EXPLORING THE ROLE AND IMPORTANCE THAT INDEPENDENT LIVING HAS IN THE LIVES OF DISABLED PEOPLE

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Abstract

The objective of this study was to identify the role and importance that Independent Living has in the lives of disabled people. I am a disability activist and involved in the Independent Living Movement both in Ireland and in Europe. Sadly very little research has been conducted into the Independent Living Movement in Ireland, this encouraged me to select this area to research. The purpose of this research was to get the views of people connected, from a Leader's, Manager's and Personal Assistant's perspective.

The research was carried out using qualitative research methods. The qualitative data was gathered though a focus group who met twice and twelve individual interviews. The focus group was comprised of disabled people, Personal Assistants and administration staff involved in promoting Independent Living. The focus group was representative of the disabled people and included people with mobility difficulties, people with visual impairments and people with hearing impairments. The twelve individual interviews included Leaders from all over Ireland and a Manager from the Centre for Independent Living and a Manger from the Health Service Executive. I also interviewed a leading Independent Living activist from the UK.

The interviewees explored various aspects of Independent Living and participants were encouraged to identify the issues which they wanted to explore. The process was student led rather than tutor led. This approach led to some extremely interesting and informative discussion. The process produced very useful data which will be given to the Centre for Independent Living to reflect on and take action.

This research demonstrates the usefulness and importance of conducting research in this area and endorses the approach and slogan of the Farther of the Independent Living Movement, Ed Roberts:

Nothing about us without us

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CHAPTER ONE: INTRODUCTION

"Strong. Proud. Visible."

Norwegian Independent Living Parade 2013

CHAPTER ONE: INTRODUCTION

1.1 Introduction

I was fortunate enough to be able to attend a parade promoting Independent Living in Norway in June 2013. During the parade people attending the event chanted "Strong. Proud. Visible" whilst onlookers in the streets applauded. As a disabled person who has campaigned for equality, rights and inclusion for over three decades, the event made me reflect on the discrimination that I and other disabled people had experienced and several times moved me to tears.

This thesis explores the role and importance that Independent Living (IL) has in the lives of disabled people.

Using information obtained by the transcripts I was able to identify key themes.

The themes identified were:

- Defining IL
- How people became aware of IL
- The link between poverty and IL
- Challenges for the IL to consider

These will be explored in Chapter 4.

1.2 The origin of this research into Independent Living

The Independent Living philosophy recognises ‘the right of all persons regardless of age, type or extent of disability to live in the community, as opposed to living in an institution and to participate in the social, economic and political life of their communities, to have a family; to live as responsible respected members of their communities with all the duties and privileges that this entails and to unfold their potential (CIL Adolf Ratzka [online]).

I was encouraged to conduct research into the area of IL because of the dearth of research material and literature from and by disabled people; in all the books I have read within the Irish context of disability and disability studies, I have only seen a few examples of when researchers have sought the opinion and views of people directly involved in the ILM. In the Irish context, I wanted to approach this from the perspective of how individuals got involved in wanting IL, and how they defined IL and its philosophy. I also wanted to discover what people directly affected by IL considered to be the challenges and where they felt the future of IL lay, and to this end I ensured that the vast majority of people interviewed were actively involved with the Irish ILM. It became apparent in the early stage of my research that these questions had not been asked by other researchers. I recognised that without this information it would be difficult for the ILM to develop and for people involved in IL to have their views and concerns heard.

The National Disability Authority (NDA) commissioned research into the situation of social inclusion and exclusion of disabled people in Ireland (NDA, 2011). The report shows that disabled people are disadvantaged in various aspects of Irish life including education, employment, poverty and social participation. It is evident from this report and from my research that people are disabled by society. These factors influence the general socioeconomic situation of disabled people in Ireland. Evidence of this is shown within my findings in Chapter four.

1.3 The move from institution to community, and its drawbacks

There has been a shift in the past few decades to move from institutional care to more community based provision. In response there has been a series of measures attempting to encourage IL. Unfortunately the measures can create dependency rather than independency. For example the government provides tax relief for disabled motorists. It gives €9,525 for a disabled driver and €15,875 for a disabled passenger (Citizen Information 2013 [online]). This can be seen on the one hand, as a financial benefit if you are driven by someone else, and on the other hand, as a disincentive to be independent by someone seeking independence.

Although some policies identify with IL they do not do always have the intended effects. It is important to recognise that legislation regarding the provision of IL does not exist within an Irish context. There is no right to IL in Ireland.

The development of Centres for Independent Living in Ireland has challenged the traditional viewpoint of disabled people of being cared for informally by family members or within residential units.

The National Disability Strategy was launched by the Government in 2004. The aim of the strategy was to bring together new and existing disability legislation and policy to improve the lives of disabled people in Ireland. Although Ireland has drafted key legislation in the area of employment, education and access to public services, it has not fully implemented the strategy which was aimed at providing disabled people with a framework for equality. In 2005 Bertie Ahern introduced the sectoral plans under the Disability Act 2005 and referred to the strategy in the document. He stated that ‘the Government acknowledged that there needed to be meaningful changes to the way in which disability issues were addressed across a range of policy areas’ (Disability Act 2005, Sectoral Plans, p.3 [on-line]).

The UN Convention on the Rights of People with Disabilities (UNCRPD) has been signed and ratified by the majority of countries in the European State. The convention advocates that disabled people should have the same rights as everyone else to freedom, respect and dignity. Article 19 regards IL as being a fundamental right for all disabled people. It is important to recognise that IL is not just a legal issue but also a political issue which is connected with the social and political milieu in which people live. Sadly austerity measures have had a profound effect on the ability of disabled people to live within an IL philosophy. Article 19 promotes IL and the right for disabled people to have equal participation. If implemented, Article 19 could have a major influence on the role IL has, moving it from an entitlement to a right.

1.4 How to improve the present situation

My hope would be that people would get a greater understanding of how IL has come to be of central importance for individuals, the challenges they have identified and issues they would like to be highlighted. Through this study, I intend to challenge the current understanding of IL held by public bodies such as the National Disability Authority (NDA), the Disability Federation of Ireland (DFI), and the Centre for Interdependent Living (CIL), of which I am a director. The ultimate aspiration for me would be to influence in some way the European Network on Independent Living (ENIL), and more locally, the Donegal Centre for Independent Living (DCIL).

Through a series of interviews with 12 individuals and with input from a focus group consisting of disabled people, Personal Assistants (PA) and IL administrators, I obtained details of what IL meant to the interviewees. From this feedback, I hope to provide a clearer understanding of IL as it is practised, and be able to suggest ways in which it can be developed to the benefits of those involved.

The contributions from the interviewees helped direct this research. Interviewees explained what Independent Living meant to them, how they got involved in wanting Independent Living, and those who influenced their decision in adopting this approach to living their life in this way. Participants discussed whether they considered the philosophy of Independent Living had changed and the new challenges facing the Independent Living movement. Lastly interviewees were asked to identify any specific issues they wanted to be addressed within the thesis.

People were selected for interview because they are either recipients of Independent Living or provide resources through the Health Service Executive (HSE) or Donegal Centre for Independent Living (DCIL). Some of the interviewees were involved with establishing Independent Living in Ireland and the creation of the independent movement which exists today. Interviewees included people experienced in the Independent Living movement and others experiencing Independent Living for the first time and people responsible for the administration and funding of Independent Living.

I am a disability lecturer and a board member of both the Centre for Independent Living Carmichael House and of The European Network on Independent Living. Therefore for the past 30 years I have been playing an active part in the development of the disability movement. Examples would be: protesting as part of the campaign for accessible transport, lobbying parliamentarians for equality legislation, and advocating for people unable to represent themselves. I also have the core belief that the choice, control and responsibility provided through IL are the ideal way to emancipate disabled people within our society.

Due to the involvement I have in both the IL and disability movements, it was important that my research influenced change, and so I adopted an emancipatory approach to it. Disabled people and organisations of disabled people had a pivotal role in the control and direction of the research. Emancipatory research demands the ‘transformation of the material and social relations of research production’ (Barnes, 2001, p.5). The direction of the research was influenced through the continual involvement and contributions made by both disabled people and organisations of disabled people. It was the intention that the emancipatory approach should empower those involved and it is hoped the findings will add to research conducted in this area. This will be explored further in Chapter 3.

My research focuses on people whose lives are determined by the provision of Independent Living. In this thesis I will demonstrate how IL and its philosophy can be interpreted differently, depending on the circumstances of individuals and influences they may have had in opting for IL. It will also consider if IL has changed and identify the challenges for the development of IL in the future, as determined by the interviewees.

1. 5 A short history of the evolution of the Independent Living Movement

The concept of Independent Living originated with the establishment of the first Centre for Independent Living, which was established in Berkeley, California in 1972. It was a 'self-help group managed by disabled people' (Barnes and Mercer, 2010, p.142). The individual credited for this development was Ed Roberts, often referred to as the 'Father of the Independent Living movement'. It should be acknowledged that Ed Roberts' determination to challenge the accepted institutionalism which prevailed at that time was perhaps influenced by the Free Speech Movement which made the University of Berkeley into an area of student protest in 1964. The level of student protest was unprecedented during that period and could well have influenced Ed Roberts' thinking in demanding to be treated not as a 'patient but as a person' (DCIL [online]). This enabled disabled people to move away from the then current medical model to that of a social model approach. The Civil Rights movement was also very active during this period and many disabled people including Roberts could relate to the segregation which Black people were experiencing with the non-inclusion and isolation they were experiencing in their own community.

Steven Pinker (Pinker, S., 2011) has written a long, and in my view, persuasive book on the evolution of human society from violent beginnings to one where violence of any sort is now at the lowest point in human history. Surprising, but it is hard to argue with his statistics and observations. In Chapter 8 he outlines various paths in the general Rights Movement which have brought about this change: a lessening of ignorance and superstition; an ability to adopt the viewpoints of people unlike oneself; and a widening of human society's horizons because of the increasing use of electronic media which connects all of us. Although he doesn't single out disabled people as objects of this new understanding and empathy, he might well have done, as he names feminists, homosexuals, blacks, animal rights - the principle is the same.

In 1979 the demand for Independent Living had travelled to ‘Le Court Cheshire Home in Hampshire’ (Barnes and Mercer, 2010, p.143) in the UK. A group of disabled people (influenced by John Grimley Evans) established an ‘innovative scheme of indirect payments in lieu of institutional services to purchase personal assistance to enable Living in the community (Barnes and Mercer, 2010, p.143). John Evans defines Independent Living as ‘the ability to choose what a person wants, where to live and how, what to do and how to set about doing it’ (Barnes and Mercer, 2003, p.2). He explains that ‘Independent Living was started by disabled people to overcome social isolation’ (Barnes and Mercer, 2003, p.2).

First to develop the social model was the British Union of the Physically Impaired Against Segregation (UPIAS). Key contributors to UPIAS were Vic Finkelstein and Paul Hunt. Paul was also a resident at Le Court Cheshire Home in Hampshire where John Evans helped establish IL. UPIAS developed new ways of thinking about disability and impairment. They defined impairment as ‘lacking part of or all of a limb, or having a defective limb, organism or mechanism of the body’ and disability as ‘the disadvantage or restriction of activity caused by contemporary organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities’ (Barnes and Mercer, 2011, p.30). Paul Hunt played a key role in the development of disability rights as will be explored in Chapter 4.

The first CIL was founded in Dublin in 1992. Today there are 22 CILs situated across the country. The main aim of CIL is to enable disabled people achieve choice and control over their lives and enable full participation as equal citizens in society. It advocates on behalf of disabled people who require personal assistance to be included in society.

1.6 Examining the social model of disability

A basic premise of CIL and the disability movement is the social model of disability. The social model of disability supports IL and identifies that it is the barriers in society (organisational, environmental and attitudinal) which create disability and not an individual's impairment (Johnson, 2001, p.20). These are mostly out of the control of the individual, for instance, where one is born, the society one is born into and the learned attitudes passed on through family, school, and friends. It should be noted that lots of service providers and organisations for disabled people use the medical model or the individual model of disability as it is commonly known when assessing an individual's need or allocating resources. The medical model views disability as a personal tragedy and one to be pitied (Johnson, 2001, p.20).

My own discovery of the social model helped liberate me as a disabled person. No longer did I need to apologise for who I was or trivialise the discrimination I was experiencing. The social model enabled me to challenge the system and how I was being oppressed. It truly led to my emancipation and has influenced my activism within CIL and as an educator. That is why I have used the social model when conducting my research because I found it to be the most emancipatory approach. The social model does however have its critics and I will discuss this in Chapter 3.

