and they're not cheap.
362. R: No
363. J: So then you are taking out money on loan, the
364. Credit Union is great, they are very understanding
365. and they give you good rates but you are paying in
366. money every week, one of our allowances goes
367. completely on paying back loans, so we're living off
368. (.) not very much (.) so we are blessed that Aldi is
369. ***** ** **.
370. R: Absolutely.
371. J: Everybody goes (mimicking voice) 'oh the food in
372. Aldi's' but as far as I can see the food in Aldi's is as
373. good asTesco.

374. R: Well I always shop in Aldi, I never go to Tesco if I

375. can avoid it, or Dunnes for that matter.

376. J: Some of their meats are very good and the fish is

377. very nice (.) but yeah.

378. R: And that is something else that came up was say

379. if you are only near a corner shop or you know if

380. you're not somewhere that offers good value in food,

381. convenience stores, that is something that adds up

382. for people. I suppose they are kind of the ongoing

383. costs and you spoke a bit about once-off costs like

384. the bus and adaptations to the house (.) and

385. environmental controls, I see you have some electric

386. doors, were they things that-

387. J: (overlapping) Yeah, some of that stuff, it's very

388. strange people see that stuff and think (mimicking

389. voice) 'Gee you're equipped, you're well set up,

390. you're doing pretty well', all of the things that came

391. our way, such as the house (.) *****

392. *****, we were

393. paying I think a thousand euro a month in rent-

394. R: A mortgage.

395. J: Well we were turned down for a mortgage, we

396. weren't viable for a mortgage, we had to go around

397. *****

398. to guarantor our mortgage and do it together, not one

399. person you know (..) the idea then would be when

400. ***** (..) it took a while

401. to get it all together but we did it and that's how we

402. did it, only for that we'd still be renting and we

403. mightn't have been able to stay together because my

404. needs have changed, you know, disability would

405. have pulled us apart but the plan came about and

406. Colette's *****and rather than let it

407. sit there and dissipate she decided to use it to get on

408. with her life, fantastic investment, it's changed our

409. lives dramatically (..) well *****laborers

410. and electricians and they all gave their time

411. voluntarily, we were very lucky, just at the end of the

412. Celtic Tiger, everybody was in a good mood.

413. R: Yeah.

414. J: So it went up, in three to four months from

415. planning to designing and we designed it ourselves

416. on the computer with a €10 package bought in

417. Easons for designing a new house we took it to an

418. architect in 3D and he revamped for the plans so we

419. could plan everything the way we wanted.

420. R: Yeah, that's the ultimate, designing your own

421. house and having everything where it should be.

422. J: Yeah, it's great.

423. R: Another thing that came up, is that people felt that

424. it would be easier to rent from the Council almost,

425. that the waiting list is so long to get adaptations, that

426. there is a difference in how fast you get something

427. done or the cost to yourself even?

428. J: We were on the housing list (.) a guy came out to

429. our apartment to interview us and he said it would be

430. six years until they could supply a house that could

431. accommodate both of us, based on an independent

432. OT assessment, personally we didn't know what

433. would happen in six years so we felt we had to move

434. ahead (.) about three years later, I think we had just

435. got married, we got a phone call saying

436. that there might be a possibility of a downstairs (.) oh

437. no, what was it, a two storey house that the

438. downstairs could be converted into an apartment and

439. the upstairs then they said it could be used for guest

440. bedrooms storage that we basically would wouldn't

441. use the top of the house, but it was in *** ***** and

442. although I'm sure every area has it's social

443. problems, when we went up there the windows were

444. boarded up and there was (xxxx) around the garden.

445. R: You wouldn't exactly be getting a nice homey

446. feeling!

447. J: There was nothing there, there was just a burnt

448. out car in the grass (.) I said to Colette, we can do

449. it ? Do you think we'd be safe? And we spoke to

450. people, to our carers and they said if ye go there lads

451. but I'm sorry I'm not going there at night, people on

452. bikes, you know.

453. R: Yeah, there is nothing worse than living

454. somewhere that you don't feel that you can safely go

455. outside.

456. J: Yeah, I said to the Council, you are putting us in

457. danger, you know, is there anything you can do

458. there? He said, (mimicking voice) 'nah, if you refuse

459. you go you're moved down again, we do our best but

460. that's all we can do', so I formally refused because I

461. said we have to, so he said 'grand you are down to

462. the bottom, start all over', they are a bit pushy, but I

463. suppose they are frustrated as well because

464. they have to meet quotas and things (.) but I

465. shouldn't be making excuses for them.

466. R: No and I think, I know they've tried to improve the
467. areas and they are rebuilding parts of Knocknaheeny
468. but ***** is probably one of the worst.

469. J: I know a few people that live up around the area
470. and one girl she told us that she finds it horrific at
471. night in particular, she has metal doors and windows
472. I said what about fire, if there was a fire and you've
473. got those big metal shutters, she said that's the risk I
474. have to take, otherwise they'd break my windows.

475. R: A prisoner in her own home.

476. J: She won't leave the house at night she has to wait
477. until it's daylight, like that's no way to live.

478. R: No, that's unreal really and what I always think
479. about Cork is that it's only a five minutes away.

480. J: I knew a group of people who used to share a
481. house in ***** and the kids used to put gravel on
482. the wheelchair ramp so that when they'd come out of
483. the house the chairs would get stuck and the kids
484. could laugh at them and film them for You Tube.

485. R: Oh Jesus!

486. J: Yeah, so they're the kinds of thing you're putting
487. up with so that's why when people are offered
488. somewhere they are desperate to get places and

489. because they've been waiting so long they are willing
490. to accept anything.

491. R: Yeah and when you're in how are you going to
492. move, you know as in, they are not going to say I
493. want move somewhere else.

494. J: Yeah, inside will be fine for what they're needs
495. are, but it's the social aspect, they become totally
496. dependent on the house, you can when your outside
497. environment is inaccessible, outside is an
498. inaccessible environment, inside can become like a
499. cocoon, it happened to me several times,
500. when I came back here after ***** in
501. hospital, I was totally institutionalized, it took me a
502. long time, I don't know how my wife put up with me
503. because I was very, very moody, I didn't want to do
504. anything, didn't want to leave, just be inside and
505. that's it.

506. R: ***** that would definitely do that to
507. you.

508. J: I was very much involved with the *****
509. before that, I was chairperson of the board for a while
510. and then I was in the middle of writing a book and
511. then I got sick, I must finish it.

512. R: So, I am just conscious of time, it sounds like a

513. long time but it flies (.) like other issues, a question

514. would be what would you spend money on if you

515. could, I know it's incredibly general but if say, if

516. someone had a win fall where would you see it go?

517. J: I suppose in the current situation, I suppose it

518. would go on repairs around our home, possibly, more

519. support from a travel point of view, insulation for the

520. winter, preparing the house for the cold, because I

521. think now people are really starting to think, you

522. know, like last winter was ridiculous

523. and there is nothing we can do about it except stay

524. wrapped up.

525. R: Two winters like that in a row!

526. J: We're due another bad one, we're going to have

527. bad winters, from now on, I think people are just

528. going to have to realise it, government are going to

529. have to provide snowploughs.

530. R: And isn't the Gulf Stream supposed to be moving

531. down, I mean it was four solid months of very cold

532. weather (..) so something you mentioned earlier was

533. socializing, like with the washing machine breaking

534. down, is the social aspect of things the first to go?

535. J: Yeah, like any other married couple we set out a
536. budget at the start of the week so we have this much
537. money for that, that thing I bought on EBay that has
538. to be paid for, do your know what I mean, small
539. luxuries (.) ESB bill, phone bill, is there a cheaper
540. way we can do this, or, trying to catch up where we
541. can (.) so yeah you wouldn't go out socially,
542. you wouldn't go out to dinner that often maybe to
543. celebrate something now, birthdays, we tend not to
544. get each other very extravagant gifts for Christmas
545. only token things really, we have family coming in at
546. Christmas, so it's great to be able to save up and get
547. a few toys (.) we do, we have a couple of
548. sponsorships that come out in direct debit, a child in
549. Africa and we support Worldvision and we've got
550. Concern, Colette has Barnardos, she supports
551. them, so there are a few costs, but they are by
552. choice, they are small in comparison (.) we don't
553. have any children but we have *****
554. that live next door so you get to borrow them and
555. give them back.
556. R: Yeah, that can be good too, that's the best of both
557. worlds I think myself (.) are either of ye working at

558. the moment?

559. J: No, I used to work for ***** up to about

560. three years ago and they shut down their outsourcing

561. department and moved it to ***** so I got one of their

562. severance packages (.) it was grand, but I haven't

563. had any work since, there's just nothing out there.

564. R: Yeah.

565. J: So I was a graphic designer for their European

566. website, it was just small work, a couple of hours

567. everyday, graphic design team, get a list at midnight

568. and then it would have to be ready at 11am ready to

569. go on the website.

570. R: So work through the night?

571. J: Yeah, odd hours but it was fine, I was able to work

572. from bed, so it was grand, so long as I didn't keep

573. the missus awake with my typing.

574. R: (..) So things get covered as you are talking, but

575. things like the cut backs have they affected you?

576. J: Yeah, the cutbacks started affecting us, but the

577. PA's before I got sick in hospital, before I got sick,

578. they'd started cutting PA hours and the **** was

579. extremely worried because it was impinging on

580. people's lives, people were losing from six hours

581. down to one hour and if they needed help getting up

582. to have a shower, that hour was consumed

583. straight away, some people, they weren't getting

584. enough home help, the home help was literally

585. coming in at the weekend, when the PA's weren't

586. there, helping the person get up and have a shower

587. and getting breakfast for the person and that person

588. would have to run then and the person would have to

589. manage themselves for the entire day and then they

590. might have someone in the evening to cook a meal,

591. we're talking people who would have serious needs,

592. like diabetes with injections and the rest of

593. the time they are begging family and friends to help

594. them out.

595. R: An issue that came up too, is that the home helps

596. kind of have a very certain job description and if they

597. were allowed to do something else then it might save

598. money in other ways, like one woman was saying

599. that she had guests arriving and they wouldn't

600. prepare the bed for the person who was arriving, is

601. that like a (.) are they very kind of (.) what's the word

602. (.) strict?