An essential element of the research is the philosophy of IL. The philosophy states that all life is of value, that whatever the impairment a person is capable of exercising choice, that people are disabled by society and that disabled people should have the right to fully participate in life (Leitrim Association of People with Disabilities [on-line]). It is important to draw attention to this, because I witness the opposite being promoted generally within society, with consequently a very negative effect with the people I work with. It is not surprising, given the negative portrayal of disabled people in the media, that the disabled people I work with have a very low opinion of who they are and of what they can contribute to their community and society as a whole.

1.7 Investigating for change

In Chapter 3 I will provide deeper profiles of the interviewees, and my reasons for their selection. The rationale for the questions will also be explored.

I employed Participatory Action Research (PAR) to explore my research. PAR is a research process where participants identify an issue or problem and are encouraged to explore solutions and prepare and implement an action plan. Participants then reflect on the changes and effects brought about (Irish Development Education Association [online]). PAR is a way of collecting data which reflects the experiences of people most directly affected by issues in their communities. PAR was used in this study because there is a shortage of information available that reflects the role and importance that Independent living (IL) has in the lives of disabled people. PAR enables people to freely contribute to the issue and to reflect on issues which may arise before taking action when required. PAR has been used by movements for change and gathering information on a particular issue.

I will explore the methods I used during the research process and the rationale behind the methodology and explain why such an approach was used with reference to this specific type of research.

Data for my research was gathered through interviews, using qualitative research methods and collecting data from a focus group which comprised 13 interviewees. In addition I conducted 12 individual interviews. The reason for using qualitative research methods was because I wanted to gain a greater insight into the issues relating to IL and I felt this method would allow interviewees to be more relaxed and more comfortable in talking about their experience of IL. It also helped me gather substantial data, from which I was able to identify ‘unique themes that illustrate the range of the meanings of the phenomenon rather than the statistical significance of the occurrence’ (Zhang,Y. and Wildemuth, B.M. [online]).

The findings reflect the experiences of similar research within the area of Independent living from across the world but in the case of this research some of the findings show that:

- The experience of independent living may vary
- People are influenced mostly by peer/family support
- People fear that IL is being watered down and consequently risk isolation

In Chapter 4 I will explore these responses from the interviews.

1.8 Methodology

My research topic will be researched through Participative Action Research (PAR) and qualitative research methods. I elected to use mixed methods of research because it was the most effective way to gain the feedback required to direct the research. As a disability activist I am keen that the research would be guided by my interviewees and that the findings coming from the research would make a difference.

The process of PAR enabled me to draw on the implicit and explicit knowledge of my interviewees and therefore enabled a joint ownership approach. PAR is influenced by the works of Paulo Freire who promotes a need for a reciprocal relationship and that is what I wanted within my research. It was important to me that I should provide my interviewees with the opportunity to reflect on their involvement in the ILM. Freire states that 'true reflection – leads to action' (Freire, 1970, p.48). I want my research to influence change. Freire's Critical Pedagogy states that it is important to develop a sense of confidence and efficacy, in particular the desire to change, not only one's self but the circumstances of one's self, and the circumstances of one's social group, (Freire, 1970, p.47). I do however acknowledge that it is not always possible to implement action in all circumstances and there are limitations of Freiean pedagogy within IL circumstances. Some of the reasons limiting people could be, for instance, their social, educational and financial status – these can prevent them from even starting to think outside these boundaries.

The thesis topic will be researched by using the qualitative research method. Qualitative research enables a researcher with a method to gaining explanations to 'social phenomena' (Hancock, B., 2002, p.2) The qualitative research method will provide me with the opportunity to fully appreciate the individual experiences from people directly involved with the ILM, and this method will also provide me with the opportunity to explore in depth the personal experiences of people directly involved with IL and discover how it impacted on their lives.

The structure of the research is influenced by my ontological and epistemological views which provided direction for the research. The research is therefore influenced by my ontological views, which will be explored in Chapter 3 on Methodology.

1.9 Personal reflection

As a board member of the European Network on Independent Living (ENIL) I visited Oslo in Norway. This was an enlightening experience for me, not only did Norwegian society treat disabled people as equal members of society through its funding, but also showed it in the way we were treated by everyone we met, both inside and outside the IL movement. In this they met the expectations as outlined in The Norwegian administration changed in recent years from a medical approach to a social and human rights based approach. This approach actively promotes the removal of the barriers which may exclude disabled people. Norway has led in in its approach to mainstreaming. This is reflected in its accessibility and its low, high education standards and unemployment figures (NORAD, 2012).

During my visit I spoke with representatives from an organisation called ULOBA. Uloba is a cooperative which is controlled and run by disabled people. It is committed to the philosophy of Independent Living and provides a PA service, advocates and accessible transport services. It was founded in 1991 and is based on the principles of empowerment, full citizenship and human rights.

I was really impressed by the approach to disability in Norway. To give one example, there is an expectation that you will work and that you will actively participate in the community. On reflection, in comparison with the approach to the disabled people I work with in Ireland, there is an expectation that you won’t work and that a person’s contribution to their community is often determined by the accessibility of the venue and the attitudes and awareness of the organisers. A recent survey conducted by a student I taught on a disability studies course into access to football clubs in Donegal showed that only one out of forty four clubs had taken initiatives to encourage participation by disabled people. I consider this is replicated across the country and in other community activities. It is easy to see why inclusion and participation by disabled people into mainstream society is so small. I feel Irish society has been slow to respond to the potential and benefits of including disabled people, and believe that as a society if we want disabled people to make a positive contribution and to live with dignity and respect, that Independent living should be a fundamental right and available to all disabled people.

I decided to conduct this research for both personal and professional reasons. Due to my involvement in the ILM I wanted to find out what people's attitudes are to IL. I wanted to gather data to make changes within CIL and lobby for policy changes if required. I found the experience very informative and rewarding and look forward to using the information for any changes that are required.

Researching Independent living enabled me to consider many different theories and challenge my own ideas and beliefs in relation to the provision of IL.

It was as a result of feedback from the interviews that I began to view Independent living in a different way.

In particular I studied the works of :

- Paulo Freire – Pedagogy of the oppressed
- John Evans - Disabled People in Europe are Demanding the Right to Independent Living
- Colin Barnes and Geof Mercer - The New Politics of Disablement Second Edition (pp.146 – 150)
- Jenny Morris - The Meaning of Independent Living in the 3rd Millennium –
- Jane Campbell – Fighting for a slice, or bigger cake?
- Michael Oliver & Colin Barnes – The New Politics of Disablement
- David Egan- 2 Go Direct

I will demonstrate in the following chapters, I am fully committed to understanding and being influenced from the struggle and experiences of others.

1.10 Thesis structure

In this chapter I have introduced the research topic contained in this thesis and my personal reasons for choosing IL as research topic. PAR was mentioned along with my reasons for selecting qualitative research methods to gather data contained within the thesis.

In Chapter Two I will provide an overview of relevant research. My direct experience of disability will first be explored. The literature referring to IL will be explored and related to the difficulties which the IL movement is experiencing.

Chapter three will discuss the methodology employed in this thesis. It provides the background to why a particular approach was used.

Chapter Four provides the findings from the research. It highlights key issues coming from the data with reference to the literature reviewed. I will also refer the main themes and concerns identified within the research question.

Lastly Chapter Five will consider the key points of my research and conclude with considering the research topic and the implications of the study.

In the course of this chapter I have explained my motives for selecting the topic, and given an outline of the way I will research it. One of the paths is to study the literature surrounding the topic of IL, and this follows in the Chapter Two.

1.11 Conclusion

In this chapter my aim has been to introduce the concept of Independent Living both in the international and national contexts. I wished to show how it fitted in with the broad acceptance of disability as a human right, and how society might be persuaded to improve on what, at the present moment, is a patchy and disconnected attempt to acknowledge the entitlements of disabled people. In the chapter that now follows, I will continue with an examination of this theme as it is reflected in current literature.

CHAPTER TWO: LITERATURE REVIEW

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

In an effort to understand the role and importance that Independent Living (IL) has in the lives of the disabled people and commencing the Literature Review, I have identified different theories and approaches to IL and reflected on the data produced in the form of literature, articles, speeches and from the interviews I conducted. This information will be brought out in the rest of the chapter.

First I will consider the influence of Paulo Freire, in particular his approach within the area of critical pedagogy and how this may influence IL, and then I will consider rights and disability; following that, I will address issues of feminism through the writings of bell hooks. Finally I will conclude by providing details on the future of Independent Living and issues which will have to be addressed.

I began my life as a disability activist when I discovered the Social Model of Disability. The Social Model was explained to me over thirty years ago by Jane Campbell, who went on to become an IL activist in the House of Lords. Jane defines the Social Model as:

> a crucial role in enhancing the collective consciousness of disabled people and the emergence of the Disability Movement It gave disabled people a framework to distinguish between organisations, policies, laws and ideas which were emancipatory, and those which were oppressive or inadequate (Campbell, 2008).

It enabled me for the first time to place the responsibility for my exclusion and mistreatment onto a social rather than an individual context. Prior to my introduction to the Social Model I internalised the way I had been treated and made excuses for the way I had been oppressed. Rather than seeing a person's impairment as the problem, the Social Model focused on identifying the barriers which excluded disabled people and identified solutions to be implemented in order to remove the barriers and allow inclusion.

An important fact about the Social Model and its link to critical pedagogy is that it was written by disabled people for the liberation of disabled people. Paulo Freire says that 'only power that springs from the weakness of the oppressed will be sufficiently strong to free both' (Freire, 1970, p.26).

Examining the difficulties which the ILM have to consider will enable the movement to progress. Such an approach underpins critical pedagogy.

For the purposes of this study, I have selected four key pieces of literature to critically evaluate the views of my research which is in the area of Independent Living; other supporting literature will also be referred to where appropriate.

I examined *Disabled People in Europe are Demanding the Right to Independent Living* which was written by John Evans, a leading IL activist. The literature provides an excellent insight into IL from a Leader's perspective. The second book reviewed was *The Meaning of Independent Living in the 3rd Millennium* whose author is Jenny Morris. Jenny's methodology in this literature is both rights-based and from the feminist perspective, which adds greatly to the chapter. The next book I investigated is the book by Colin Barnes and Geof Mercer, *Exploring Disability Second Edition*, 2011 (pp.146–150). It provides a critical look at IL and challenges the IL's consumerist approach. Finally I examined *2 Go Direct* by David Egan. This publication considers direct payments and how it affects people involved with IL. All the writings chosen provide a good insight into IL and the issues faced by the movement.

The literature selected also supports my epistemological views on the subject, in that it backs the research and its findings, given the qualitative research method I chose, namely Participatory Action Research (PAR) – this will be spelt out in the Methodology section in Chapter Three, and the findings in Chapter Four, entitled Reflective Findings.

2.2 Critical pedagogy and Independent Living from a Freireian perspective

Critical pedagogue Ira Shor, who is imbued with the thinking of Paulo Freire, defines critical pedagogy as:

> Habits of thought, reading, writing, and speaking which go beneath surface meaning, first impressions, dominant myths, official pronouncements, traditional clichés, received wisdom, and mere opinions, to understand the deep meaning, root causes, social context, ideology, and personal consequences of any action, event, object, process, organization, experience, text, subject matter, policy, mass media, or discourse. (Calgary Centre for Global Community, [online])

This approach is very relevant to what is happening now to the Independent Living movement, because it is going through a period of reflection and change. I feel that a critical pedagogy approach is essential if the ILM is to adopt an emancipatory approach to the disabled people it represents. From my practice as a disability educationist I believe that the critical approach to pedagogy can be effective in encouraging a two-way dialogue, because it is as a result of dialogue that people become engaged in the issues connected with IL.

Critical pedagogy deals with the consciousness of both the oppressed and the oppressor. It is vital that people involved with IL educate and inform people both inside and outside the movement. The low numbers of protesters and the age of the protestors would indicate that lots of people are detached from the ILM.

> You know I remember last year up outside the Dáil, Jesus I dunno if there was anybody under forty there. You know I'd be surprised if there was. And you know that's not a good thing. That's not a good thing. We need new blood coming through to push things. (Transcript MC, p.6)

Critical education considers this issue when stating that the oppressed 'adopt an attitude of adhesion to the oppressor'. Freire goes on to explain that the oppressed are fully aware that they are downtrodden, but 'their perception of themselves as oppressed is impaired by their submersion in the reality of oppression' (Freire, 1970, p.27).