603. J: They do the job (.) like my wife has a home help,

604. she comes in (xxx), a nice lady, but she wouldn't do
605. any bed dressing, she'd get Colette, give her a hand
606. (xxx) (xxxx), it was my team who were doing the
607. cleaning, but (.) I did question her once about it, in a
608. friendly way, okay is there a reason that you don't
609. tidy up and she goes, got very narky and said
610. (mimicking voice) 'I don't work for you, I work for
611. Colette' and then she said 'I've a family, I don't need
612. this job', very threatening like, don't question me I'll
613. quit kind of thing and I said there is no need to take
614. offense, I am just wondering because my staff are
615. asking me why they have to clean up after you that's
616. all and now she won't speak to my staff.
617. R: They'd want to redefine the term home help!
618. J: That's down to personality.
619. R: It's true.
620. J: There are other people out there (.) I remember
621. one (.) Colette's home help comes in and I'm still in
622. bed, because I need specific care when I'm getting
623. up, it takes a while, it takes up to two hours, Colette
624. can get up in ten minutes so I let Colette get up first,
625. it's easier, so the regular home help was way and
626. Colette's home help came in, a fill in lady, at twenty

627. five to seven in the morning, a real bouncy lady, full
628. of beans (mimicking voice) 'come on, come on, mad
629. busy', you're very early, 'I know, I know sure, busy
630. day, I was making lunch for my daughter last night
631. and she didn't like the rolls that I was doing, she
632. wanted fresh rolls baked out of the oven this morning
633. for school, so I had to get up, they are in the oven
634. now, so I'll have to get back home' and Colette said
635. ah you had to get up because of the rolls she said
636. 'yeah, after all family come first'.
637. R: God!
638. J: Yeah, and Colette was in a bad mood then all day
639. because she had to get up all that week and I just
640. though okay family do come first, but you have to
641. take your job seriously too.
642. R: Yeah I mean you are getting paid to do a job.
643. J: Yeah and the home help manager (.) I had sparks
644. with her because I started saying, so do not you think
645. that there is something wrong there (mimicking
646. voice) 'nah, she couldn't see anything wrong with it,
647. my staff work very hard, they don't just work for ye,
648. they work for other people too', I said I recognize
649. that, it's just what is the practice, I said do

650. you think anybody considers dignity or is it the right
651. thing maybe do we, need to sit back, 'oh no, there are
652. cutbacks here, there and everywhere we are lucky to
653. be having a service, I've got twelve hundred people
654. on my list, that are waiting for home helps'.
655. R: It almost comes into a lack of understanding of
656. independent living.
657. J: It's not even that, It's that you are seen as just
658. moaning, that we should consider ourselves lucky
659. that we are there and not dumped into a big home
660. somewhere like a big concentration camp, you know,
661. this is what you get, deal with it, don't be annoying
662. me, that kind of thing (.) like did you see that
663. documentary on TV, the one about the -
664. R: (overlapping) the one about the elderly care? I did.
665. J: The home care service, it was a very good
666. documentary.
667. R: Very disturbing (.) and isn't that the worry now,
668. that the services are going to procurement, that the
669. *** has to, what's the word.
670. J: Tender.
671. R: Yeah, tender, in competition with those
672. companies.

673. J: That was always going to happen and in some
674. respects that's going to be good because *****was
675. meant to be an advocate, not a service provider,
676. across the world CIL's don't provide PA's they
677. advocate for the people with disabilities to hire PA's
678. and that needs to be done because then the waiting
679. lists can be shortened, the onus isn't on the
680. CIL to provide the PA's these agencies will do it, but
681. CIL will be appointed by the HSE to oversee it, that's
682. the idea, but will the HSE recognize CIL as an
683. advocate if they are not provided with funding for
684. PA's, that's where the crux is.

685. R: And it's probably a tricky relationship, because
686. you are providing a service you don't want to upset
687. the **** too much if you know-

688. J: (overlapping) My personal situation is, I was in
689. hospital and I was on an assisted ventilator system
690. called a tracheoscopy, it just keeps your lungs going,
691. by-passes your breathing and stuff, invasive, but it's
692. a necessity for me at night, but they couldn't send me
693. anywhere, they wouldn't let me home, that was the
694. biggest thing and then, they started looking at
695. nursing homes and now I was dealing

696. with all of this in hospital thinking, I can't get home to
697. my wife, I'll never sit at home and watch a DVD with
698. her, or the kids, that I'm now in the medical system
699. after living independently since 1991, throw a switch
700. and I'm in this, my body changed but my mind didn't
701. and luckily enough the disability services in the HSE,
702. recognized the fact that I wanted to get home and
703. Colette wrote a fantastic letter, to the HSE, which
704. actually I think opened a few doors and she
705. actually *****
706. I just want my husband back and it was
707. lovely, very nice (.) now, she kills me of course.
708. R: Yeah that's par for the course! We miss ye when
709. ye are not there, that's the way it works.
710. (laughter)
711. J: Yeah, that's the thing (.) yeah so finding them was
712. the thing, ***** provide my care, they tendered for
713. the job, there was an assessment done, staff were
714. trained, staff were hired, all was done in the hospital,
715. I was sitting in a ward, I was in a high dependency
716. unit and I was sitting surrounded by elderly people
717. myself and two other girls, designing this care plan in
718. the middle of thirty two degrees and there were

719. people with (.) pseudomonas and what's the
720. other one (.) MRSA, we were all wrapped up in
721. aprons and masks, it was surreal (.) God it would
722. make a good film!

723. R: The hospitals are getting pretty frightening now in
724. terms of what you can get there.

725. J: Yeah, I remember, there was another girl up there,
726. she had been in hospital for *****, it was very
727. sad, because she had been married and she had
728. kids and her husband turned his back on her, it was
729. very sad (.) but yeah she was waiting to get
730. somewhere to live.

731. R: So I'd just like to move onto the section on
732. independent living itself even though you have
733. spoken about it a lot already (.) like what it means for
734. you?

735. J: What independent living means for me in a
736. nutshell is that I have a disability, but I don't let it rule
737. my life, I wake up in the morning next to wife, she
738. gets up has breakfast, I get up a little bit later, we
739. come up, we discuss what we're going
740. to do for the day we go around, we do it, we have
741. support, they don't intrude if I need help, I have a

742. pendant, I can call for help, we have a room down
743. the back, a small lounge, that the support stay in,
744. they just hang out there, they are paid to sit there, I
745. don't have to worry about them being bored, we have
746. made some allowances for them, they have
747. a TV, they have Sky, kettle, toasters, papers, they
748. are well set up, they're not just sitting in a chair in the
749. corner, you know, if they go out with us they keep
750. their distance, they give us our own space, okay we
751. have people in the house 24/7, but independent
752. living, we have a house, we are in a happy
753. relationship together, we are stronger now than we
754. have ever been, we have our ups and downs and it
755. can be challenging, but if it wasn't challenging
756. then it would very boring and that's life and
757. everybody has life and that's what independent living
758. is, life.

759. R: And the research then is trying to look at how the
760. extra costs impact on that, this is the direct question
761. but much has been covered by what you've said
762. already (.) so kind of the main elements of
763. independent living, the twelve needs that
764. were identified by the independent living movement

765. like PA's, technical aids and equipment, transport,

766. what would be the biggest thing that would be

767. impacted on for you because of the extra costs of

768. living?

769. J: As I said earlier, the bills for domestic things and

770. things like that and we also have repairs for medical

771. equipment, because some of the agencies when you

772. buy medical equipment because the HSE wouldn't

773. provide it (.) we need two profiling beds in our

774. bedroom, two single beds that are locked together

775. just bed because of health and safety policy,

776. so the beds can separate, but we didn't want two

777. hospital type beds in our bedroom, so we got divan

778. style beds, you know the divan?

779. R: Yeah

780. J: So we got the factory to cut out spaces under the

781. bed so that the hoist can go underneath them, so

782. they did that for us you know, but those beds had to

783. come from the UK and we had to pay for them

784. ourselves, we didn't get support, we got the VAT

785. back, but that's about it, but the repair, for them

786. to come out and look at the beds, you need to pay up

787. front, if we need the ceiling hoist serviced, then it's a

788. hundred euro up front, so that has to be done every
789. six months, if one of the wheelchairs breaks down,
790. then they will cover it but you are waiting four to six
791. weeks to get it done, it's the day to say costs if they
792. get more expensive then they're going to
793. be (.) the government doesn't give any money to
794. cover those costs so it impacts on independent living
795. then.....

796. Colette joins the interview at this point.

797. R: The final question is about what solutions to the
798. extra costs living would be a good idea from your
799. perspective, you know, because for example there
800. was a study done in 2004, an Irish, study for the
801. National Disability Authority and they suggested that
802. there would be cost of disability payment per
803. week, based on level of need, so they suggested
804. €10, €20 to €40 a week and I'm just wondering what
805. you would feel about that?

806. C: Well, actually if they came up there last week
807. wanting to know what issues would be important for
808. us, a big one for me is that, you see, we have a
809. ceiling hoist, and we didn't get it through the health
810. board, because it would have taken too long so we

811. got a private grant which is fine until it comes
812. to servicing or any other costs we have to pay it
813. ourselves, so you get a grant or whatever or you
814. have to get a loan because the waiting lists
815. are so long, so you call them out afterwards and
816. there are extra payments, so I did suggest that there
817. be a fund or something that you apply to for stuff like
818. that.

819. R: And that was highlighted that in the UK there is
820. the Independent Living Fund and I suppose the issue
821. of Direct Payments.

822. C: Yeah there is a piloted in Dublin, but you can
823. either sit and wait or you can find a way to buy it
824. yourself but then you've got the extra cost of
825. maintaining it yourself.

826. R: So if you install it privately they won't actually
827. come out and service it?

828. C: No, we have to pay for the service ourselves and
829. if something breaks.

830. J: That's what I was saying and even before they
831. come out it's a €100 before they even look at it.

832. C: To get it serviced is over €300 and they want
833. payment up front before they come out and we have

834. to pay that and then they had to put in a new motor
835. there today, and that's another €200 and we'd just
836. paid for a service, €500.
837. R: €500 for a service!
838. C: Yeah
839. R: And how long would they spend servicing it?
840. C: About twenty minutes.
841. R: Is it!
842. J: There are questions over particular companies
843. that provide these services.
844. C: Yeah the mark up seems to be huge.
845. R: That just doesn't make sense.
846. J: Plus what they use to repair it, they take things out
847. to the van, a ceiling hoist, to take it apart would take
848. approximately two hours because the people who
849. installed it came from the UK, it took them two hours
850. to put it together just the hoist unit and these guys
851. came out we thought we were getting our motor
852. replaced, so on the docket they have, they said
853. service, and I said I thought we had the motor
854. replaced, they said, (mimicking voice) 'oh yeah,
855. yeah, that's all done', but it wasn't written in the
856. docket so they were very cagey.

857. C: Yeah and the same problem occurs so we had to
858. ring them again and they wanted a second payment
859. to call them out.