The Critical Pedagogical theory is a philosophy that considers social systems and interactions by the way it empowers or disempowers individuals (Giroux, 1988). This philosophy enables students to increase their consciousness of freedom, to be able to identify oppressive tendencies and to use the power of knowledge to develop change. I applied a critical pedagogical approach to this research, to encourage radical change, and that is why I took care when drafting my questions to ensure they enabled interviewees to think about the issues of IL in a deeper way. This will be seen in Chapter Four which deals with Reflective Findings.

Here it can be said that responses from the interviews show that more dialogue is required within the CIL. Paulo Freire in his 'Pedagogy of the Oppressed' places an emphasis on change. 'The pedagogical method also encourages dialogue' (Freire, 1970, p.47). Unfortunately my research and feedback from the interviews have demonstrated a distinct lack of critical pedagogy in the area of IL which in turn has led in some situations to people being passive recipients of services and often not aware of their rights and entitlements.

2.3 Rights and Disability

Traditionally disabled people are conditioned to accept rather than demand. In addition disabled people are often unaware of their rights and entitlements and will often settle for a poor service rather than risk losing what they already receive, and in some instances, will even tolerate abuse (Age Action, 2011). I would like to consider the reasons for disabled people's reluctance to embrace the area of IL and the emerging politics of disability.

Historically disabled people have been viewed as deserving, dependent and incapable. This portrayal has been used to great effect by charities for the disabled. By portraying disabled people in this way, it provides them with a good income stream and can often influence how disabled people feel about themselves. Such an approach may also influence how disabled people feel about themselves. For the few who do complain, they are often described as ‘the crip with a chip’, in other words, ungrateful.

In order for disabled people to gain access to their human and civil rights, entitlements are of the utmost importance, as is shown by Jenny Morris. To take but one example: Morris asserts that for a disabled women to have a child is a human right, for mother and child to gain access to the cinema is a civil right and the provision of a personal assistant to enable the mother to do the things she would physically be unable to without assistance is an entitlement. (Morris, 1999, p.9)

The link to entitlements is very important as it is a key element. Without entitlements and proper resources disabled people are unlikely to access both their Human and Civil Rights. The National Disability Authority 2005 Report *‘How far towards equality’* highlights how discrimination and inequality occur in almost every aspect of a disabled person’s life. Unfortunately entitlements in the area of IL can be unfairly distributed and are dependent on a person’s location. This is often due to the piecemeal approach adopted by policy makers and its method of implementation. For example, the Disability Act 2005 provides the right for disabled people to have their needs assessed (Disability Act 2005), but fails to spell out what should then follow, i.e. implementation. Just because a person may identify as having a need does not mean that the individual will qualify for the entitlement or have those needs met. The legislation includes the term ‘reasonable and appropriate’ which means that if the Government does not consider it reasonable or appropriate, they do not have to allocate the resources. In addition many of the other recommendations in the Sectoral Plans written by government departments in response to the Disability Act 2005 have not been implemented.

There is an obvious gap in proper transport provision for disabled people, between the wish and its fulfilment. The Department for Transport outlined their sectoral plan in a document titled ‘Transport Access For All’ (Department of Transport 2006 [online]). It stressed the importance of an accessible transport system if disabled people are to participate fully in the economic and social life of the country. It outlined how all public transport services would become fully accessible and that bus and coach services would be fully accessible by 2015. Sadly disabled passengers are discriminated against and often experience barriers when travelling, as vividly described in the Irish Independent (21 Dec. 2011 [online]).

The research also highlighted an anomaly within the benefit system. Social welfare payments are paid to address some of the inequalities which disabled people experience and to encourage an element of independence. However, due to the disability benefit being means-tested, it can prevent some disabled people gaining the independence they desire.

One of the interviewees for the research related that because her partner works, she is unable to claim and is reliant on him. She said ‘it makes me feel like one of the children, a burden’ (Focus Group, 14 March 2013, p.6). Although government policies support the concept of IL, the practice does not reflect this. These issues will be explored further in Chapter 4.

2.4 The contribution of bell hooks

bell hooks commented that ‘there are as many definitions of Feminism as there are feminists’ (hooks, 1984, p.37). I also acknowledge that there are similarities between how disabled women have been treated within the disability movement and the women’s movement, and how Black women were treated within the Black people’s movement and the women’s movement. bell hooks observed that white female scholars have generally ignored the contribution of Black women. In the same chapter bell hooks writes about Josephine St. Pierre Ruffin who comments that:

> Despite the fact that white racial imperialism excluded black women from participating in groups with white women, they remained committed to the belief that women’s rights could be attained only if women joined together to present a united front. (hooks 1999, pp.160 & 164)

This approach is supported by Jane Campbell, a disabled activist, who feels that disabled people will only achieve real power by building alliances

(Campbell, 2008). However there are pockets of resistance within the ILM; some people are questioning the role and power of non-disabled people and are threatening to set up rival organisations. Others think that the ILM itself has become a gravy train (Transcription, LG, p.10).

Following on is the issue of intersectionality and its relevance within the ILM. Intersectionality is a feminist sociological theory first highlighted by Kimberle Crenshaw, and looks at the interactions which occur between overlapping categories of discrimination or oppression. Crenshaw highlights that Black women are sometimes excluded from feminist theory and antiracist policy (Crenshaw, 1989, p.140). This approach of intersectionality was addressed in a paper by Jane Campbell where she emphasises the dilemma experienced by Nasa Begum who identifies her situation as simultaneous oppression within a movement. Nasa describes the appalling treatment she received in hospital and not being sure if this is due to her being disabled or being black or being a woman. She also expresses ‘frustration with the disability movement and how race and gender are often ignored’ (Barton & Oliver, 1997, p.87).

I have to agree with Nasa. In my experience intersectionality is not on the agenda of most CILs. Intersectionality was not an issue identified during my interviews for this research. However just because it was not identified does not mean it is not an issue. I certainly feel that it is an area requiring further research.

2.5 Literature and Independent Living

All four papers highlight direct payments. Direct Payments is money, paid to individuals, to enable them to recruit personal assistance, either directly or indirectly, that is, helping them with everyday tasks to facilitate their living independently. Direct Payments has not officially been provided in Ireland. However there is a number of pilot schemes in place, and in some situations cash is paid to a third party known as the broker and then paid to the individual. Frances Hasler states in her paper in Direct Payments that ‘Direct Payments are a means to an end, that end is Independent Living’. (Hasler, 2000)

Barnes and Mercer write that:

> A central aim of the disabled people's campaign for Independent Living has been their choice and control over service support and remove some of their dependency on family and friends, with personal assistance a primary target. (Barnes and Mercer, 2010, p.146).

They provide a historic perspective of how direct payments evolved. Their paper highlights that 'Independent Living options provide significantly more benefits than conventional forms of service provision for the individual user' (Barnes & Mercer, 2010, p.146). In the same paper is a description of the benefits which direct payments can provide by, for example, allowing wider social participation and increased self-esteem and a 'greater personal responsibility' (Barnes & Mercer, 2010, p.147), so leading to improved mental health. The paper not only highlights the benefits of direct payments but also potential difficulties, 'inadequate support service for users; overly bureaucratic paperwork; and difficulties with recruiting personal assistants' (Barnes & Mercer, 2010, p.148).

Barnes and Mercer also bring out what they see as shortcomings of the development of direct payments. They state that rather than be

> a catalyst for self-determination, direct payments have their basis in consumerism, individual responsibility and enterprise. Rather than promote social justice, they potentially undermine collective service provision and encourage privatization. (Barnes and Mercer, 2010, p.146).

However I consider Barnes and Mercer's assessment of direct payments to be strange. Consumerism is one of the principal cornerstones of the Independent Living Movement. "Consumerism" means supporting the principle that it should be individuals who decide which product or service suits them. The advantage of direct payments is that it is an individual provision and tailored to meet individual needs rather than collective needs. This permits individuals to decide what time they get up, get dressed, eat and use the bathroom rather than be dependent on an institution's staff rota.

The 2 Go Direct paper looks at direct payments from an Irish perspective. Colin Barnes provided the foreword and says that direct payments:

> may include purchasing technical aids and equipment and, or more commonly, the employment of personal assistants to do the things they are unable to do for themselves due to the effects of their impairment. (Egan, 2005, p.4)

This supports the ‘consumerism’ concept which Barnes and Mercer described in 2010 (Exploring Disability Second Edition p.149), even though they also went on to report the danger of direct service payments potentially undermining collective service provision and encouraging privatisation. I think the balance which must be found will come only from dialogue.

The paper emphasises the fact that in Ireland direct payments are not formalised, for example showing that a small number of people have an informal arrangement where the Health Service Executive (HSE) pays money for the employment of personal assistance. However because Ireland does not have direct payment legislation, the majority of disabled people cannot avail of this option and are at the mercy of a HSE manager to decide if they are indeed deserving.

Egan goes on to list the various direct payments employment models which are used in other countries. I am confused as to why he includes the ‘self-employed model’ which is unlikely to be accepted by Irish policy on taxation grounds. Although he provides options of employment models, he does not list some of the difficulties which can arise from choosing them, such as difficulties recruiting suitable staff, management skills and budgeting.

He gives a very good overview of where direct payments are implemented, the reason for disabled people choosing the system of direct payments, and what disabled people hope to gain. The paper also gives instances and possible reasons for disabled people not considering direct payments along with the benefits, for example, lack of accessible information, an over-bureaucratic process and difficulties recruiting staff. Although Egan describes the role of a personal assistant (PA) he does not, however, separate out the difference between a home help and PA. Nevertheless his paper provides an excellent brief introduction to IL, stating that:

> Independent Living is a philosophy and lifestyle choice which enables people with disabilities to make and implement decisions about how they wish to live their lives. (Egan, 2005, p.11)

Egan provides two very interesting case studies for the reader to consider (Egan, 2005, p.13), and which I would like to comment on.

a) Damien O'Reilly’s situation was very complex and he had to overcome numerous barriers. He appears to be extremely resourceful and capable of dealing with huge challenges. However in my opinion it is unclear if a disabled person with less determination and knowledge would have been able successfully to implement a direct payment scheme. It is also unclear how he was able to address the deficit in assessment hours from his assessment of 112 hours, and the 40 hours actually awarded by the HSE.

B) John Dwyer was awarded a considerable amount of hours. He seems to be very creative in how he uses his hours and the methods used for recruiting his PAs. John seems to be in a fortunate position to be able to take ‘a sun holiday’, but also explains the additional costs he personally incurs as a result. He also explains some of the disadvantages of participating in a PA scheme. However no explanation is given as to why he receives so many hours, is there an urban-rural issue? I also wanted to know why the HSE had to pay Cheshire - who would then pay him? What was the need for a broker, and did Cheshire receive a payment for this role? Is it a way for the HSE to perpetuate the ‘adult child relationship’?

Egan identifies that a ‘Personal Assistance Act’ is required if direct payments are to become a reality. He also states ‘that personal assistance is part of social policy rather than health policy’ (Egan, 2005, p.20). Egan demonstrated the benefits of not only promoting Independent Living but the recognition that without direct payments, Independent Living is not possible.

It is sad that five years on from Egan’s paper, legislation regarding the rights to Independent Living and to access direct payments have still not been implemented. The implementation of this legislation would not only save the taxpayer money but empower disabled people to live a fully inclusive life. This point was made by two interviewees (PM; JC). PM said:

> On the broad perspective, if government viewed money spent on disability as an investment rather than a cost, they would discover many more people with disabilities would become tax-paying productive members of society. (Transcript, PM, p.1)

This point was echoed in my interview with DC:

> It’s public money, so what’s the accountability on the individual to spend the public money? Umm, but that’s not only for people with disability. When you give people money because they’re on the dole for example, sometimes there’s comments about oh they bought a big TV, but they’re not buying food, or not the food we would choose for them to eat. So, so what is the community’s feeling about how public money should be spent? How we spend the money that we raise in our taxes and give to people? So that spreads across over all of the social welfare payments, not just disability. (Transcript, DC, p.7)

2.6 Concluding thoughts on literature review

The survey I have undertaken of the four main pieces of writing and supporting literature points out the way in which society would benefit by bringing the views and concerns of disabled people into a two-way dialogue. The alliances which can be made between the varying groups experiencing discrimination work on both the human and civil level. Everyone wins. All gain.

It was to this end that I decided to use a participatory method of research, in the hope and expectation that a co-operative rather than a positivist and factual analysis which is based on something no more than a poll, would enable me to come to conclusions benefitting the ILM. The following chapter on Methodology will spell out how this was done.

CHAPTER THREE: METHODOLOGY

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3.1 Overview

In the previous chapter I outlined some key literature and considered its relevance to the research question. This research is based on the responses gathered through a focus group and twelve individual interviews, and is centred on the responses of the people interviewed, both as recipients of IL and also administrators of IL. I am taking a critical approach to demonstrate some of the difficulties the ILM has to address. Having explained the background of my research in the previous chapter, I will explain the methodological approach I employed within this one.

3.2 Research Question

The aim of the research is to explore the role and importance that Independent Living (IL) has in the lives of disabled people.

My research aims to provide an insight into the experiences of people involved with the Independent Living movement. I adapted my approach when conducting interviews with both the focus group and directing the individual interviews. In the focus group I would pose a question and wait for a response. I encouraged all the members of the focus group to engage with the process. As a consequence group members often asked follow up questions, leaving me to facilitate the process. The resulted in group members asking questions or challenging what had been said. The approach adopted in the individual interviews was somewhat different in that I tended to ask the same question of each person and facilitate the response. Although some people gave the same response very often interviewees would respond in a different way.

3.3 Research Methods

I wanted to use a research methodology which would enable me to hear directly from people engaged in the IL provision either as a recipient or provider. Prior to conducting the research I thought about the research method I could adopt. The options seemed to be two in number, the quantitative and qualitative methods.

3.3.1 Quantitative Research Method and Independent Living

I first considered employing a quantitative research method. Quantitative research is often used in surveys and questionnaires. It has the advantage of being able to be anonymous and data can be converted into numbers to produce statistical data (Palgrave Study Skills 2013 [online]). I was unsure given the nature of my research and target group if quantitative research would provide me with the information I sought. Quantitative research methods would have allowed me to quantify and see how prevalent the response was, whereas qualitative engages participants through individual interviews or focus groups (Palgrave Study Skills 2013 [online]).

3.3.2 Qualitative Research Method and Independent Living

In the end I selected the qualitative research method because it offered me the opportunity to engage with my interviewees, something which I judged to be essential given the sensitive nature of the research identified. I also felt the direct communication nature of the interviews would enhance my own knowledge of the subject and provide direction for the research. Lastly I wanted my interviewees to have a sense of ownership and identity with the research process, something which I consider the qualitative method alone gave, precisely because they were offered the chance to become participants. (Freire, 1970, p.47)

Qualitative research focuses on who is listening as well as who is speaking. It engages both the researcher and those being researched. In order for the qualitative research process to work there has to be an interaction between the interviewer and the interviewee so as to gain a true insight into the experience of the individual. A crucial element in this process is actively to listen to the interviewee and take on board what is being said. By doing this it provides a greater opportunity for the research to reflect a more realistic account of the situation. Personally it was important to show respect to my interviewees even when their opinion differed from my own. This reflection of a wide variety of opinions enables the research to gain validity and is more likely to deliver change.

I found qualitative research essential for conducting my research as I needed to hear from people who are directly connected with IL. Without their input I would have been unable to have a true understanding of what life is like for people availing of IL. As a non-PA user it is next to impossible to imagine what life is like in not having choice and control over how you live your life. Conducting my research in this way allowed me and others who may read my research a deeper understanding as offered from the people directly affected.

3.4 The use of Participative Action Research

Having chosen to go the qualitative route, I adopted Participative Action Research (PAR) as the main method for gathering information from the interviewees. PAR is a way of collecting data which reflects the experiences of people most directly affected by issues in their communities. I employed PAR because there is a shortage of data available from the perspective of the people directly engaged in IL. PAR enables people to freely contribute to the issue and reflect on issues which may arise before taking action when required. It has been used by movements for change and gathering information on a particular issue. PAR offered me the opportunity to understand the personal experiences through the interviews with people connected with IL.

Conscious of the various hats I wear (as a disability activist, an educator in disabled studies, and a disabled person myself), I felt it was necessary to use an approach which was sufficiently flexible to allow for varying responses from those interviewed, and which could even alter the direction the questioning took. At times in the interviews, the reaction was sometimes quite unexpected, and the conclusions I thought might emerge were contradicted.

While there is a range of definitions connected to PAR, I consider the following provide a clear understanding of PAR and are in line with the approach used in this research. Although these definitions were used in the area of public health, they could be adapted for the use in IL.

> Community-based participatory research (CBPR) (in health) is a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community (health)… (W.K. Kellog Foundation, Community Health Scholars Program, 2001, quoted in Minkler and Wallerstein, 2003: 4 p.1)
>
> Participatory research is defined as systematic inquiry, with the collaboration of those affected by the issue being studied, for purposes

> of education and taking action or effecting change. (College of Natural Resources, 2013 [on-line])

Both these definitions are similar in that they are about partnership, collaboration and action. This is the approach taken within this research. I identified a research topic, consulted with relevant parties, facilitated discussion, included a wide range of input, encouraged discussion and used the findings of the research to influence change or to help me to discover the best ways to bring about change in this area.

The basic principles of PAR are that we are experts in our own experiences and recognise that there are different ways of knowing and getting information. PAR develops the control, gathering and use of information. It assists with deciding what information is needed to make the changes people want and how they may get it. It encourages people to decide what questions they need to answer and how. It also encourages the involvement of people in all aspects of the design and implementation of the research, and the analysis and distribution of the information gathered. PAR helps with the gathering of information to direct their actions for change. It also encourages people to reflect on the actions which they have taken and then decide if further action is required. All in all, it is very much an assertive response to research, to help build the community/movement that in turn encourages leadership, empowerment and change. ‘We want to learn more about ourselves and our communities as a way to make change’. (Incite. PAR [online])

I had to personally consider my own approach to PAR whilst trying to identify an area to research for this course. The area I originally identified was the link between poverty and disability. It was my intention to explore the additional costs incurred by disabled people living independently as a result of having their impairment. Unfortunately I was assuming, without real discussion, the type of research disabled people required and I was attempting to impose my ideas. However after studying PAR, I now realise that I had been conditioned to approach research in a non-PAR way, that is, I had identified my area to be researched by using the same method I would have previously used when purchasing a laptop, an iron or booking a holiday. Fortunately I was able to identify that this approach was completely wrong and implement a correct PAR process. I have numerous examples where, on paper, organisations indicate that people have been consulted but in practice it has not happened or has turned into a tick box process. For example a disabled woman I work with attends a day provision for adults with intellectual disabilities. The staff at the centre she attends holds a six monthly meeting where they ask if there is anything she would like changed in her programme. When she identifies activities she would like, they say it's not possible and to come back when she thinks of something else. For the staff concerned it's a tick box process but for the individual it's yet another thing she has had rejected. Consequently the people who use the service play bowls every Friday. For this privilege the private operator is paid €75 per session for what I see as a containment process or what is sometimes referred by people using the service as adult babysitting.

3.5 Choosing the Target Groups

I deliberately identified people who would be representative of the people involved in the ILM. This included people with different impairments, mixed age and an equal gender mix. It also included disabled people who were born with their impairments and those that had acquired them. This ensured the research had input from people with a variety of experiences. Again this was done in order that the qualitative research might give a true reflection of the people whose lives are affected by this research.

From the outset I decided to confine myself to people living or working within the ILM, partly because of having to establish workable parameters, but also because the status quo is one where IL is not the norm, and the arguments for institutionalisation are much better known. In this regard, it is interesting that JC, to whom I referred above, commented in her interview that there had to be a period where disabled people got together as a group, in order to analyse and investigate matters for themselves. This is the stage at which I judge us effectively to be, in trying to bring about changes.

Collins (Collins,P. [on-line]) herself makes the effective point that having a sense of self-value (and I think that can apply to a group, as well as to an individual), and a stable self-definition not obtained from outside influences, helps overcome oppressive societal methods of domination. Drawing on her thinking and using PAR as a qualitative tool, I would wish to explore an alternative epistemology which a) is built on the lived experiences of groups of disabled people with the ILM b) uses dialogue for evaluation rather than adversarial debate, allowing the author (myself) a centrality which excluded in a positivist approach) c) allows for a holistic acceptance of empathy and compassion, and can include my own experiences as part of the dialogue and d) makes both parties accountable in the sense of allocating responsibility.

For that reason I decided my research paradigm would be confined to those living and working within the ILM, though also aiming to broaden its conclusions to the ultimate benefit of all disabled people. Neither does my thesis deny the obvious intersectionality with other oppressed groups, be they feminist, lesbian/gay/transsexual, black people etc: it aims to draw conclusions from within the study which are also valid for all these various groupings. To the best of my knowledge, this would be the first time that a disabled person addresses the issue of IL from within the lived experience of the Irish IL itself.

It was important that the views of disabled women were included within my research. The ILM is generally dominated by the voice of disabled men as is the disability movement. It was notable that during the interviews that for the most part, the feminist issue was ignored. I feel that the ILM is a reflection of general society where feminist issues tend also to be overlooked. It should be noted that my own journey in the area of disability activism was heavily influenced by very active and prominent disabled feminists. I know that the input received from these disabled women played a big part in my own liberation and led to my adoption of the social model of disability. It therefore comes as a surprise to me that in the thirty years since my own liberation, feminism and disability have not been pushed further up the agenda. I recognise that disability and sexism are both social constructs based on physical characteristics. bell hooks commented that ‘there are as many definitions of Feminism as there are feminists’ (hooks 1984, p.37). I also acknowledge that there are similarities between the way disabled women have been treated within the disability movement and the women’s movement, and the way Black women were treated within the Black people’s movement and women’s movement.

bell hooks noted that white female scholars have generally ignored the contribution of Black women. I found that disabled feminists had a similar experience. Sojourner Truth stated, ‘that not only women of colour are overlooked but their exclusion is reinforced when white women speak for and as women’ (hooks 1984, p.37). Jenny Morris, who is a feminist and disability researcher, stated that ‘gender has generally been omitted from traditional disability research’ (Morris, 1993b). Morris goes on to explain within the same paper that ‘unless gender distinctions are dealt with as a matter of urgency, the oppression encountered by disabled women will be compounded and our powerless position will be exacerbated’.

However Jenny Morris’s views are not shared by all. During my interview with Jane Campbell, a leading disability rights campaigner, she stressed the importance of building alliances with other oppressed groups. Campbell goes on to state:

> We needed to evolve the same way as the women’s movement, so we needed an opportunity, and we needed a period of separatism in order to find out who the bloody hell we were as human beings and as disabled people. And once we’d realised that, and once we’d developed the social model and the training courses etc., once we’d got the power away from all those who spoke on our behalf and decided what we wanted, then we could, it was important to move forward and create alliances and make our contribution to the history of oppression. And that’s where we’re still struggling. (Transcript, JC, p.10)

However although I agree fundamentally with the essence of Campbell’s statement, it must be highlighted that her views are biased towards a UK agenda where equality legislation is far stronger than in Ireland. The National Disability Authority commissioned a report in 2006 highlighting the discrimination experienced by disabled women. The report provided evidence that disabled women were at higher risk of poverty, being attacked, being without paid employment and acquiring a mental health related condition (NDA 2006, pp.11-13). Kimberle Crenshaw stated that ‘white is the perceived norm’ and there was no need to justify or quantify who they are. This issue was further expanded on by Crenshaw’s paper on ‘Demarginalizing the intersection of race and sex’ (Crenshaw, K. 1989). Consequently Black women felt excluded from both the women’s movement and black people’s movement.

I feel this is true within the ILM, as evidenced by the absence of the mention of feminism. Likewise non-disabled feminists have been accused of failing to address the concerns of disabled women and ‘sometimes actively excluding them from participating in feminist events’ (Thomas, C., 1999, p.66). It is as though disabled women do not exist. Jenny Morris stated that when non-disabled feminists do highlight disabled women, it often seems to focus on their double disadvantage (Morris 1998, p.5). Jenny Morris refers to non-disabled women tending to ignore the barriers created by society and maintains that ‘disability and old age should be added onto existing feminist theory’ (Morris 1991, p.8). She also feels that very often disabled women are seen as passive victims of oppression.

Crenshaw also wrote that Black women felt excluded from feminist theory and anti-racist policy because it often did not reflect the interaction of race and gender. She argued that ‘any analysis which does not take intersectionality into account cannot sufficiently address the particular manner in which Black women are subordinated’. It is Crenshaw’s belief that the women’s movement has a tendency to ‘treat race and gender as mutually exclusive categories of experience and analysis’ (Crenshaw 1989, pp.139-140).

I have interpreted Crenshaw’s Intersectionality in this example as recognising the experience of Black women as whole, rather than treating it as a situation of double discrimination. There are also issues connected with the ‘body perfect’ within the women’s movement and the gay, lesbian and transgender movement that exclude a wide section of disabled people and people whose bodies are not deemed as being acceptable **(O’Keefe???????). I will return to some of the issues of intersectionality in Chapter four.