860. J: Yeah, a second payment.

861. R: So if you just replaced a motor it's unlikely to be
862. the same problem.

863. C: Yeah, so I said no, we're not paying, get out here,
864. three times they came here and they finally fixed it,
865. but they want the payment up front every time.

866. J: We have a nice OT and she will push agencies to
867. come out and repair stuff but she can't get money to
868. pay for it, we have to do it.

869. C: But she's good, she will advise you to ask for
870. dockets and say check everything before you pay for
871. anything, so, (.) but they are deadly, any medical
872. equipment the mark up is huge (.) I mean these
873. chairs are about thirteen grand.

874. R: Thirteen thousand?

875. C: I mean for a wheelchair yeah, you'd buy a car for
876. it.

877. ((laughter))

878. C: And they are guaranteed for a year.

879. R: For only a year and I mean for a car you'd get a

880. seven year warranty now on some.

881. C: Yeah a year, but like you'd get loads of them,

882. because I'm very hard on the chair, I use it so it does

883. get damaged and I do have to get my tire's changed

884. and they give out over that I mean what am I

885. supposed to do sit in a corner with it all sparkling up

886. in case I damage it.

887. R: Well it's there to be used like.

888. C: Yeah well it's my legs they can't say that, so yeah

889. you are fighting a lot.

890. R: So the equipment is a big issue.

891. C: The equipment is the biggest issue because it's

892. not like we just do it because it looks nice and we

893. want the house to look nice but we actually need this

894. equipment but, they don't see it that way.

895. R: Because the other person I just interviewed said

896. she wanted a ceiling hoist but they just wouldn't fund

897. it.

898. J: They won't fund it, it was the same with us, when

899. we (..) ***** Ireland heard about this

900. grant in Dublin, a one off, basically some agency was

901. trying to get rid of money-

902. C: (overlapping) Yeah a one off grant for medical

903. equipment and we just chanced our arm and luckily

904. we got it.

905. J: They got us so much of the money towards it, then

906. we wanted an extra three meters and it's a €1000

907. a meter so we just through some savings at it and

908. extended it into the living room.

909. C: Yeah so it goes from here to all the way down to

910. the bedroom to around the bed and then in the hall

911. there is a turn table so you can go into the bathroom.

912. R: A thousand per meter to do that.

913. C: Yeah

914. J: You can see the track,

915. R: Oh yeah.

916. C: See the turntable, you just put it at the black mark

917. and it turns into the bathroom.

918. R: It's good.

919. C: Oh yeah it's brilliant but you have to fight for

920. everything and then you have to consider if you do

921. want to go ahead and get it yourself what you pay

922. extra is on your head and these are things that are

923. being used two or three times a day and they get

924. wear and tear.

925. R: The system seems just very unfair.

926. C: Well I was at a talk the other night, you know
927. Kathleen Lynch the new disability minister she was
928. telling us about all the money they waste in the
929. government, money that's put aside for disability
930. services but they are spending it on something else
931. so then when they go looking, they say they
932. don't have it, but she said there is something like a
933. three million budget, more than enough to cover, but
934. it's just that the government are so stupid and
935. careless.
936. R: Yeah I don't know if the change is really a change.
937. J: I was explaining there a while ago Colette, I didn't
938. do a very good job of it I don't think, about you know
939. the way that my needs are always prioritized, you
940. know if I need something-
941. C: (overlapping) Yeah your disability, yeah John,
942. unfortunately could drop dead at any second, no
943. offense John but you know what I mean, so he is
944. prioritized-
945. (laughter)
946. R: You wouldn't want to be too sensitive anyway.
947. C: You're number one on the list.
948. J: That's a priority number one.

949. C: Because his level of disability would be more than
950. my level, you know, John can do probably less than I
951. can, so I'm priority twelve, so John can get whatever
952. he wants, where I can ask but there is no guarantee
953. that I'll get it because I'm not at risk of everything.

954. R: And what's their priority list, what does it go up to?

955. C: I'm not sure but there is no one there.

956. J: I just know if I ring them up and ask any

957. department in the HSE what's happening, they ask

958. for my PPS number and straightaway it's like, I can

959. almost picture the screen flashing in red.

960. C: Yeah, priority one, priority one, (laughter) and then

961. they go (mimicking voice) 'yes John, whatever you

962. want John' and I ring and it's-

963. R: (overlapping) They put you on hold for two hours!

964. C: Yeah, you're onto the wrong department.

965. J: That's their favorite one.

966. R: Yeah, or the other one where they shorten the

967. hours if they are getting too many calls.

968. C: But then as well if you ring you're given a number

969. and name, lets say its welfare, you ring them and

970. then you get (mimicking voice) 'oh no that's not my

971. department', then they give you another number and

972. it's wrong and then you go back to the first one and
973. so eventually you just give up because you get
974. nowhere, or you spend the whole day on the phone.
975. R: You definitely wouldn't want to be on a mobile
976. anyway (..) just getting back to the solutions to extra
977. costs, would you agree with a disability payment or
978. would you prefer an improvement in benefits?
979. J: I think an independent survey would need to be
980. done you know of departments at different levels
981. about the needs of the person, like when I was
982. drafting my care plan to allow me to return home and
983. it was put out there to tender, all the different aspects
984. of my life had to be put down in different ways on
985. paper, everything from my care needs to
986. my nutritional needs, to you know, my physical
987. needs, my sensory needs, they were all documented
988. and I had to go through the things, you know it was
989. very, very invasive for the mind, you had to put your
990. life down on paper, but once I did I got more of an
991. idea (..) now it wasn't exhaustive, a lot more could
992. have been added and adapted but, you know,
993. it's something that should be done for every person
994. (..) there was a survey done years ago, the physical

995. and sensory database (.) the idea for that database
996. was that the government would make more
997. equipment, more services available, it was almost
998. like a census for disability, but that database-
999. C: (overlapping) I don't agree with that at all.

1000.J: Okay

1001.C: I find them very invasive and I also find that they,
1002.you know, they assess your needs, so they put you
1003.in a box and your needs are here and put you there
1004.and our needs change.

1005.J: But that's what I was talking about.

1006.C: I think maybe a central fund or increase the
1007.welfare (.) why can't we just live like everyone else,
1008.have the money available if you need to pay for
1009.something or just be able to just go and say I need
1010.this or whatever.

1011.J: That's really interesting.

1012.C: I don't like the idea (.) I find it very invasive, it's
1013.wrong, I did on essay on this, on the whole
1014.assessment thing, it's wrong to do that, say if you
1015.had a child with a disability and you have to take him
1016.to be assessed for their hearing, their eyesight, how
1017.far they can walk, how intelligent they are,

1018.you are making that child feel different from the very
1019.beginning.

1020.R: Yeah, it's very medical.

1021.C: Yeah, so I'd rather a fund to meet certain needs
1022.for the child or whatever.

1023.J: I wasn't talking about somebody making that
1024.decision for me.

1025.C: No, but I don't agree with the whole medical
1026.model side of it, having OT's and nurses saying that
1027.this is the way it should be (.) like I have a manual
1028.wheelchair, now, before I got the wheelchair I went
1029.through months of assessment to say what I wanted,
1030.what wheelchair I wanted, but they gave me the
1031.wheelchair that she felt I needed, so I said no,
1032.wouldn't sit in it, wouldn't take it.

1033.J: They brought in a seating consultant who was
1034.very strong willed.

1035.C: They put me in a chair (.) I couldn't push the chair,
1036.I felt really uncomfortable in it, I said no, I'm not
1037.having it, and I made them take it back and I ended
1038.up having to buy one myself, €5,000.

1039.R: So even though you are saying you know what
1040.you want yourself they still ignored you.

1041.C: They came and they listened and they wanted to

1042.know what your needs are and what you want, but

1043.that doesn't happen.

1044.J: Did they service that chair?

1045.C: That's more, I had to pay for that.

1046.J: You had to pay of the service on that?

1047.C: Yeah, that's the other thing, because I bought it

1048.myself, I have to pay for the service, because I used

1049.to do wheelchair karate, so I need a specific chair for

1050.that and the chair that they wanted to give me, there

1051.was no way, you could hardly move it, never mind

1052.and go and do karate, you know, I said no.

1053.R: And you would think that the logical thing would

1054.be to think that's great someone has bought it

1055.themselves and meet someone halfway and lets

1056.service it you know.

1057.J: Yeah

1058.C: No, they were going mad because I refused to

1059.even sit into the chair and they said but this is what I

1060.asked for and I said no it isn't, it's the complete

1061.opposite of what I asked for, even the colour was

1062.wrong.

1063.(laughter)

1064.J: The cost of disability, it's one of those things
1065.where, as I was saying earlier about independent
1066.living, like what does independent living mean to me
1067.and I said life, it's the same with the cost of, you
1068.know, how your disability (.) you can guess what
1069.certain costs will be, but it depends on what the
1070.person wants from their life as well, you can't put a
1071.price on life, you can't put a price on (.) I suppose, in
1072.some ways, the point that Colette was making about
1073.not agreeing with the idea of your medical needs
1074.being classed and put in a box.

1075.C: I mean the cost of disability on the one hand
1076.obviously is money but on the other hand you are
1077.stripped of everything, they try and take your
1078.independence, your choice, all your needs are
1079.pricked and prodded, it's like you do what we say,
1080.we're the experts, no your not, we're the experts
1081.because we're the one with disabilities (xxxx) (xxxx)
1082.(xxxx).

1083.R: Yeah, just one final question, would ye be in favor
1084.of Direct Payments as I know they have that system
1085.in the UK.

1086.C: I was in with ***** today and there is a pilot

1087.project in Dublin, four people I think trying the direct

1088.payments.

1089.R: That's right I heard that.

1090.C: So yeah we would be in favor of direct payments

1091.because that would give you huge control, because

1092.having a PA is great but it's still controlled by who

1093.ever pays them, so you are independent but only to a

1094.certain extent.

1095.J: But I still think though that there should be an

1096.independent living agency, to help the person, to

1097.advocate on behalf of the person, with regards Garda

1098.clearance, I don't think they have to sort out the

1099.payroll, but just to be there for the person who is

1100.taking on the role with direct payments, because I

1101.think if you are doing it solo, well I know I would find

1102.it very exhausting.

1103.C: Yeah it is especially with direct payments because

1104.you'd have to have an agency like CIL there as a

1105.back up.

1106.J: With a full ethos of independent living.

1107.C: You know for everything, to know you are not

1108.totally on your own.

1109.R: Yeah because you are employing somebody,

1110. which is not an easy thing to do, you have to work

1111. out somebody's PRSI you have to do all that stuff.

1112.C: Yeah and to try and keep it in the whole

1113. independent living movement, like CIL would switch

1114. from delivering PA's to just being there for

1115. information or advice.

1116.J: And you would buy products from CIL, like (xxxx)

1117. products like training seminars, lets say you wanted

1118. your staff to do a days manual handling, that CIL

1119. would provide the training course and you would pay

1120. to have that.

1121.C: Yeah, like disability awareness training, they are

1122. very important I think.

1123.J: And education and you would make it part of your

1124. assistant's contract to learn.

1125.C: And to keep these things as well as much as

1126. possible within the disabled community because no

1127. non-disabled people really have an idea.

1128.R: And that's the thing there are a lot of non-disabled

1129. people making decisions for disabled people.

1130.C: For us, we live it everyday, we are the one's that

1131. use the wheelchair, that bugs me all the time, having

1132. someone telling you I think this is what you should do

1133.now and they're thinking they know all that, because
1134.(mimicking voice) 'you have a curvature of the spine'
1135.or 'your foot is turning' or this is wrong so they look at
1136.you like a medical object rather a person with a
1137.social life and your chair is your legs and the
1138.ceiling hoist is also your legs because it takes you
1139.from one end of the house to the other, so if we could
1140.just get that through to their heads.

1141.R: Yeah, I mean I think that there are a lot of
1142.disability organizations let's put it that way who aren't
1143.tuned in and the organization I worked for are there
1144.was no disabled person calling the shots in terms of
1145.where the training was going and ***** is a
1146.very big organization.

1147.C: Like even on the boards or anything there is no
1148.one with a disability on it.

1149.R: Like the woman who runs it, came up there
1150.recently in an article in the newspaper, she's on
1151.***** a year or something.

1152.F Yeah, they are all on huge money, no one needs to
1153.get paid that (.) it's a sad state of affairs, like it could
1154.be fixed so easily because the other thing is that it
1155.costs the government €10,000 more a year to put

1156.someone in an institution than to live independent

1157.living, so the government are wasting money (.) I

1158.remember years ago before***** CIL used to go

1159.up to Daíl Éireann with pre-budget submissions,

1160.begging for funds and we're the ones that told them

1161.you'd basically be saving money if you'd leave us live

1162.independently and they couldn't see it at all.

1163.R: I suppose too, like this course is based in the

1164.University of Leeds and so much is done on the UK.

1165.C: Because I'm a Disability Awareness Trainer.

1166.R: Oh Yeah, sure you'd know well so.

1167.C: Like all my videos and everything are all from

1168.America or the UK, there is nothing available in this

1169.country.

1170.R: No, nothing (.) and do you deliver that for

1171.companies or?

1172.C: I did one last week for ***** and

1173.I do a lot of schools (.) I'm a registered *****

1174.trainer so if someone is looking for a trainer they can

1175.just look up, they have a list and they can tell where

1176.you are.

1177.R: Yeah because there is a version of it out there.

1178.C: Well yeah.

1179.R: Kind of watered down versions of it.

1180.C: Yeah, you see (.) but that's the other thing, I'm up

1181.against able-bodied people even in that field and a

1182.company would pick an able-bodied person faster

1183.than me, because picking me means getting

1184.accessible premises, somewhere with an accessible

1185.toilet, then I have to bring a PA with me so they have

1186.to get paid, so all this is more work for them.

1187.R: But that's what it should be, like, you doing it.

1188.C: That's the idea, but I have personal experience,

1189.whereas an able-bodied person is just saying what

1190.they've learned in a book (.)

1191.R: Yeah

1192.C: But there are enough doing it and I've two

1193.diplomas in it and I've been doing it off and on for

1194.eight years, but I haven't been able to get more

1195.funding to get anywhere again but I will.

1196.R: I don't know ***** it's

1197.just that they are always advertising, I suppose it's

1198.because they're big.

1199.C: I just thought of something there, I don't know if

1200.you covered it with John, but that's the other thing, if I

1201.got a full time job, my welfare would be taken away

1202.but I'd lose my medical card as well, now we're hit

1203.with that as well because I'd love a full time job but

1204.then you're worried like, if you lose your medical card

1205.you're screwed.

1206.R: Yeah, everything is tied to the medical card isn't it,

1207.every single thing is tied to it.

1208.C: Yeah, every step of the way you're (.) it's like an

1209.elastic band, you are going forward but something

1210.always pulls it back.

1211.(laughter)

1212.R: That's a good analogy or is it a metaphor! But you

1213.can work part time isn't it.

1214.C: Yeah I think you are allowed earn, I was on a

1215.scheme with ***** and I use to get €220 a week

1216.and they deduct €40 from my welfare so I was on

1217.€196 on the welfare but now I'm not on the ****

1218.scheme anymore so now I'm only earning welfare (.)

1219.and ***** is supposed there for people go back to

1220.work, now I worked for three years for ***** I started

1221.the newsletter for them and now I'm gone,

1222.someone else took it (.) so you go on a job, I went on

1223.every course ***** threw at me, I started a

1224.newsletter, I did loads of stuff, I loved working there

1225.and now it's gone.

1226.R: And how did you find the scheme, I mean I think

1227.there should be another level when you are finishing

1228.up.

1229.C: Well, ***** the head of *** he's the

1230.guy you apply to for extensions, I wrote to him and

1231.he was very good and you could see he really

1232.wanted to give me the extension because he could

1233.see I used my time well, but *** now have put a cap

1234.on all the extensions so now you are allowed do two

1235.years and no more.

1236.R: You are allowed three up to a certain age and

1237.then another two over 50 isn't it?

1238.C: Yeah well I'm 37 so I can't be waiting until I'm 50.

1239.R: Yeah

1240.((laughter))

1241.C: If I have to wait another thirteen years, you know.

1242.R: Yeah, you don't want to be wishing your life away

1243.for a *** scheme you know.

1244.C: Yeah, sitting around waiting, so that's what we're

1245.up against now, so yeah basically everything is a

1246.fight (laughter) you just have to weigh up your

1247.options the whole time, like, you can't be

1248.spontaneous.

1249.R: Like, John was saying earlier about the taxi fare

1250.into town being €37 one way, like that's very

1251.shocking really.

1252.C: Like I use the public bus because I'm used to it

1253.and some of the drivers are lovely but some of them

1254.wouldn't wait for you, like one day, do you remember,

1255.they'd look at us like (mimicking voice) 'for God's

1256.sake will they ever get up' and I actually take longer

1257.and then sometimes you're on the bus and the pull

1258.up to the bus stop and there is this big buggy and he

1259.goes (mimicking voice) 'I've a wheelchair on board, I

1260.can't let you on' and the whole place is (xxxx) and

1261.you're mortified (laughter).

1262.J: Do you remember the taxi that we took with that

1263.taxi driver with the fuzzy white hair and you got out of

1264.your chair on to the seat and I drove up into the taxi.

1265.C: Yeah

1266.J: And he passed one of his colleagues on a bridge,

1267.rolled down the window and started giving him two

1268.fingers (mimicking voice) 'I've got two, I've got two in

1269.my cab'

1270.R: Yeah, I mean taxi drivers are not noted for their

1271.tact or PC behavior, oh my God!

1272.J: Do you think you've reached enough information

1273.or do you want something more specific?

1274.R: No, I think I'm happy to end the conversation here

1275.if you are.

[Recorder switched off. Discussed transcribing, sending a copy to participants and thanked participants]

Appendix 8

Transcript: Don, 07/06/2011

*The names of participants have been changed any personal information has been removed and has been replaced by the following symbol: *****.*

R: Researcher

D: Don

[Discussed the project, read out consent form and gained consent]

1. R: To start I have some questions to guide the interview,
2. it's a semi-structured style to help with the conversation
3. really, I suppose the first question is about what your
4. experience of the extra costs of living would be?
5. D: What I've found was over the years that there is two

6. distinct things that happened to change my (..) that led to
7. much greater costs to occur, one was that my needs
8. changed, the second was that items that were previously
9. available through the public health nurse became
10. unavailable (..) and with the HSE I was never
11. really, if you were ever given an excuse at all, and
12. sometimes you weren't, I was always a bit dubious
13. about the explanations of why these items were
14. removed (..) they kind of made sense but you couldn't
15. help thinking or suspecting that they were excuses just
16. to have the items removed from the public health
17. nurse's budget and what I found was public health
18. nurses themselves were often very irritated about that
19. because they appreciated helping me out on a certain
20. level and that recently, in the last two years it made a
21. big difference, one item, micro-enemas which I use for
22. bowel management, they are €50 a box, so €50 a
23. month more is quite a lot really and that's on top of
24. disposable pads being removed (..) incontinence
25. sheets as people would call them, that's a couple of
26. boxes every month as well which I import because
27. I can't find them here and they were previously
28. available on the public health system as well.

29. R: So they were say, if you are on the medical
30. card, they were available through the medical
31. card?
32. D: Not quite, I have a medical card, the way it
33. was done I think, was that the individual budgets
34. that the public health nurses had in the health centres
35. (.) so a bit of a grey area and I suppose that's probably
36. why they could remove them so easily (.) now what
37. the told me about the micro enemas was that it was
38. classed as a medicine and that's why I couldn't get it
39. anymore but the public health nurse did try because I
40. said well look if I get a prescription from the doctor and
41. give the prescription to you would that work and they
42. denied it, (.) with disposable pads similarly they made
43. up some sort of cock and bull about them being
44. unsafe.
45. R: Yeah, that came up with somebody else as well in
46. the focus group.
47. D: I think it's just bullshit (.) and you know in reality
48. then, that is kind of an ongoing cost month to month,
49. but that's a problem, so you are talking about a
50. €100 a month more which eats up the
51. mobility allowance that I'm given which is about €104

52. (.) and that mobility allowance if you break it down over
53. four and a half weeks in a month you get about two,
54. two and a half trips in a taxi per week, em, so it's a
55. useless thing really in terms of mobility but I've used it
56. to subsidise whatever disposable income I have with it
57. (.) the only other benefit that I receive is (.) well that's it
58. actually because I don't receive rent allowance
59. anymore, so the only supplementary welfare
60. allowance I receive is the mobility allowance, (.) a
61. couple of years ago, three years ago now my (.) I
62. was injured ***** and I developed DVT blood
63. clots in the leg .
64. R: Yeah
65. D: And I had no idea what was going on for about a
66. month, I left it go very long and long story short I
67. ended up in considerable pain for a very, very long
68. time, my convalescence in the end *****
69. overall, but during that time I needed to buy absolutely
70. everything but the welfare officer denied every single
71. request that I made for supports so that was, in terms
72. of additional personal assistance (..) you know items
73. like, things like these (.) I was really concerned about
74. veinus return so I (.) because I was in bed a lot I was