I was fortunate that my experience and activism in the disability movement enabled me to gain the respect of my interviewees and produce an open and honest dialogue. I have been a disability activist for thirty five years and have delivered training courses throughout the country. In addition I have specifically delivered leader training and PA training. These courses are very well respected and consequently I have built a reputation within the ILM for being knowledgeable and innovative.

My reputation assisted me greatly when requesting interviews. Ordinarily lots of people involved in IL are suspicious of people asking questions. This could be because they are scared that their PA hours will be cut as a result of saying the wrong thing or that they may not see how their participation will assist them or the ILM. It usually takes time for people to give an honest opinion. But because the interviewees respected the work I was involved in, and because of my direct experience of disability, it was generally easy for people to open up and say what they thought. It is important that this relationship exists in order for the interviewee to have control rather than feel they are being controlled (Gumba and Lincoln, 1994, p.175 [on-line]).

3.6 The Research Process

The process began with gathering thirteen people together to participate in a focus group. I than invited an additional twelve people to participate in individual interviews. A focus group could be defined as:

> a group of interacting individuals having some common interest or characteristics, brought together by a moderator, who uses the group and its interaction as a way to gain information about a specific or focused issue (Marczak, M & Sewell, M [on-line]).

Focus group participants were selected because they were all involved in IL either as a leader or a PA or as an IL administrator. I encouraged discussion and ensured that everyone had the opportunity to participate equally.

The group met on two occasions. I planned this because I knew that some of the group participants were new to IL and that they might require more time to express what they felt. I was fortunate that I was familiar to all of the participants in the focus group. All members of the focus group also knew each other. This was very beneficial because trust and respect was evident among all group members. That this happened is supported by commentary in the transcripts and the open and honest discussions which people had, thus enabling me to have an excellent insight into how people in the focus group were experiencing IL. The feedback in the focus group benefited from the fact that I am an experienced and trained group facilitator and that I am familiar with many of the issues which the participants addressed.

The makeup of the focus group was comprised of seven disabled people, four wheelchair users, two people with a visual impairment, two people with a hearing impairment, four Personal Assistants and two Independent Living administrators.

The focus group enabled me to get a collective view. It included people who were experienced in IL and people who were relatively new to the concept of IL. I conducted the focus group interviews prior to my series of individual interviews and so the focus group helped raise my consciousness of the issues experienced by people involved with IL. The group also raised themes during the session which I had not thought about prior to meeting with them. These themes will be explored in Chapter four in the findings. The makeup of the individual interviewees was ten Leaders and two PA Administrators.

The people interviewed were very experienced with IL. As reflected in the transcripts they were able to bring a wealth of knowledge to the research. I knew four of the interviewees through being an activist and educationist in the ILM. The remaining four came from recommendations from people I interviewed. The interviews allowed me to research IL in depth and discover how individuals interpret IL. This was extremely useful because a number of the interviewees' approach to the development differs from my own. I also felt that given the experience and the position some of the interviewees have in the ILM, other people would be inclined to withdraw if they had been included in the focus group. The data gained from the interviews were very beneficial and will be addressed in the findings in Chapter 4.

The questions in the focus group were designed to engage people within the group and to explore issues they had experienced with IL. The focus group met on two occasions. Each session lasted an hour and a half. Because some group members were new to IL, I felt it was important to meet the group twice. By doing this I could ensure that everyone had an opportunity to speak. Since I was implementing PAR, I wanted to keep my own input and interruptions to a minimum, and so limited the questions to the minimum and used the technique of active listening to get the maximum input from the group participants. The questions I asked were:

- Can you outline the benefits you gain from IL?
- In what way is IL understood by people?
- In what way do you think your impairment adds additional costs to the way you live your life?

- How does your impairment affect your daily life?

I used the same format of questions during the second time the focus group met and asked follow-up questions if required. Delivering two focus group sessions was very useful as it permitted people to expand on what they said, and those who were perhaps scared to speak during the first session felt more confident and participated to a greater extent during the second session.

The questions for the individual interviews were designed to provide a general insight into IL, and to elicit from people actively involved in the ILM what they considered the new challenges to be. The questions I asked during the interviews were:

- What does IL mean to you?
- How did you become involved in wanting IL?
- What is the philosophy of IL and it what way do you feel it has changed?
- What are the future challenges for IL and is there any specific issue you want this research to highlight?

The questions provided me with the data I required and comments made challenged my own views and opinion regarding IL. I found the interviews useful because it provided a forum for interviewees to give their own point of view and also gave me the opportunity to ask interviewees to expand on what they highlighted. Due to the relationship I had with the majority of interviewees, the interviews were conducted in a very relaxed and informal way.

I wanted to explore their interpretation of Independent Living, who influenced their decision and what they considered were its future challenges,

After each interview, the tape was transcribed. Because I was conscious of my close connection with IL, I asked a person unconnected with the IL or the individuals involved with the interviews to read through the transcripts and highlight any key issues that stood out. I then compared the findings with the information I had extracted to ensure I was not biased in my approach.

3.7 Ethical Aspects

I took the ethical considerations of the research very seriously. There were many ethical issues to contemplate as part of the qualitative research process. I first ensured that potential research participants were told what the purpose of my research was, what was required of them, how long the interview process would take and that they would be able to withdraw from the interview process at any time. I also informed them that I would provide them with a copy of their transcript and they could make any changes or delete information they wanted to withhold. I also wanted to ensure that I was being true to what had been said. Once they had agreed to be interviewed I emailed the information sheet containing information regarding the aim of the research and interview process along with the consent form (see Appendix 1). At the beginning of the interviews I repeated the research topic, its aims and its likely benefit to the interviewee and the ILM. I also explained that the interview would be audio-recorded if they gave permission. At the end of the interview I asked if they had any further questions and explained how the data would be used. I also notified them that they should contact me if they required any information and that my contact details were on the information sheet which I had sent to them.

Confidentiality and anonymity were issues I addressed as part of the interview process. I assured all participants that the issue of confidentiality and anonymity would be respected and took care to ensure that all the audio recordings and transcriptions were kept in a locked filing cabinet. Last of all it was essential that the interviewees had trust at all stages of the process in order for the research to be emancipatory, thus encouraging participants to be open and honest. I did my best to be equally open and honest, and provided opportunities for the interviewees to influence the direction they wished the interview to go.

3.8 Implications and Consequences of this research

Despite being personally involved in the ILM, I had to make sure that my approach to interviewing was a readiness to accept all responses, insofar as I could. It was paramount that I made known my own background and interests at all times, and to be prepared to alter the direction and flow of the interaction, either with the Focus Group or with individual interviewees. It also influenced the choice of questions that I made, questions which were formed not only from my own experiences but also from the CEESA course I was following, and the literature that I studied.

In the light of what I had prepared, therefore, I undertook the sometimes lengthy process of dialogue with the group and individuals. The findings from that process have been put into the following chapter, Reflective Findings. I hope that the end result will be of use not only to the ILM but also to the wider community, disabled and non-disabled.

CHAPTER FOUR: REFLECTIVE FINDINGS

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4.1 Introduction

I conducted research which explores the role and importance that Independent Living (IL) has in the lives of disabled people. This chapter provides the responses from the people I interviewed. The findings offer the responses given during the qualitative research process which was employed with a view to enabling the various people involved with IL to have their voices heard. The data gathered was from the perspective of both the Leaders, PAs and administrators of Independent Living.

From the data, I will provide feedback on IL which is a subject that is not always given a forum. IL is in the process of change. The issues of direct payments, cuts to social hours and the role and function of CIL are just a few of the concerns identified. I am adopting a critical approach to pedagogy to highlight the limitations in terms of the future direction of IL. This research allowed interviewees to reflect on IL and their role within the ILM. Critical reflection is essential if oppressed groups are to act and change their situation (Freire, 1970, p.48). The response from the interviews reveals a less complacent approach is required for the future direction of the provision of IL in Ireland.

This chapter will highlight common issues which came from both the focus group and the individual interviews. I will consider the findings from the focus group and then from the individual interviews, and at the same time offer my own assessments, which will conclude with a summary analysis.

4.2 Findings from the research – The Focus Group

The findings contained within this research are taken from interviews conducted with a Focus Group. I invited thirteen people to participate in a focus group. A focus group is a group of people that have been brought together to discuss an issue with which they have a connection. All those invited were people involved with IL either as a leader, PA or an administrator. The group met for two one and a half hour sessions which I facilitated. The role and purpose of the focus group was explored in Chapter 3 Research Methodology. The makeup of the focus group was comprised of 13 in all, breaking down to: seven disabled people, of whom four were wheelchair users, two people with a visual impairment and one with both a physical impairment and a hearing impairment; four PAs and two Administrators.

Two participants in the group had acquired their impairment. This is an important factor especially in the area of IL. Unlike people born with their impairment, people who acquire their impairment may have a memory of when they were not faced with the barriers they now experience as disabled people. As a result they may connect with the injustice of not being able to participate in life as they did previously. Generally people in these situations are more willing to speak up and challenge what they see as the unfairness of the situation.

I facilitated both group sessions and asked the interviewees their opinion on the benefits they gain from IL and in what way it was understood. I also asked if they experienced additional costs as a result of their impairment and how their impairment might impact on their daily lives.

These questions were asked because there seems to be a range of opinions as to the benefits of IL and the way in which people interpret what IL is. I also asked about the additional cost and impact of their impairment because I have an interest in this topic. Due to my IL activism I wanted to get greater clarity of how costs and the impact of various impairments can affect a person’s life in an IL context. From these questions common themes emerged. I will now highlight the key themes from the focus group along with a sample of some of the comments which participants made.

The themes that will be discussed in the reflective findings are as follows:

- Choice and Control
- Understanding of Independent Living
- Transport and Related Costs

- Impracticalities of some Means Testing and Allocation of Resources
- Barriers experienced by people with visual impairment
- Failure to plan for accessibility

4.2.1 Choice and Control

IL enables people to have choice and control in their lives. It allows people to live on their own, do their shopping, cook and do things independently of family and friends. People are able to come and go as they want and not have their life be dictated to, by others or institutions.

> I don't feel like every time I contact my family that it's for them to do something for me. I feel more equal to my brother and sister that way. (Transcript 7th March 2013, p.1)

IL provides people with the autonomy to choose how they live their lives. Properly resourced IL can enable disabled people to be a husband, a wife, a brother, a sister, son or daughter, and a friend on equal terms. It also changes the power dynamic which may happen if you are perceived as needy or incapable. One of the group, a person with a visual impairment, commented that due to the small number of hours he receives, that if he chose to leave home and live on his own**,** then he was at risk at losing his social skills because the PA hours which he uses for social integration would be absorbed into managing his personal needs. The social activities he participates in are vitally important because he went to residential school for the visually impaired. This means that he knows very few people in his home town, and so having the chance to socialise and mix with people outside his family is crucial.

> I think for me, it just means that I can use the PA to do things, rather than the family all the time. I can decide that if I want to go away somewhere or do something and the family don't want to do it.
> When I go to the gym there is always somebody there, so I'm not always trying to suit someone else. I can just suit me, or I can change things. I can use it the way I want it, rather than someone saying, we're doing this every Saturday, and this every Monday or whatever. (Transcript 14 March 2013, p.1)

Regretfully without a PA helping to facilitate social inclusion in this manner it could mean the person remaining in his or her own home staring at the four walls. This issue is supported by research conducted by the National Disability Authority (NDA) which highlighted that disabled people were over twice less likely to go out than their non-disabled peers (NDA, 2005). I asked the interviewee if he had considered using a volunteer to help meet the hours he required to participate in social activities. His reply was that the dynamic would be different because with a PA he had control, whereas with a volunteer he'd be at the mercy of their goodwill.

A number of interviewees stressed that the role of a PA was different from that of a carer.

> To be independent is to be able to live your life the way that you want to, and it's much much more than just being cared for. Yeah. You know when you think of being cared for, you just think about being taken out of bed and put in a chair, and helped to do that. But independent living is much more than that. (Transcript 14th March 2013, p.2)

There is often confusion by people outside the ILM about the difference between a Carer and a PA, as many outside the ILM consider them to be the same thing. This confusion is added to because many of the private care providers have adopted language and terminology taken from the ILM. Unlike a carer a PA is employed to facilitate the wishes of the Leader rather than the profit-making care organisation they are employed by. The PA only takes instructions from the Leader and their relationship is based on trust. They report solely to the Leader. Any information regarding the Leader is confidential and not viewed by others, unless instructed by the Leader to do so. The tasks of the PA are defined by the Leader and are tailored to meet their specific requirements. Finally the duties of the PA are designed and managed by the Leader directly and not determined by an outside agency or organisation.

4.2.2 Understanding of Independent Living

A constant theme raised during interviews with the focus group was that participants felt IL was misunderstood especially by the people who conducted the assessment of people's needs. The assessors assess people for the purposes of allocating the time they consider necessary for personal needs. However, little consideration is given for those who have deteriorating conditions or that conditions which can change from day to day. A time and motion approach is being adopted to assess the needs of the disabled person. This then places undue pressure and stress on the Leader, PA, and where applicable, the person's carer.

Cuts to PA services have meant that social hours which had previously been allocated have been withdrawn. People are only assessed for their health care needs which mean that hours designated for social care provision have been withdrawn. This has resulted in some people, like the person highlighted above, choosing to use some of their personal care allocation to go shopping, to go to the gym or to the hairdressers. Throughout the interview group participants stressed the importance of social activities. Participants stated that it helped them feel part of society and part of their community. This also gives the community a chance to engage with them and challenge myths and ignorance. One case that springs to mind is what happened to Fiona Pilkington (Mail online, 18 Sept. 2011). The alternative for some is to stay inside their home and not engage with anyone apart from their PA.

Everyone interviewed felt that the situation had got more difficult since austerity measures were introduced. One group member had been assessed for twelve and allocated two hours.

> I have only recently started living on my own, not through choice, it sort of just happened. I don't think I actually would have ever moved out of home, but I am there on my own now anyway. Independent Living just gives me the power and independence to be able to do the things that I wouldn't be able to do without the help of a PA. Essential things like food shopping and washing, and essential things. (Transcript 7 March 2013, p.3)
>
> I would find the HSE up here in Donegal very knowledgeable about the Independent Living movement, but I think their hands are tied by the hierarchy. They are being told, there's a task allocation sheet to go out and assess somebody, so it might be that they have half an hour to get up, washed and dressed. That's not independent living at all, and that's the difficulty now since the austerity measures came in. I think locally, people are knowledgeable about the Independent Living movement but nationally I don't think they are at all. (Transcript 7 March 2013, p.4)

Another group member questioned if during the Celtic tiger money had been distributed fairly.

> You'd imagine that, take Cheshire apartments, where there's how many, twelve apartments here, twelve apartments for the whole of Donegal. That's what came out of the Celtic tiger for Donegal. (Transcript 7 March 2013, p.4)

Confusion exists not only from the general public point of view but also from the political as to what IL is and the difference it can make to people's lives. IL is a much cheaper alternative than institutional care or hospitalisation and these benefits need to be promoted and publicised.

4.2.3 Transport and Related Costs

People highlighted transport as being a major cost factor especially living in a rural county like Donegal. They were concerned about the impact of the cut to the motorised transport grant. Without transport people would be unable to get further education or seek employment. A number of the group members live in Inishowen in County Donegal, an area with a population of nearly 40,000.

Public transport is provided by the Northwest Bus Company (NWB), the Lough Swilly Bus Service (LS). The Inishowen Rural Transport Scheme (IRT) provides an auxiliary service for those in areas not served by the two main bus companies. Due to recent cuts the IRT has itself been constrained in the hours it can offer. Unfortunately they only offer a very limited service offering two bus journeys per day to Derry or Letterkenny, the main urban areas. Again this highlights the fact that a real rural-urban divide operates.

None of the main buses, NWB and LS, is wheelchair accessible and this obviously restricts where people with reduced mobility can go. Even when a bus is accessible (IRT), there can be problems, as accessibility itself can be limited.

To give an example: as part of my work with a cross border group I tried to organise a trip from Strabane into Derry as part of the City of Culture celebrations. Although the Translink Bus Company (operating in the North) has an accessible bus, the rules state that only one wheelchair user can travel at a time, and that the bus must be booked 24 hours in advance. Because the group has three members who use wheelchairs, the planned trip to Derry had to be cancelled. The alternative would have meant hiring a separate coach, and would have been an impossible cost for the group. Having to book 24 hours in advance prevents people being from being spontaneous, something most can take for granted.

> It just affects… It just means that I can't make any last minute decisions. I have to plan my journeys ahead and I have to arrange a lift, either a lift or a taxi. A lot of places that I would go in a taxi, there's no point in getting a taxi anyway because I need someone with me. It holds me back a lot. I don't get to do a lot of things I want to do
> I need to plan it all. I don't really have a night-time social life because of that. I've just never had that because it's just too awkward, and it takes too much planning and hassle. I do get places, so I'm lucky in some ways but I don't have a social life as such, going out to nightclubs and pubs and stuff. (Transcript 14 March 2013, p.8)

Responding to this lack of accessible transport, lots of charities like the Irish Wheelchair Association, The Multiple Sclerosis Association and Muscular Dystrophy Ireland purchase and operate their own coaches. Although this meets the need of their members, for large periods of time it can result in buses lying unused. Despite attempts being made in the past by People with Disabilities Ireland (PWDI) in Donegal to have a transport sharing scheme, none of the groups involved could agree. It appears that the organisations concerned would like to maintain their autonomy and, frankly, justify their existence. It is also a way for some groups to maintain power.

Another person was concerned that due to her deteriorating condition, she had to purchase alternative medication which was costing her €100 per month. Still other people mentioned the cost of equipment which is not covered by the HSE.

> Even to go to the shop for example. A non-disabled person can just jump in her car and go to the shops. For me to go to the shops on my own, I need to take my scooter that I have paid for. I need to put it in the car, and I can't physically put it in the car, so I need to use a lift, which I had to buy as well. Then do the opposite on the way back. So there's quite a bit of extra cost associated with being disabled. (Transcript 7 March 2013, p.6)

It was highlighted by one person who had lost both her parents in the past two years and who now lives on her own, how the allocation of a power chair by the HSE did not improve her access. She expressed her frustration at being unable to access the bus service or taxi service because it was not wheelchair friendly. As she comes from a travelling distance of 25 minutes outside Letterkenny, in a rural setting, she can only make use of the power chair to travel around the country lanes where she lives, and is unable to benefit from the allocation of the chair. She would need to have changes made to the current transport provision or to be able to purchase her own accessible van for this expensive piece of equipment to be of any benefit. A power wheelchair can cost between €2500 - €7000. There appears to be a lack of joined-up thinking. Why are funds used to provide equipment which a person is unable to benefit from without other resources being in place?

There was also the case of the interviewee who couldn’t use her chair because she was unable to drive and therefore unable to transport her power chair to where she wanted to go. No wheelchair accessible transport operated where she lives. She is therefore reliant on her PA or family or friends to push her to the places she wants to visit. Her power chair would give her major freedom and independence, but with no accessible transport and recent cuts to the adapted vehicle grant, meant that her freedom is restricted.

> I have a power chair but I can’t transport it anywhere. I had it for college, but if wanted to go away for a weekend or something it would be great. It would give me more independence but I can’t transport it and I have no one to push it. (Transcript, 7 March 2013, p.7)
>
> I get a lot of taxis because of where I live because there is no public transport. I depend either on taxis or my PA, and either way I pay. A taxi to Letterkenny costs about €45 euros. (Transcript, 7 March 2013, p.7)

The cost of using equipment came at a price. People with restricted mobility were allocated power chairs. However to make use of the equipment the battery to operate the chair had to be charged for twelve hours, which was an additional cost from a person’s allowance.

A PA in the group also expressed her outrage at how some service providers could try to exploit disabled people. She recounted a story about a taxi company:

> I got a taxi in Letterkenny, which advertised all local runs for 5 euros. Myself and my leader went down the town at Christmas and it was 14 euros return. I disputed it and said that that was discrimination, and that

> we should only pay 10. He said it's because I've to get out and take down the ramps and da da da. I put up a fuss and I got it for 10. I told him I would be taking this further. A large number of the group had bus pass…….
> Probably most of us here have the bus pass, but we can't use it if there is no accessible transport. (Transcript, 7 March 2013, p.11)

Even when an accessible taxi operates in an area, some people are reluctant to go out in case they can't get home or are charged a levy simply for being a wheelchair passenger in that taxi. Another person in the group who only has one arm and uses a wheelchair expressed his frustration at the inflexibility of the transport service.

> I got a bus pass for me, just for myself, so I can't take someone with me. I don't know how that's supposed to work. (Transcript, 7 March 2013, p.11)

It would be reasonable that a PA should be able to travel free with his or her Leader. Other group members had to purchase a trailer specifically to transport their power chair, in order for them to make use of it.

4.2.4 Impracticalities of some means testing and allocation of resources

Participants also objected to the way in which disability benefits are means tested. They said that the provision of benefit was an acknowledgement that society was unequal and that the benefit acted as a way of trying to address some of this inequality which existed. However the means test meant that some people in the group did not qualify due to a partner's income and therefore became a burden.

> One of the things that I object to is because I am married, in order for me to get a disability benefit, it depends on my husband's salary. For a good while I didn't qualify for a disability benefit, so I was a dependent of his, the same way that the children are dependents of his, and I don't think that's fair at all. (Transcript 7 March 2013, p.6)

I acknowledge that we are in a time of austerity. Nevertheless means-testing benefits which are meant to challenge address inequality only seem to direct people to becoming more dependent.

A situation was also reported in the focus group where a couple who had been married for over twenty five years required an adapted bed which would enable his wife to sit up and be able to transfer to her wheelchair. The HSE would only fund the purchase of a single bed. Her husband offered to pay the difference in order to buy a double bed, but the HSE denied the request saying that they could only purchase a single bed.

> The HSE would provide that profiling bed, but it means then that the husband or partner is in a single bed, so you've lost all the husband/wife relationship. (Transcript 7 March 2013, p.7)

This is an example where red tape and unnecessary bureaucracy prevent the exercise of commonsense.

4.2.5 Barriers experienced by people with visual impairment

Another member of the focus group who has a visual impairment highlighted the cost of technology.

> The biggest cost that I would find is technology. For a blind person to use that phone, they have to buy talking software called "Talks" to put on to the phone which can cost up to 200 euro. "Talks" costs more than the phone. Jaws, (software for computers which enables the visually impaired to access information from a computer screen), costs about 1200 euro. If you go in to buy a laptop, I bought a laptop last year and I think it cost just under 500, so you're paying twice, maybe nearly three times the cost of the technology for the piece of software to make it work. (Transcript, 7 March 2013, p.9)

Not being unable to afford adequate equipment means he or she becomes dependent and reliant on others to perform what are considered everyday tasks.

Another group member observed that the maintenance and upkeep of a guide dog also added to the expenditure for people with a visual impairment.

> When you get a dog, it is trained and is eating a certain type of food, a high quality good food that costs about 70 euros a bag. They used to give a feeding allowance of 40 every two months, but with the cutbacks they took it away, and they sent an email saying, if your struggling, contact us and we'll put you back on it, more or less making you feel guilty about taking it. You can get the food cheaper from a certain company, but you have to order two bags to get it delivered, which costs 110 euros. That could last three months, but if you run out of

> food, you might not just have that amount of money. Now they insist that you have your dog insured, which costs about 200 for the first year and like every insurance, it goes up every year. And then the vet. It just depends on the vet how much they charge you, but you have to take your dog twice a year for check-ups, and more if it gets sick. Anyone who has dogs will know the price of vets! People automatically think that you get everything for guide dogs free, but you definitely don't. (Transcript, 7 March 2013, p.10)

This is a cost I was personally unaware of before conducting the research. It shows that attempts to live with a degree of independence can come at a price.

4.2.6 Failure to plan for accessibility

Group members also expressed their annoyance and frustrations at how planning is approved. In lots of instances wheelchair users are denied access. In Letterkenny for example, group members said that although the pavement is wheelchair friendly on the right hand side of the main street, that none of the shops is ramped to allow wheelchairs in. Letterkenny is the largest town in Donegal and has been allocated substantial regeneration funds invested in the past ten years. Yet it remains inaccessible as highlighted by a quite a few of the focus group.

> I don't be in Letterkenny that much, I have it set up so that there aren't that many barriers. Whereas if you go to Letterkenny, there's no guarantee that you are going to get a disabled parking spot, or there's no guarantee that you are going to get around the shops easily, or even if you want to get a disabled toilet open. (Transcript 7th March 2013, p.13)

It is really frustrating that planning regulation is ignored by the Local Authority who is supposed to administer it. Millions of euros have been spent on developing the town centre of Letterkenny and yet the high street remains largely a no-go area for people with restricted mobility and wheelchair users. It is an apartheid system against disabled people.