75. very concerned about blood circulation in the legs so I
76. wanted to buy a pad, a calf and heel pad which
77. effectively cushions the entire foot, the calf and it
78. squeezes the calf (.) it improves blood circulation
79. basically.
80. R: Yeah.
81. D: €200 each! if you can believe it, each and they
82. denied that on the grounds that the supplementary
83. allowance did not cover such items, now I also, I
84. mean (.) to really clarify why I think it was nonsense
85. these blinds that you see here, these wooden blinds
86. (.) they cost a bit when I moved in and she denied
87. them as well, now I know for a fact that that's not
88. something that they don't support, when I moved in
89. here all of the items that I tried to, that I needed to
90. buy for myself after moving house she denied as well
91. as not appropriate for assistance on supplementary
92. welfare allowance (.) so that was €2000 at the time all
93. in all, I asked them for a €1000 I wasn't even asking
94. for the full amount.
95. R: Yeah
96. D: Two or three years before my needs changed as
97. well (.) I wanted to travel a bit more, I wanted to move

98. around (.) and get out of the house a bit more, I
99. applied for a hoist that broke down and could be
100. brought with me.
101. R: Yeah
102. D: That was denied by the occupational therapist, that
103. cost €3,500 at the time (.) and what
104. was particularly unpleasant about that refusal is that I
105. had just bought a car and I needed to put a ramp and
106. a hoist into that as well and the excuse that was given
107. was just again this cock and bull, she said it was over
108. the allowed weight for somebody to carry a single item,
109. but it wasn't (.) it wasn't it was twelve kilos, each part
110. was twelve kilos, now the European Union regulations
111. specify twelve kilos is the limit.
112. R: Okay so there would be no problem somebody
113. bringing in that.
114. D: There never was (.) now on top of that of course
115. there was an eighteen month (.) the reality was even if
116. it was requisitioned there was an eighteen month delay
117. in terms of (.) between the decision being made, the
118. item actually being provided (.) I've never bothered,
119. ever since my first wheelchair, I never again got a
120. wheelchair from the occupational therapist because

121. my expectations were just so low and I think that was
122. a mistake actually on my part because things change
123. so much with me, I mean it was twenty years ago
124. when I had a spinal injury and things were very, very
125. different then, there was only one occupational
126. therapist in the city (.) basically what happened was
127. when I got home, I wanted to use different kinds of
128. wheelchairs, lighter wheelchairs, faster wheelchairs,
129. wheelchairs that look better (.) it was almost
130. impossible to defend yourself on those terms because
131. it was seen as a sort of luxury so at that time I started
132. buying my own equipment and since then I don't think
133. I've bought a single item in Ireland because the costs
134. are grotesquely higher than the US and even the UK
135. so I import everything from the US, absolutely
136. everything I have exercise equipment in the bedroom
137. which was 50% the cost of the UK cost so I had
138. it shipped over and still save 40% of the UK
139. cost, so these kinds of things certainly didn't help (.).
140. R: That is something that came up with another person
141. that was interviewed and it was the same thing that
142. she came across, she was getting a wheelchair
143. because she was doing karate and she wanted a

144. wheelchair suitable for that, even though they went
145. through a whole process of choosing it and they just
146. went her something completely different.

147. D: Yeah, I mean I think that the claim is that it's
148. legitimate given the expertise that the professionals
149. have but I think that there is a level of paternalism as
150. well, not good paternalism but I think they just (.) I
151. mean it's tricky I would imagine from their perspective
152. because people do, I think, demand things perhaps
153. that are not suitable for them at times, I've made
154. mistakes myself (.) however there is (.) it is very
155. difficult to deal with these people, I mean my
156. experiences, my overriding memory of dealing with
157. occupational therapists was humiliation and you know
158. as a consequence my expectations are really, really
159. (.) lessened and I've been buying them ever since, I
160. use Credit Union loans, so I take maybe two or three
161. thousand out of the Credit Union every five, six years
162. to buy a chair, best money I ever spend you know, I
163. have no interest in allowing my body to deteriorate or
164. use substandard equipment simply because I have the
165. principle that I should get the right equipment, I used to
166. think like that when I was younger but I (.) it's a

167. mistake you know, it's the best money you'll ever
168. spend really buying the right equipment for your body
169. and of course my needs changed and my needs are
170. different on a week-to-week basis so I use a higher
171. when I'm at home, when I'm working at home but
172. when I'm out and about I use a lower back and that
173. sort of thing (.) and it seems absolutely outrageous
174. there's no occupational therapist would accept that
175. kind of cost, providing that kind of cost (.) what can you
176. do? (..) I don't know because I don't have nothing to
177. do with them anymore, however, as my needs have
178. changed I have recently become aware of the need
179. for a power wheelchair so I've got to start dealing
180. with them again and I'm not looking forward to it,
181. but I'm led to believe it's a lot easier these days you
182. know (.) I mean I know the occupational therapists and
183. I've dealt with them for a shower commode chairs
184. over the years and they are quite pleasant people
185. they have constraints on them of course, I suppose
186. it'll be grand for the next year or so but God only
187. knows what's going to happen in the years that
188. follow (.) I mean if you are talking about taking another
189. €4 billion out of general government spending,

190. where the hell is that going to come from you know?

191. R: I know.

192. D: I mean wages can only be lowered so far but

193. lower them too much and you cause aggregate

194. problems but it's not something to look forward to

195. anyway.

196. R: No, it's looking very grim, like I've given up watching

197. Prime Time!

198. D: So I'm not, in terms of a universalised cost of

199. disability payment or a disability inclusion payment, is

200. what the Australians refer to it as, it's a pipe dream

201. really, unfortunately but it's not, just because it is at the

202. moment doesn't mean that it's not worth fighting for of

203. course, it's just something that will be very, very

204. difficult to encourage people to see (.) now of course

205. you might be able to, you might be able to form

206. something like it, through some method of direct

207. payments but I don't know, I don't know how much,

208. you know people say there is support for that but

209. I don't know, I'm kind of suspicious of it and again

210. it's tricky, you know it's something that some people

211. could manage and others couldn't.

212. R: Yeah.

213. D: And there's a risk you know (.) people who are
214. independent, independently minded are (.) can be
215. stubborn and make mistakes, but that's okay too I
216. guess, it's really tricky, the question is how much
217. would you save, where are the savings to be made?
218. R: Yes.
219. D: Because if you (.) if you look at the ****, they kind
220. of, it's not, it seems to me it's a kind of skeleton kind
221. of staff anyway so who would you take out of that
222. equation to save money and provide direct payments?
223. I mean if you take one of the coordinator's out, the
224. other coordinator is just going to have all the work
225. if you take the programme manager there is no point
226. of contact for support either so it's tricky, so I guess
227. my (.) my hope is that when the resolve, I mean, once
228. the (.) I think the shock and horror at the amount of
229. money that has been thrown at disability organisations
230. over the last ten years I just hope that the **** isn't
231. going to be landed in with the likes of the *****and
232. other charities who have loaned money right, left and
233. centre and have no, there's no accountability.
234. R: No and they are huge and I do some work for an
235. organisation *****.

236. D: Is that *****?

237. R: Yeah

238. D: I mean ***** was a favourite of the political

239. party, you know in power and as a consequence she

240. was asked to do everything, I mean unambiguously put

241. in positions where she was it was questionable.

242. R: Yeah.

243. D: I mean being put in charge of ***** when she

244. was head ***** for example is extraordinary.

245. R: A total conflict of interest, a very ***** type

246. of person.

247. D: ***** and the disability legislation

248. group, I was part of, do you remember this? It was

249. another bloody consultation group.

250. R: Was that part of the *****?

251. D: No, it was set up as a group, I mean every large

252. disabled organisation was represented on it, I was with

253. the ***** in Dublin at that time.

254. R: Okay.

255. D: So that's why I represented them, so it was just, as

256. I suspected from the beginning it was just a charade

257. you know, it was just another consultation group that

258. went around the country, you know, determining what

259. people wanted and I just you know God only knows
260. who even read the report in the end because the
261. disability legislation that they produced was nothing
262. like what people wanted (.) now (.) you know and
263. *****I mean
264. I used to go the meetings in Dublin there and I just got
265. fed up, you end up thinking they are just parties or
266. just social outings for people and you know, with
267. Fianna Fáil everytime you mention something it was
268. a consultation group you know, we need a consultation
269. group, we need a constitutional consultation group over
270. everything, if you mentioned a (..) *****as you
271. know kind of propagated this idea
272. that disabled people would be contravening the
273. constitution if they were provided with say with
274. disability, now I'm kind of making some of this up,
275. I don't think it was along the lines of a cost of disability
276. payment but it was along the lines of say rights based,
277. now she encouraged the belief that that would be a
278. contravention of the constitution because it would
279. make disabled people special citizens above other
280. people.
281. R: Yeah.

282. D: Which is just extraordinary, I mean it's in an
283. unbelievable misunderstanding of basic principles of
284. equalisation, you know, it was really quite shocking,
285. but you know, now obviously, how can you even talk
286. about it now because as it transpired for people who
287. were apparently so concerned about costs, you know
288. they were throwing money everywhere, except, it
289. seems to people who actually really, really needed it.

290. R: And the National Disability Authority did a big report
291. on the cost of disability payment.

292. D: Yeah I remember that.

293. R: And in the end they came out with, oh, a €10, €20
294. or €40 payment per week depending on level of need,
295. now, that's not exactly going to make a dent in much
296. is it, when you are waiting for a piece of equipment
297. that you really need (.) and that came up in the
298. conversations that I've had more than anything is
299. that the waiting lists force you in to buying the
300. equipment yourself, you know?

301. D: I think reports from the National Disability Authority
302. are of questionable quality aren't they?

303. R: Well they say that they have around 5% of
304. research is social model based research in Ireland

305. and yet they are responsible for promoting that.

306. D: Yeah, I've never really been (.) the purpose of

307. the National Disability Authority has never been that

308. clear to me, but I know that in terms of these reports

309. I just didn't trust the quality of them, I just thought they

310. were somebody somewhere who needed a grant

311. and the idea was maybe to come up with some idea

312. and we'll be able to pay you the grant, which I suppose

313. that individual is just trying to help somebody out,

314. I don't know, some of these reports seem to be just

315. picked from (.) out of the blue and I think there is

316. obviously conceptual problems right, what is a

317. cost of disability allowance (.) there's far too much

318. feeling as well that people just want hand outs, that

319. people just want to be given money and that'll sort

320. of cheer them up a bit (.) I don't know.

321. R: Something that came up was that it wasn't

322. the idea of, oh great an extra €20, it was the fact

323. that the system itself is inconsistent and like you said

324. you are waiting at the behest of somebody else,

325. whether that suits you or not.

326. D: It's tough alright (.) it's really tricky, I mean the costs

327. of course of equipment is absolutely fantastic and it's

328. because I think they pay it.

329. R: Yeah

330. D: I mean I don't know, but like it's one thing to say to

331. somebody you are not getting that wheelchair because

332. it's 25% to 30% above the cost of what we think will do

333. you but why don't they try and save costs by denying

334. the suppliers the absolutely extraordinary write ups that

335. they have on them, I mean charging a 100%

336. more for a wheelchair than the US market, you know,

337. 25% to 30%, 40% more than the UK market, I mean

338. that's just.

339. R: Would they just not say, okay if you are not going to

340. give us the price we are going to get it from the States?

341. D: Yeah, they should just ship it directly in my opinion

342. (.) and if they did do that from companies, like say,

343. Sportaid, they would actually get what they asked for

344. rather than these suppliers who supply half of the

345. equipment that's wrong (.) 50% of the time I've dealt

346. with them these people they've turned up with wrong

347. equipment so there seems to be, just, I'd say they just

348. don't seem to give a toss.

349. R: I suppose they have a cushy number.

350. D: I know the government pays you see, this is the

351. problem, they might pay late but the government
352. always pays, so I mean if you look at America, I mean
353. that's where the game is now, that's where these
354. military contractors are doing, and the same in the UK,
355. military contractors, or people who started as military
356. contractors, now in education, in cleaning up streets,
357. you know, because they know that the government
358. will always pay and it's just a way milking, you know,
359. these people who have this mad idea, you can't deny
360. right if I was paying 40% tax now I wouldn't be that
361. happy because you don't get anything back for your
362. taxes in this country.

363. R: No.

364. D: You have to pay for everything again, now we are
365. paying, I mean I have private health insurance, you'd
366. like to think you were saving the HSE some money but
367. now I have to pay for somebody else's insurance as
368. well from the state insurer.

369. R: I suppose that's the charity aspect of things, like if
370. our taxes were used properly there should be no need
371. for anybody to step in to do anything.

372. D: That's right, yeah, it remains to be seen whether
373. there is really political will to sort of say how do we

374. spend money, what actually do we want to our taxes to
375. be spent on, are we going to stop people building
376. crappy roads, that kind of thing, it is a really tricky
377. question (.) and there is misunderstandings as well on
378. the other side as well (.) people don't generally
379. appreciate the fact that it's the very rich that pay for
380. welfare, it certainly isn't the standard working man,
381. because it's the very rich who are taxed, I mean they
382. pay extraordinary amounts of tax, I mean if anybody
383. is going to save the world it'll be rich people
384. unfortunately (.) I mean people who have problems
385. with that will just have to wake up to the reality, this
386. idea that the welfare system and you know is being
387. paid by ordinary people is unfortunately an illusion
388. because when you look at the exchequer accounts
389. most of the money comes from rich people (.) now
390. that doesn't mean (.) I'm certainly not saying rich
391. people should get more, because obviously what
392. rich people seem to refuse to understand as well is
393. that even if you are paying 40% tax you are still going
394. to earn a hell of a lot more at the end of the week than
395. somebody paying 21%.

396. R: Yeah exactly.

397. D: So I think disabled people are sometimes
398. unrealistic in their expectations that they can some
399. how carve out this idea of a universal cost of
400. disability payment within the sort of capitalist economy
401. we have, it's very socialist orientated you know, it
402. would be, trying to separate from that kind of idea, of
403. (.) I don't know how that might be done other than a
404. rights based direct payments kind of system that we
405. know what we want, if we had the, if we actually had
406. the finance, the money, we could demand better
407. services because we could refuse to pay (.) and that
408. would empower us (.) the idea of changing people
409. from charity to consumer, you know, (.) I think it
410. would work because people would just start
411. importing all their equipment, you know, just
412. start importing it from the US and they wouldn't
413. be long bringing down their prices.

414. R: They were saying in the UK that the take up isn't
415. actually as big as they expected and they are looking
416. at why that is.

417. D: It's responsibility.

418. R: Responsibility and I suppose not everyone wants
419. to employ somebody directly or deal with all the issues

420. that come up.

421. D: Yeah, I mean I would never have doubted my ability

422. and will to be part of say direct payments but recently

423. that period was an absolute catastrophe and I was

424. being supported by the *** and it was still a nightmare

425. so if I was paid direct payments then, would it have

426. been better? I don't know actually, but I probably

427. would have made loads of mistakes, because I was on

428. huge amounts of painkillers.

429. (laughter)

430. R: Yeah, here you go take it!

431. D: At the same time though the *****became a hassle,

432. it just became a burden to deal with because I just got

433. sick of dealing with the coordinators, I find the

434. coordinators intrusive, badgering and unhelpful at

435. times (.) but they are great on an individual level don't

436. get me wrong, but I think they (.) it's a really

437. disappointing thing to say, but something changes

438. when disabled people aren't in control of the services

439. you know, I wish it didn't, I wish I didn't have to say it

440. but it does something changes, I suppose some days

441. I'd like to get these coordinators into a hoist and get

442. them, you know, remove all control and see how it

443. makes them feel, now at the same time I know that
444. they are concerned about their PA's and (.) the
445. PA's can often put themselves in a powerful position
446. by going to the coordinators and talking about work
447. you know, behind the leader's back, which is important
448. because they need to be supported, at the same time
449. however, it's very important, now this is going off the
450. agenda a little bit, it's extremely important for PA's to
451. bring problems to the leader (.) I'm very lucky at the
452. moment that the people I have, I mean I had a lot of
453. difficulty with my PA's and I ended up paying
454. everything, every penny of disposable income I had as
455. well as my savings on PA's because I just couldn't hire
456. anybody through ***** it was just a nightmare, it just
457. didn't work out, you know (.) but fortunately the people
458. I have now are just really, really great.

459. R: And is that because it's kind of an unusual situation,
460. in the sense that there is an organisation involved and
461. you are the leader and the employer as such?

462. D: I think what was wrong was that I kept hiring people
463. that worked really well for me when I was extremely
464. active, you know when I was teaching in *****
465. and I was studying there and I kept hiring that sort of

466. personality, but my needs have changed so much,
467. almost all the work was going on inside the house,
468. there was a huge amount of personal care and I think
469. it wasn't what they wanted you know and so what I did,
470. I realised quite late in the game that I needed to hire
471. people with experience and accept no compromise
472. you know and it's worked out really well as a
473. consequence you know.

474. R: And do you get any home help?

475. D: I do yeah.

476. R: And how do you find that?

477. D: Home helps I actually find great these days
478. because you know, originally the home help was
479. provided to you by the HSE and that was like, I mean
480. I had a spinal injury ***** and when I
481. started living alone there was no personal assistants,
482. I mean the first ten years of my life as a quadriplegic
483. there were no personal assistants so it was all informal
484. care and home helps were a nightmare at times but
485. now it's great because they really just, like one of my
486. PA's is paid through the home help system as well,
487. so it became a very important supplement to *****
488. hours, I'd be lost without it , so the only times really

489. that, the only problem I suppose is that if my desires
490. change on a daily basis I will need to pay myself but
491. at the moment it seems I'm managing because I'm not
492. doing anything, you know, I don't go out, I don't travel,
493. I couldn't even dream of going on a holiday at the
494. moment (.) and that's fine for me right now but yeah,
495. I've got to be really careful because there's a real
496. danger of isolation.

497. R: And would that be because of cost or?

498. D: Well it is partly isn't it, because I have zero
499. disposable income at the end of every week, my loans
500. to the Credit Union are €50 so that already brings it
501. down to €140, I try to eat well I don't eat much but I
502. try to eat what I actually like rather than, you know, it's
503. not always easy to cook because my PA's are
504. engaged in other things when they're here.

505. R: Have you come across any costs like, things that
506. came up in relation to something being recommended
507. by somebody and then finding that it was like a very
508. expensive vitamin?

509. D: Exactly, supplements are really, really important to
510. me because I don't eat enough fresh fruit and
511. vegetables (.) and I obviously (.) my skin needs to be

512. protected so, potassium, calcium, now calcium is
513. available on prescription, it's calcitube, so that helps
514. obviously when I don't get enough sun (..) magnesium,
515. all these kinds of things, they really do add up, they
516. really do (.) and it, you know, some times works out
517. and sometimes it doesn't (.) I get informal support
518. from *****and I have no idea how people
519. survive on disability allowance alone, absolutely no idea
520. (.) I don't think I've bought my own clothes in years, you
521. know, I mean I couldn't possibly buy clothes with that
522. allowance and I was so humiliated by my experiences
523. over the past couple of years with the *****
524. health centre I just couldn't approach them for clothes,
525. no way, no way, I just couldn't do it, it destroys you, it's
526. so soul destroying, you know and it's tricky really, it's
527. not something that (.) you see I moved catchment
528. areas, I lived in ***** and the welfare officer I had in
529. ***** was absolutely class, you know the guy
530. would never deny you anything, this is why I know that
531. these items were, they were able to provide assistance
532. through the social welfare somewhere else.
533. R: Isn't that disturbing though in the fact that it comes
534. down to personality, you know.

535. D: That's right I think it does, I mean of course it's also
536. a question of pressure on the health centres you know,
537. I don't really know how they worked it out, but I think if
538. there is a lot of payments going out, it's definitely hard
539. to get anything for them, you know, so you've got to
540. look for, if you really know what you are doing, you've
541. got to look for a catchment area that's pretty well off
542. because the welfare officer isn't going to be bothered
543. by that many people and that's what it was like down
544. there, I lived there for ten years and it was very difficult
545. to move and I made a mistake I think, this area is
546. really tough, it's a really rough area at times (.) I get
547. a lot of trouble, just bored kids you know, breaking
548. windows, scaring the living bejesus out of the
549. neighbours and stuff, it's pretty nasty though at
550. weekends, I know that the guy next to me is disabled
551. as well and he's got some pretty tough characters at
552. the other side of that wall at the weekends and it's
553. extremely intimidating because they get drunk I think
554. and stoned over there and-

555. R: (overlapping) Groups of kids like or?

556. D: They are older (.) but I'm trying to get out of here,
557. it's a shame because it's a great house, loads of

558. space.

559. R: It's lovely, it's a Council house?

560. D: Exactly, but it's way too rough for me.

561. R: And how would you get out, would you apply for a

562. transfer?

563. D: Yeah, apply for a transfer first and housing

564. associations.

565. R: That came up with somebody else, they were

566. offered a house up in the ***** after six years on

567. the waiting list.

568. D: Twelve years I was before I got this place, twelve

569. years.

570. R: And I mean the *****.

571. D: Yeah, I grew up there for a few years and it's as

572. rough as you can get really and it's on a bloody hill.