4.2.7 Penalised for social activities

A PA in the group stated that she considered the assessment system to be a tick box exercise. She expressed her concern with having only 15 minutes to shower a Leader. Others expressed how cuts to PA hours had restricted their opportunity to socialise. A person in the group who has a visual impairment and who is in his early twenties, explained that due to being sent to Dublin to boarding school, he knows very few people his age in his home town. This has a big effect and he ends up using his PA to socialise with. The funders regard this as very contentious because they consider this as paying for friendship or company. The alternative for him means that he will do things just to get out of the house even if they are not suitable, stimulating or of value. To give just one example: he attends a Special Olympics Club even though he does not have an intellectual impairment, or goes with his parents for beach walks which have limited value for people with visual impairment in his opinion.

One of my students researched the number of football clubs that have a programme to include disabled people. Sadly only one out of forty clubs had a programme in place.

The opportunity for leisure also seemed to be an expensive option for people to consider:

> Attending sports or activities like that, there's nothing accessible around here so you have to travel a lot further than you would have to if you were an able bodied person. You know, like football or table tennis or whatever, there's clubs in my local area where you can do that but there's nothing accessible. Well the table tennis would be, but there's nobody like you there to play it (Transcript 14th March 2013, p.3)

However it could be argued that a person's physical and mental wellbeing might be harmed if they are denied access to social activities. Research by the University of York demonstrated a firm link between the role of social interaction and people's health (Fiorillo and Sabatini, 2011). Their report states that there is a close connection between poverty and poor health and that people who are unemployed experience a much higher risk of ill health.

The National Disability Authority has commissioned a report linking disability to poverty, poor education and unemployment. Poverty is widely thought of as inability to participate in the life of one's society due to lack of resources, and that is the way it is defined in Ireland's National Anti-Poverty Strategy (NDA, 2010).

The same report stated that Disability would increase a person's chances of living in poverty. It recorded that 38% of adults with disabilities were at risk of poverty, a rate twice that of other adults.

> So there's no social interaction for leaders at all. And as Frank says, that's just leading to depression for leaders who can't get out of their own homes
> A HSE worker is telling you that you have so much time in the morning, in the afternoon and at night, so the choice of what you do with your hours is gone. The choice you have depends on what time the PA comes in for them hours. (Transcript 14th March 2013, p.5)
> It's harder for people to go where they want, or do what they want in their community, or get jobs. Then it forces people to either not be employed, or not have the freedom to live where they want. (Transcript, 14 March 2013, p.7)
> If you take it that you're getting €188 a week on disability benefit or whatever, if "A" pays €60 to come here every week, that's her down to €128 every week. Who lives on €128 a week? What quality of life do you have on €128 a week? Take your electric bill coming in once every two months, at €120. That's € 60 in the month, €15 in the week. (Transcript, 14 March 2013, p.9)

People in the group felt they were being exploited for being disabled. One person mentioned getting their toilet adapted to make it wheelchair accessible: the toilet was priced at €1100 whereas a mainstream equivalent would be €150.

4.3 Findings from the research – The Individual Interviews

Twelve individual interviews were also conducted. Participants came from various parts of Ireland, with one person from the UK. The interviewees were comprised of ten Leaders, one CIL director and a manager from the HSE. I will respect the confidentiality of the interviewees by using their initials.

The interviewees were all asked the same questions. I did however ask different follow-up questions to clarify some of the points being made. It was important that the interviews were conducted in a relaxed manner and that I did not want the questioning to be too robotic. Although some people provided very similar responses to some of the questions, this was not reflected in all cases. The following are examples of the responses to the questions raised.

4.3.1 What does IL mean for you?

The majority of the people interviewed stated that IL was about having choice, control and responsibility over how they live their lives, to have the freedom to take charge of their lives and to make decisions for themselves.

> Independent Living is the difference between having a life worth living, and having a life not worth living basically. A life that I probably would have terminated some time ago, had I not had the capacity for independent living. (Transcript MC, p.1) .
>
> Independent Living to me was a super wake-up call, right. I was never, I was to escape from who I was, a person of dependency, a person of very low esteem. (Transcript MN, p.1)

One interviewee felt that this choice should be solely up to the person concerned.

> So it can be living on their own, or living with their family, or living in a shared house as students, umm, and determining how they want to live their life. And that is usually needing supports of some sort, be it aids or appliances, or being additional help, to get up, washed and dressed for example because they can’t manage that on their own. But they are directing the help themselves. They are making those choices. (Transcript DC, p.1).

Remarkably the data from the focus group is in line with the definition given by Adolf Ratzka (2002).

> The right of all persons regardless of age, type or extent of disability to live in the community, as opposed to living in an institution; to have the same range of choices as everybody else in housing, transportation, education and employment; to participate in the social, economic and political life of their communities; to have a family; to live as responsible respected members of their communities with all the duties and privileges that this entails, and to unfold their potential (Centre for Independent Living Carmichael, 2013 [on-line])

4.3.2 How did you get involved in wanting IL?

I was surprised by the influence Martin Naughton had in encouraging people to strive for IL. Martin is a leading Irish disability activist, and has been at the forefront at developing ILM in this country. He suggested that we name him in this report because he thinks it is another important way of getting the message across that peer support is essential for the future development of IL. A variety of the people interviewed had either heard him speak or been given training by him. It demonstrates the influence peer support has in the education of oppressed people. I feel Paulo Freire supports peer support when he states that 'critical and liberating, which presupposes action, must be carried on with the oppressed at whatever the stage of their liberation' (Freire, 1970, p.47).

Peer support also played a big part in people adopting an IL lifestyle. Two of the interviewees run summer camps for young disabled people in an attempt to replicate some of the peer support and IL experience they themselves had experienced at a similar age. A couple of interviewees were the beneficiaries of IL while attending university and realised that there was no going back.
Others were encouraged by their family to opt for IL. Some were swayed by TV programmes or documentaries highlighting it.

4.3.3 What is the philosophy of IL?

The majority of the people interviewed acknowledged that the philosophy has evolved. It is about 'being able to take responsibility for my own life and actions' (Transcript, MC, p.3). Sadly a number of interviewees felt the philosophy had been watered down and had been high-jacked by profit-driven private care companies who are using the language taken directly from the ILM. Many observed that large institutions were being replaced by singular or individual institutions. The end result is that funding is now restricted, meaning they have to stay in their homes and cut off from society.

> The concept of independent living has become very, I suppose bastardised you know, and watered down. It's much more about, it's much more about umm. I think it's more about, seen more about

> keeping people in their homes now, with a certain amount of support calling in during the daytime or night-time or whatever, rather than. That's what it's about. It's more about keeping people out of institutions rather than actually letting them live as functioning members of the community. (Transcript MC, p.3)

One person felt that even by identifying it as an area of research was to create a mystique that he felt didn't exist.

> I've been a person, all the time I've been disabled. Just because somebody else didn't really think of me that way, didn't mean that that I was or wasn't. They were, they were the ones out of step. (Transcript MC, p.3)

He went on to express his frustration and anger at what he sees as the creation of paper institutions and the tick box process and what he sees as the 'gravy train' (Transcript MC, p.4). He felt the professionalisation of the sector was the biggest mistake that the Irish ever made, because of our reluctance not to challenge professionals. He also observed that the majority of professionals are trained in the medical model which then influences their approach.

> Professionals came in and they said there was this that and the other, and if you're disabled you need this and you need that and you need the other. And you need a rake of OTs and a rake of physios and a rake of psychologists, and a rake of this that and the other services, and ummm, you know, every single one of those people was trained in the medical model (Transcript MC, p.3).

He was very concerned by the systems that were introduced to determine his life. These systems included Personal Outcome Measures (POM), and risk assessments, which limited the way people can live their lives.

Historically there was a move away from the 'judgements of social deviance rooted in religious criteria of badness towards medical judgements of sickness' (Barnes and Mercer, 2003, p.8).

This approach was illustrated by the following response from one interviewee:

> Their comfort zone was in keeping track and in measuring etc. You know so I see their instinct is to throw some kind of a measuring tape on you. You know and find out what you're capable of, or what they think you're capable of, and then set up a whole, a whole plan around it

> you know. My idea of independent living is, get the fuck out of my way! (Transcript MC, p.5

One person believed it was a set of principles rather than a philosophy.

> It's a practical set of principles that are not based on your physical or mental umm, capability, but on your, your, your need to be able to contribute in a way that is human, in a way that is dignified, and in a way that is fair to yourself and to others. So I don't know If you'd call that a philosophy. (Transcript JC, p.5)

I personally consider IL enables an individual to have choice, control and responsibility over his or her life through the facilitation of a PA, who acts as that person's arms or legs. Like JC, I am unsure if this can be regarded as a philosophy.

4.3.4 What are the challenges facing the Independent Living Movement?

Concern was expressed about where the new generation of IL activists were going to come from. **While improvements in medical science and the drive towards mainstreaming have resulted in there being fewer young disabled people (a positive), these same improvements also provide less opportunity for the disabled young people to engage or see relevance in the ILM (a negative).

As a young person and adolescent I attended 'special school' and clubs for 'the disabled'. Although I am a keen advocate of mainstreaming and inclusion, I can see that it was my involvement with people from my own community which gave me my political awareness and belonging. Without role models and peer support, it is difficult to have a sense of connection and so it is not surprising that the ILM is headed up by older disabled people.

Another issue raised through the interviews was how organisations like CIL which had begun as a lobbying organisation had over time slowly become a service provider and therefore is now considered as part of the system. It was felt that too much time was spent building empires rather than educating people on what IL actually means.

One of the people interviewed who is very political and sits in the House of Lords, suggested that change was required at a political level if disabled people were going to be able to secure the equality they were demanding. In addition she felt that the ILM needed to link in and make alliances with other oppressed groups.

> The only way that you're gonna change any culture is if people with disabilities are just commonplace. If you're just you know, people are tripping over you in the shop. You get ignored in a queue, you know rather than shunted up to the front of the queue. (Transcript MC, p.7)

Another interviewee highlighted the majority of the people she provides assistance to, do not want IL. This was supported by an IL coordinator who said that out of the 140 leaders she works with, only 18-20 of them would have what would be regarded as a traditional IL provision. This acceptance of the status quo may force CIL to consider these issues and how people choosing a different type of IL provision can be incorporated into the ILM.

> I think the people that I first met wanted to be independent, and had the capacity to be independent. So I didn't meet a whole section of the community that I've now met, that maybe don't want to be independent, are choosing not to go out and fight about rights and live on their own (Transcript DC, p.5).

An interviewee who is a political activist felt that the way forward for the rights of disabled people would be the implementation of the UNCRDP. She said it would provide principles, recommendations and legislative framework.

People were also concerned about the difficulties of health and safety, saying it was being used by staff to restrict the freedom and choice of disabled people rather than prevent accidents. An ex-residential manager whom I interviewed made reference to the fact that in her early days as a manager she was very relaxed about what residents did in their pursuit of IL and she was willing to take risks. Such risks were really helpful in enabling residents to adopt IL. Sadly however, having worked twenty years in this area, she would not take the same risks again. Health and safety has not only limited disabled people but it has also placed restrictions on staff (Transcript DC, p.3).

> I mean I get outta bed, for years I got outta bed with one person lifting me outta bed. Now I'm supposed to have three. You know I'm

> supposed to have a hoist, two people in a hoist and someone supervising. Now if I was waiting for that every day to get outta bed, where would you be? (Transcript MC, p.7).

There has to be a balance between real risk and perceived risk. A Leader told me that it was in his interest to look after his PA because of his dependence on him. As a consequence he took his responsibilities regarding his PA's health and safety very seriously.

The emergence of direct payments was another concern. Interviewees expressed the feeling that not everyone would be able to manage such payments. One manager interviewed wanted all the funds that were associated with the individual to be given directly to them and encourage them to spend it as they wish. There was a slight concern that the money might be spent inappropriately. This could be connected with wanting to maintain the adult-child relationship which some service providers prefer.

> When you give people money because they're on the dole for example, sometimes there's comments about oh they bought a big TV, but they're not buying food, or not the food we would choose for them to eat. So, so what is the community's feeling about how public money should be spent? How we spend the money that we raise in our taxes and give to people. So that spreads across over all of the social welfare payments, not just disability (Transcript D.C, p.7).

In my personal experience of administering direct payments for individuals in the UK, I never came across a situation where money was misappropriated. It was too important to get up, washed and get dressed to waste it on things that would not be of assistance in daily life.

Another theme highlighted was the necessity to draw alliances with others.