573. R: And there is nothing there.

574. D: That's what I miss about ***** you know, Jesus,

575. I had only a few hundred meters to go into *****,

576. I should have asked the City Council to try and

577. buy that house ***** , but it was too small,

578. I mean I managed without an accessible, like I could

579. use the loo but I had that bathroom for ten years, I

580. used to go for a shower in my parents house every

581. once and a while and in the hospital, I couldn't do that
582. now, I just couldn't, but this place is pretty hairy like,
583. it's just rough and again it's a bit embarrassing really
584. but I get groups of kids coming over here and
585. intimidating me and stuff you know, it's really fucking
586. nasty.

587. R: Jesus!

588. D: Like I've called the Guards about six times since
589. I've moved in here, breaking windows, it's really rough
590. and it's really just a group of bored, witless kind of
591. idiots, I suppose as well as the fact that you get
592. groups playing football against the wall all day long
593. and my bedroom (.) whatever plonker designed this
594. house put the bedrooms at the front of the house so
595. that the bed is about two metres away from the fence
596. and the wall.

597. R: And that's just down there is it?

598. D: No, right outside the front of the house and they
599. play there.

600. R: So there are green areas right, left and centre and
601. they have to play there!

602. D: Yeah, they are a bit young, the parents are trying
603. to keep them out of the house and in fairness they

604. have quietened down a bit, but I (.) it's just not a
605. suitable place for me, I don't get out of the house
606. I can't get out of the house, there is nowhere to go,
607. the built environment around here is just not
608. suitable because you can't go a hundred metres
609. around here without getting up and down steps
610. and it's just not a good place, it's not a healthy
611. place and so (.) we'll see if a transfer's available
612. I mean the community Garda in ***** are very nice
613. and maybe they can give me something, a kind of
614. report you know that these things happened and
615. that might help if I need to get rent allowance again
616. but you know, getting rent allowance again after
617. having a City Council house is going to be really,
618. really hard (.) so I'm not too sure what else I
619. could help you with, I mean where have we got to?
620. R: I suppose going back a small bit to daily living
621. costs is there anything like you know, because the
622. costs can be divided into ongoing daily costs and then
623. the capital expenditure that you would have and you
624. covered that really, what about heating, do you pay
625. extra for that or, there's no issue there?
626. D: No, I'm fine with heating actually, electricity of

627. course is expensive but I (..) let me think well capital
628. expenses we went through a bit you know because
629. I need to use two backs, these backs that I'm using
630. were made for me in the US, the chair I'm sitting in is
631. kind of €3000 you know, because the chair was one
632. thing but as soon as I, again I need to remove the
633. brake system and replace it with one that works for
634. me, I use one that's operated by one lever, I mean
635. I need to lean myself back a lot during the day to take
636. the weight off my upper spine and normal brakes are
637. not safe so I use a disk brake system that you can see
638. there so that's a \$1,000 right there, it's mad
639. money, the carbon fibre, I use carbon fibre backs
640. because they dampen the vibration so I don't get as
641. much pain in the spine and they are extremely
642. expensive the materials alone are expensive (.)
643. I have the wheels and rims, guys in the US make
644. these special size rims for me, because I (.)
645. unfortunately, I suppose, I'm in a way not just
646. a quadriplegic, I had injuries before I had a spinal
647. injury and led to impairment of the shoulder and right
648. forearm which cause a lot of problems for me these
649. days and that'll need to be corrected, but as a

650. consequence you know I had major difficulties using
651. a normal hand rimmed wheel so these are built up for
652. me as well and in fairness to the guy who does it, he
653. gives me a lot at cost price so he gave me the wheels
654. for just a few hundred dollars with the hand rim so
655. that's about half the price that you'd even get on
656. Sportaid, which is a direct buy, reduced cost retail,
657. (.) not retail Internet provider, what's the word I'm
658. looking for? (.) have you ever seen Sportaid?
659. R: No
660. D: Take a note of it and have a look at it, it's
661. www.sportaid.com the are fantastic people and
662. I'd recommend them to anybody, obviously you
663. need to pay the cost of carriage so (.) but to
664. get a wheelchair, complete, you're looking at
665. maybe \$300 for UPS these days and the cost
666. of importing has gone way down, like I got this
667. for, you know the basic chair for €900 and you're
668. talking €1,800 here at least I think, probably more
669. I mean they give you all this, you know, spiel about we
670. can service it you know and you can't deny I mean
671. when you get something from the HSE it's their
672. property so they are obliged to service it, maintain it

673. repair it.

674. R: Yeah, that was something that came up before as

675. well.

676. D: And it's a pretty good thing you know, that's right,

677. now I would say to people however that they shouldn't

678. be too hasty in assuming that the HSE won't look after

679. it, because if you have a good relationship with your

680. OT, I mean I have talked them into maintaining the

681. equipment I have bought.

682. R: Okay.

683. D: And very expensive equipment as well.

684. R: Because it came up as well that they wouldn't

685. maintain it, like they would get someone out but they

686. wouldn't pay for it.

687. D: Yeah, I mean it depends really, you've got to do a

688. bit more you see, it's not good enough to just ask

689. them, you've got to write to them, you know write a

690. letter that they can read out to the (.) whatever group

691. they have deciding on payments and stuff but you

692. know sometimes you're in a catch twenty-two situation

693. if you are too stubborn and you are too strong and if

694. you haven't got additional income, if you haven't got

695. compensation, if you haven't got a wealthy family,

696. what can you do, you've got to play the game, you've
697. got to be a likeable disabled person who people want
698. to help (.) I recently, I had bad experiences with a
699. charity who provide working dogs (.) I had misgivings
700. I suppose before I started with it but I couldn't believe it
701. in the end, I mean it was a really top heavy charity
702. oriented ethos, about providing dogs that would
703. change you, marvellous changes and dogs weren't
704. being trained and the support afterwards was pathetic
705. and what's worse, when things started going wrong, it
706. was the absolutely horrible reluctance on the part of
707. the trainer to accept any responsibility and in the end,
708. the dog just became a danger to me, he almost pulled
709. my (.) this bad shoulder out of my socket and I
710. reluctantly wrote to them and said if you take the dog
711. away for some intensive training for a month you
712. know, try to get him to heel better, blah, blah, blah,
713. she turned up the following morning to take the dog
714. away, I was absolutely devastated and I think she
715. was just trying to punish me for being so, I don't
716. know, I mean I was devastated like, I never saw the
717. dog again, that was about six weeks ago.
718. R: That's bizarre though.2

719. D: The dog was sleeping at the end of the bed for six
720. weeks and I had a relationship with him for over three
721. months, it's crazy, now in fairness she did email saying
722. I'm ready to talk about it if you wanted but I don't think
723. I can talk to her, I really don't, I mean what am I going
724. to say.

725. R: Can they not accept that the dog needs more
726. training?

727. D: Oh she just didn't want to, there was an
728. extraordinary reluctance to (.) she's one of these
729. people who seems to need to move forward all the
730. time and if you try to get to them to stand still or take
731. a step backwards they just, I don't know, it's really,
732. really tricky, I think she had mostly dealt with children
733. up to that point and what I know now is that a dog that
734. would work for me would have to be extremely well
735. chosen you know, I just couldn't possibly work with
736. an animal like that again, he was a great dog, a
737. fantastic character, spoiled rotten though and that was
738. one of the problems, he just jerked and jerked and
739. wanted to go one way or the other.

740. R: And that's a fundamental thing, the dog is supposed
741. to stay.

742. D: Absolutely, in the end the, the excuses were that I
743. shouldn't have been going to here and there, what
744. actually happened that caused so many problems was
745. that I got stranded, my car keys got locked inside and
746. ended up going for a cup of coffee and every
747. imaginable inappropriate thing, he did, but I was
748. devastated really but at the same time the training was
749. pathetic and the dog needed everything to be pointed
750. out to him, you know, I can't point (.) she needed to (.)
751. I mean, long story short, again I think it's a situation
752. that they could do with a couple of disabled people
753. working in the organisation as well and I suppose they
754. could re-name the organisation too***** is just
755. too (.) I think I just had bad luck really,
756. other people have had great experiences, but then,
757. what I should I wasn't ready to be fair, what I do know
758. now is that I wasn't ready, it wasn't the right time, you
759. know, it really wasn't, despite my need to have an
760. animal around, I really miss dogs, I love dogs, and
761. it just wasn't the right time and you know in a way, so
762. in one way it was a really good to experience that
763. because I know what roughly it would take, but I
764. need to wait, like I'm having***** I need to

765. wait eighteen months and you know costs for the dog
766. were high enough as well.
767. R: Yeah, because someone in the focus group had a
768. companion dog and people were saying you should
769. really get insurance for the dog.
770. D: But they can't, the dog is the property of *****
771. R: Oh really!
772. D: It's a tricky one, it's weird isn't it, I suppose you
773. could insure them anyway and just not tell them.
774. R: I'm not sure if that dog was provided by them.
775. D: Well the guy I got, got sick the first month and the
776. vet bill was €370 and in fairness to vet, he was
777. concerned because with a working dog, I don't
778. know about the guy I had but you know .
779. (laughter)
780. R: He wasn't doing too much work!
781. D: But it can working with a very expensive animal, so
782. the vet was kind of saying maybe we should keep him
783. in and keep him on a drip but €370 was a bit crazy.
784. R: So that came up-
785. D: (overlapping) So I suppose the capital costs to me
786. are really are current costs for me because it's loans,
787. so I'm paying week by week and that's €50 a week

788. minimum, you know, and then monthly costs,
789. disposable pads, micro enemas this kind of thing, you
790. know you are looking at, another, dividing that into
791. weekly income you are looking at €30 to €40 again,
792. so I start out with €80 less than the full disability
793. allowance and that (.) that's fine until the bills come
794. and then you are really, really screwed.
795. R: And are savings something you can do or?
796. D: Well I had savings because I worked for a few
797. years but they are long gone (.) they were really handy
798. actually because I was able to pay the PA's a bit extra
799. when I needed, I mean it's really tricky for me, when I
800. was really ill because you just couldn't determine what
801. kind of day you would have and (.) I think it's just,
802. unfortunately things just didn't work out with the ****
803. it just, in many respects it was just a problem of
804. communication I just couldn't communicate very well
805. and em it was very, very frustrating for me because
806. I was taking so ***** that my memory even
807. was ponce, so I would be asking people questions and
808. I'd forget five minutes later that I'd asked them, it was
809. horrible, horrible, I mean you don't want to be in so
810. much pain but it's definitely a cost, a price to be paid

811. for relief .

812. R: Yeah

813. D: And em, so I mean that's all in the past now and

814. things are working out really well again but em, it's

815. a tricky one, I don't really know and I mean, what do

816. you, if you don't mind me asking, what are your hopes

817. for the final, the final report, is it going to be a policy

818. recommendation that you are looking for or is it just

819. a kind of a study of (.) you know?

820. R: Well how it came about is that I approached the

821. CIL, saying basically I need to do a piece of research

822. would you be interested in doing something so they

823. picked the topic, so the idea would be to draw attention

824. to the facts and not have any more cutbacks, I mean

825. I don't know as you were saying it's certainly not

826. going to get any cost of disability payment but maybe-

827. D: (overlapping) The thing is as you said I would be

828. very hopeful that, you know, a half decent government

829. might do a sincere cost-benefit analysis of the way

830. they spend the tax, I don't really know, in many

831. respects the government that we have now is just

832. as conservative if not more.

833. R: Oh yeah, they are the same, probably not as

834. corrupt but they have the same outlook and they

835. have the perfect excuse now because all they have

836. to keep saying is that we are tied into the deal you

837. know.

838. D: Yeah, apparently they are just being pushed around

839. in Europe, you know.

840. R: Just looking at what another question would be,

841. what you would spend money on if you could, which

842. you also touched on yourself.

843. D: It seems, I don't know, the tricky thing I have with

844. these conversations is, is what do I deserve you know,

845. given my situation, given my condition, given my

846. financial situation, you know do I, should I feel entitled

847. to a holiday and this kind of thing, I'm challenged

848. really to answer those questions, I don't really know,

849. I mean (.) I guess I should be but I just couldn't

850. imagine saving for a holiday, you know.

851. R: And you were saying you have a car?

852. D: Yeah

853. R: So taxis, do you use taxis as well do you?

854. D: You see the problem I have is insurance, I can't

855. afford insurance right, so the way it works out is that I

856. have a deal with one of my PA's, they use the car and

857. when I'm not using it and she insures it because I
858. couldn't pay that, I couldn't pay it (.) I'd love to have
859. all the PA's insured on it, but it works out alright like
860. you know, it's better than not having it and a number
861. of years ago I got to travel around Europe and stuff
862. like that in it, you know, a couple of times and that's
863. a nice thing to remember, em, but I didn't (.) I certainly
864. didn't pay for that out of my disability allowance let's
865. put it that way, (.) I mean the way I paid for that vehicle
866. was really just a bond, a savings bond I had for years,
867. ***** it's going back twenty years ago,
868. an extraordinary time really where the government
869. were desperate for money, the interest rates they
870. were offering on those bonds were just extraordinary,
871. they doubled, the bond doubled in fifteen years, so
872. I just bought the vehicle then with that (.) I sold,
873. I had a van before it, an accessible van, that I sold
874. as well, you know.

875. R: So did you get the grant towards that?

876. D: No, at the time I thought it was exclusively for
877. people returning to work, now I've been told since
878. that's not quite true (.) but if I was to change the van
879. I'd love to start driving again you see and if the surgery

880. on the arm and shoulder worked out I'd love to try to
881. drive again, so I would definitely try to get that mobility
882. grant then, I mean it's only a couple of thousand
883. in the end isn't it because they remove your mobility
884. allowance, they remove it for three years so your
885. talking, you know, €1500 to €2000 and they give you
886. a grant of say three or four, so you're really only
887. getting a grant of €2000, it's better than nothing I
888. guess but they do act as if they are giving you the car
889. for free you know and that seems a bit.

890. R: Because the Disabled Driver's and Passenger
891. grant is there as well but that is related to if you buy a
892. new car and the VAT and VRT is given back.

893. D: Yeah, that worked out quite well for me, I don't
894. know why, but the VAT I got back, that was a second
895. hand car, but it was a good bit of VAT I got back on it, I
896. think because it was fairly new or something they were
897. allowed to charge more or else I got the VAT back on
898. a new vehicle and I wasn't going to mention it, if it was
899. a mistake, it's actually how I went to Europe that time.

900. R: Yeah.

901. D: I mean when I got a cheque for the VAT I just
902. couldn't believe it.

903. R: Yeah, when you get a cheque from the tax man
904. you don't question it!
905. D: I did for a while, I was a bit wary.
906. R: Yeah, that they'd look for it back.
907. D: That first time actually that I bought a van there
908. was some strange mistakes, a mistake, you know,
909. and they didn't, it turned out that there was like an
910. investigation because they didn't think that I
911. existed and I was getting so much grief from them
912. they were scaring me and my father and when he
913. actually saw me there was absolutely no problem,
914. (mimicking voice) 'thank you very much, so sorry
915. for hassling you' and he went away but he thought
916. I think my father and that I wasn't disabled or
917. something.
918. R: Ah okay!
919. D: But it was really funny, so there you go.
920. R: And is there anything you have to forego spending
921. on, I suppose, you touched on a lot of that too yourself.
922. D: Well I don't really have any social life.
923. R: Yeah.
924. D: Basically, em, (...) yeah, I mean (.) I am invited out
925. but I mean (.) yeah, it's embarrassing there's no doubt

926. about that you know (.) not being able to kind of pay
927. your way (...) but I don't know (.) I mean (..) I don't
928. think it's going to change for me very, very, soon, I
929. mean I hope to be able to work again for a couple of
930. hours ***** a week, depends on the wage of course
931. because sometimes it can be considerably more per
932. hour than other times (.) but my self-esteem I think
933. has, you know, has deteriorated a lot, it's not (.) it's
934. not very nice (.) there's no doubt there's an emotional
935. burden to being broke all the time (.) it doesn't
936. engender a sense of ambition if you know what I
937. mean.

938. R: Well like that constantly saying like (..) no, I don't
939. want to go out because I don't have the money,
940. like you don't want to have to keep saying that.

941. D: Yeah, exactly, yeah, it's not very pleasant.

942. R: Em, (..) I think we have covered the extra costs
943. and you spoke about the solutions that you would
944. think were suitable at the beginning, just the second
945. question relates to independent living itself and what
946. it means for you directly?

947. D: I suppose the problem I have now it seems that
948. everything is fine within the confines of the house, you

949. know, em, once I step outside the house there's a
950. problem.
951. R: Yeah.
952. D: And that's becoming really tough, recently, you
953. know the fitter I get the, you know (..) the healthier
954. I become the worse that's been (..) the car I have
955. as well, you know, it's probably not (..) I mean I use a
956. very (..) a sling and hoist system, you know, it's a
957. hydraulic system, it swings me into a car seat and
958. I love that I've had it for a couple of years but it is a bit
959. (..) you know, I'm asking a lot of my spine and joints
960. you know, getting out of the chair, swinging into a car,
961. swinging back out again and I'd like to change the
962. vehicle so I could roll in and out the back as well as
963. maybe get into the passenger seat (..) but I've got to
964. get out of this house, I've got to get out of this house,
965. It's the worst house I can imagine right now for me and
966. (..) I mean, I don't know what's going to happen to
967. personal assistance over the next five or six years, I
968. mean there is no way, there is just no way they are
969. going to be able to pay, I mean you are talking about,
970. Jesus, the interest alone is €4 billion or something a
971. year, it's half the HSE's budget, how the hell are they

972. going to pay that and maintain the level of service that
973. they do, I mean it's all well and good saying we'll get
974. rid of administrators, I mean they are talking about
975. removing 50,000 people from payroll.

976. R: Yeah, it was on the other the news the other day
977. that the only sector that hasn't lost employment is
978. the public sector and you are going, but sure of
979. course not.

980. D: Yeah, it's (.) I mean there is a dilemma for any
981. country, I mean, the problem with Ireland is that
982. there is no doubt that if the public sector grows
983. substantially larger than the private sector, then you
984. do have a problem because, the obvious, the private
985. sector pays for the public sector, so if you allow the
986. public sector to grow too big then you do have a
987. problem, it's certainly not fairytale (.) I mean what
988. seems to be happening is that they're trying to sort
989. of con us into forgetting that the public finance problem
990. was €20 billion and trying to get us to think of the
991. entire sum as the real problem, but the funny thing is,
992. recently I've noticed that not only are they doing that
993. but they are trying to about the entire sum as a
994. problem for the public finances, so we're talking

995. less about the banking and housing problems and
996. talking more about public spending and I think it's
997. a strategy to try to bring about these things.
998. R: I don't know, do you watch Vincent Browne?
999. D: Sometimes.
- 1000.R: I like that guy, I'm trying to think of his name (.)
1001. Constantine...
- 1002.D: That's right, he's good isn't he.
- 1003.R:Yeah.
- 1004.D: He's very good.
- 1005.R: The only one who seems to talk any sense, he cuts
- 1006.to the core.
- 1007.D: Yeah, he knows what he's talking about alright (.)
- 1008.I mean he does but (.) the problem of course is he
- 1009.doesn't experience the (.) life though as a vulnerable
- 1010.person and his remedies would work, but the question
- 1011.is at what cost? I mean maybe Thatcher's ideas would
- 1012.have worked as well a lot but what would be left, you
- 1013.know once they start working (.) I don't know he's
- 1014.like, I mean he's definitely on the ball you know,
- 1015.it doesn't make sense to try to solve the problems
- 1016.by borrowing more if you have no way of paying back
- 1017.what you already owe, at the same time, what do you

1018.do, do you ask, do you turn around, the manager of
1019.entire public sector and say look you've got to work for
1020.no wage for the next six months, I mean how do you
1021.do that, I don't think you'd be in government very long
1022.if you did that, but (..) he's right to be angry, I mean
1023.it's a good idea to encourage anger because it's
1024.(.) I don't think we're angry, we aren't you know.
1025.R: We're not angry enough though, as somebody
1026.said we're not actually hungry enough.
1027.D: Yeah that's right.
1028.R: Or something, because we are very passive.
1029.D: It's still too easy, that's right, it's still too
1030.comfortable, yeah, it's still far too comfortable,
1031.I don't think we're going to get it for a few years (.)
1032.the biggest fear of course is that how many people
1033.are going to foreclose on their mortgages, I mean
1034.that's the real danger, because if there is a complete
1035.collapse of that, then, apparently the banks at the
1036.moment are over extended by at least 50%, 40-50%
1037.so they owe (.) the owe 50% more than all the savings
1038.they actually have.
1039.R: So we have covered everything one way or the
1040.other, I didn't need to ask too many direct questions

1041.which is always good.

1042.D: Do you want me to actually try and cost those

1043.things and email you or something, or is that

1044.something you are looking for?

1045.R: Yeah, everything is data.

1046.D: Yeah, I will so, I suppose it would be a good

1047.exercise for me to see what percentage of the income

1048.is going out anyway.

1049.R: If you want definitely, that would be great.

[Recorder switched off. Discussed transcribing, sending a copy to participant and thanked participant]