> You go to these meetings with disabled people or whatever, and somebody "normal" in quotes stands up and says something, and they're piped down because they're not disabled. This kind of nonsense drives me nuts! (Transcript MC, p.11)

The ILM has been slow in building alliances with other groups who are affected by the same issues. For example, carers' associations and groups for the elderly are experiencing the same sort of cuts and these alliances with them would provide a stronger lobby group. Unfortunately a process of divide-and-rule operates and to get real power may mean some people and organisations giving up power and aligning with others.

4.4 Analysing and Learning

It came as a bit of a surprise to me that the outcome from two meetings with the Focus Group should be so closely mirrored by those with the individual interviewees, even though the amount of material gathered (over 57,000 words in the individual transcripts) was so different. The experience of working with a Focus Group was, in a way, self-generating, with more for the group to respond to, and with the greater freedom permitted within that setting. This was despite my being personally known to the great majority of the individuals interviewed. In either case, it was a vindication for the choice to use PAR.

The range of conclusions drawn from the answers given was fairly wide, although it would seem that the lived experience of Independent Living was enough to make the participants wish to continue in that way of life.

Probably the most common criticism of provisions that are being made is the gulf between promises and their fulfilment. I will add to this topic in the next chapter, which deals with my own conclusions.

CHAPTER FIVE: CONCLUSION

CHAPTER FIVE: CONCLUSION

5.1 Overview

The aim of this thesis is to explore the role and importance that Independent Living (IL) has in the lives of disabled people. As one who works within the Independent Living Movement, the CEESA course offered an opportunity to acquire the tools to do an in-depth analysis of IL, both inside and outside Ireland. I hoped to learn from the experiences of those who were initially involved in the setting up of the ILM in Ireland, and from those who are presently engaged with IL. I wanted this research to develop my own praxis and benefit directly those involved in the ILM.

The main purpose of this research was to give a voice to people engaged in IL. Because I am directly involved with the ILM and in particular CIL, I wanted to hear from a variety of people how they view IL and what they consider the main challenges to be. This led to a study of the history of IL, and writings revolving around IL. It became clear to me that there was a lot to be learned from various oppressed groups in the world, and that it was important to bridge any gaps, and create alliances. Until I undertook this research I had not considered the importance of forming alliances and identifying with people involved in other movements and struggles. In the course of my reading and through shared debates in the University I became aware of my own limitations, particularly those regarding feminism and considering other social movements. I learned that the experience of being able to reflect and listen to people involved in the ILM was a great opportunity and it has changed my views in a number of areas. I will address these in my personal recommendations below.

5.2 Literature and Methodology

I found myself guided by tutors to read much more widely and to learn from parallel experiences. Some of the literature I was familiar with already, but much was new, and therefore quite a revelation. The literature helped develop a wide variety of ideas which are included in this thesis. The theories and writings of Paulo Freire have emphasised that it is the contributions and experiences of people which is the key factor in the pedagogy and development of learning. This is reflected in the findings and the data produced by the participants in the study.

bell hooks raised the issue of awareness of feminism in the area of IL, or should I say the lack of it. It was very interesting that feminism featured so low down the agenda, although it's also fair to say that the ILM is a reflection of mainstream society where feminist issues rarely feature. The issue of intersectionality touched on an area often ignored within the ILM. As identified by Nasa Bagum (Campbell, J., 2008), people focus on impairment alone, and race and gender are ignored.

The literature in this thesis also drew on the writings of Colin Barnes and Geof Mercer. Although supportive of IL they challenge its push towards consumerism especially in the area of direct payments. David Egan promotes the funding of Leaders through direct payments but does not identify some of the difficulties which disabled people may encounter or why there has been a low take-up of this entitlement in the UK.

It was essential to acquire a broader range of technical language so as to be able to cope with some of the literature, but in the end it was a positive exercise, and guided me to using a methodology which was now not just instinctive, as would have been the case beforehand, but informed and structured.

The use of Participatory Action Research was chosen as a means of gaining information from the two groups I was involved with, the Focus Group and the 12 individual interviewees. As part of my research for this thesis I conducted a series of interviews with people connected with IL. The data collected from the interviews has provided a unique insight into the issues experienced by those involved in IL. I judge this approach to pedagogy to be the ideal model because knowledge and learning are a two-way process. Learning comes equally from the pupil and teacher. It should be noted that whilst the PAR process is very rewarding and provides some very original data, its implementation can be difficult, especially when you are used to leading rather than being led.

5.3 Reflective Findings from the Interviews

A great deal of information was gathered from both groups, and the task was then to read it through carefully and sift out not just the common themes, but also ideas which were unexpected, not to say contradictory at times. My job was then to extract as many of the themes as possible. These often could be linked to current literature and legislation, and the task was to find these links. However, particularly in Ireland, too often a gap was identified between theory and praxis.

The findings from both the focus group and individual interviews were very extensive and informative. Participants recognised the choice and control which IL offers them. They welcomed the autonomy which IL provides and the benefits which come from not having to rely on family. Regretfully cuts to social hours have meant either sacrificing time designated for healthcare needs or remaining within the confines of the home.

Participants had a very clear understanding of IL and their care needs. However people were highly critical of the assessment process and the inhuman way some were treated. Another contentious area was around the topic of transport and related costs. Even though the sectoral plan stated that all public coaches and bus services would be accessible by 2015, very little progress has been made. This frustration was increased when coaches had the required lift but the driver was not trained how to operate it.

People expressed the frustration of being allocated an expensive piece of equipment like a power chair, but because they were then unable to access either accessible taxis or buses, the equipment was rendered redundant.

Some participants felt the present system of means testing within the benefit system to be limiting and encouraging a model of dependency. The expense relating to people with a visual impairment in the area of technology or the upkeep of a guide dog was very restrictive. Numerous interviewees expressed their frustration at being denied access to shops and the lack of planning regulation around the subject of accessibility.

I was surprised at the influence which peer support and mutual encouragement had in fostering a person's desire for Independent Living. Unfortunately some people judge that its philosophy has been watered down and high-jacked by profit-driven care companies. Annoyance was also expressed at the paper institutions which were being created and thus turning IL into what they regarded as a lucrative gravy train – for some. It is evident from the data received that many consider the assessment process a tick box process.

Participants were very concerned by the lack of young people in the ILM. They recognised that mainstreaming had been positive regarding inclusion but negative with regards to developing an identity within the ILM. Discussion also took place over the changing face of IL. It was questioned whether a variety of alternative IL options should be offered.

An important issue raised was the role of CIL and how it had moved away from its original role of lobbying and become a service provider. It should be noted that only a minority of people considered this as being a negative. It was generally agreed that there was an urgent requirement to place IL into a legislative framework. Interviewees felt that an important element in this process was the ratification of the United Nations Convention on the Rights of Disabled People.

Lots of the participants were unhappy with the way in which Health and Safety regulation was being used to limit or restrict their lives.

Lastly the interviewees discussed the emergence of direct payments and concern over how it would be administered and supported.

5.4 Recommendations

Due to my unique role as an educationist and an activist in the area of IL, I want to continue with my Freirean approach and identify actions which could be addressed. I propose to meet with senior staff from both CIL and the HSE and to present my findings to them. In particular I will bring to their attention the following points:

5.4.1 In the area of transport:

The majority of the people I interviewed expressed difficulties with transport, consequently I recommend:

- Talking with transport operators to ensure that drivers are trained how to operate the wheelchair lift and that the bus pass allocated to any Leader who is unable to travel on his or her own, can enable the PA to travel free.
- That the requirement for people with mobility difficulties to have to book 24 hours ahead is changed along with the rule that prevents two or more wheelchair users travelling on the same bus.
- Those voluntary groups which operate wheelchair transport join a bus sharing scheme.
- That the budget which is paid for a bus pass can be reallocated to pay for taxis in cases where users denied accessible transport are unable to use their bus pass.
- That the HSE finds a solution to enable power chair users to get proper use from their equipment, with a more joined-up scheme.

5.4.2 In the area of resources:

Interviewees expressed unhappiness with how resources were allocated at present, with many feeling that they were unduly penalised because their partner worked, with a consequent promotion of dependency rather than independency. Equipment which enabled people to live independently was very expensive and beyond the reach of most disabled people. Participants also expressed alarm about planning regulation, in particular focusing on shops which they were unable to use due to poor access, something complained about often in the Findings section Chapter Four.

- I want CIL to challenge the Minister of Health over the need to means test disability benefit and to remove VAT from equipment which assists a person's ability to live independently.
- DCIL will lobby Donegal County Council and bring their attention the difficulties of access experienced by its members getting into shops in Letterkenny high street.
- CIL will promote peer support and design, distribute and deliver a module promoting the benefits of Peer Support among CILs across the country.
- CIL will build / develop alliances with other relevant groups and through these alliances organise and challenge the austerity measures which are being imposed. This will include elderly and carers groups.
- CIL will promote and advertise what they do, and the important role they have in promoting IL. They will educate people about the importance of IL and the difference and benefits it can have to the individual and society as a whole.
- I will recommend that the HSE change the assessment process, in particular the tick box scheme, and discuss a better alternative.
- I recommend that CIL organise a conference and receive feedback from leaders on how they wish CIL to progress. Leaders will inform CIL if they wish them to continue being a service provider.
- CIL will actively target young disabled people and become more inclusive by including people with a wider range of impairments.
- CIL will lobby for:
    - ➢ the implementation of the UNCRDP
    - ➢ the National Disability Strategy and direct payments.
- CIL will offer training to assist disabled people become more politically active and effective lobbyists.

5.5 Conclusion

I am concerned that my research has only scratched the surface and that the real work for the ILM will begin once this thesis has been completed.

As an activist, IL campaigner and educationist, I witness continually how discrimination and inequality prevent disabled people from participating in mainstream society. One example springs readily to mind. I work with a cross-border group and asked if they might like to participate in Derry's City of Culture activities. The group wanted to travel the twelve miles from Strabane to Derry using a public bus. To use the 'public' bus you have to book it 24 hours in advance and the bus can only accommodate one wheelchair, thus making it impossible for the group to travel together. This is just a small example of the difficulties which disabled people face on a regular basis. It also demonstrates the difficulties which a disabled person would face if seeking employment. The experience of the bus did not cause the group members to get angry or complain. It should have! They just accepted it as being the norm and no more than they would have expected.

This research was not intended to identify the all the solutions to the issues faced by the ILM but it recognises that these challenges exist and through a process of critical pedagogy that the issues are insurmountable. A more radical pedagogical approach is required to ensure that everyone in the ILM is heard and feel included and the slogan of the ILM becomes a reality:

NOTHING ABOUT US WITHOUT US!

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GLOSSARY OF TERMS USED

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CBPR	COMMUNITY BASED PARTICIPATORY RESEARCH
CEESA	COMMUNITY EDUCATION, EQUALITY AND SOCIAL ACTIVISM
CIL	CENTRE FOR INDEPENDENT LIVING
DCIL	DONEGAL CENTRE FOR INDEPENDENT LIVING
DFI	DISABILITY FEDERATION OF IRELAND
ENIL	EUROPEAN NETWORK ON INDEPENDENT LIVING
HSE	HEALTH SERVICE EXECUTIVE
IL	INDEPENDENT LIVING
ILM	INDEPENDENT LIVING MOVEMENT
NDA	THE NATIONAL DISABILITY ATHORITY
PA	PERSONAL ASSISTANT
PAR	PARTICIPATORY ACTION RESEARCH
PWDI	PEOPLE WITH DISABILTIES IRELAND
ULOBA	Uloba is a Norwegian cooperative which is controlled and run by disabled people. It is committed to the philosophy of Independent Living and provides a PA service, advocates and accessible transport services. It was founded in 1991 and is based on the principles of empowerment, full citizenship and human rights.

UNCRDP	UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

UPIAS

UNION OF THE PHYSICALLY IMPAIRED AGAINST SEGREGATION

INDEPENDENT LIVING

Independent Living is the right of all persons regardless of age, type or extent of disability to live in the community; to have the same range or choices as everybody else in housing, transportation, education and employment; to participate in the social, economic and political life of their own communities; to have a family; to live as responsible respected members of their communities with all the duties and privileges that this entails, and to unfold their potential. (Adolf Ratzka) The above for many people with significant disabilities can best be achieved by the employment of Personal Assistants.

LEADER

Leader is a person with a disability who employs directly or indirectly (through a service provider) Personal Assistants. A Leader takes full responsibility for the instructions given to the Personal Assistant, for the actions and consequences that follow from these, for training and day-to-day management of the service. The Leader is in charge.

PERSONAL ASSISTANT

A Personal Assistant, when on duty, only takes instructions from the Leader. A Personal Assistant does not report on Leader's activities to service provider, nor does a Personal Assistant write in any ledger or notebook information about the Leader to be viewed by others, unless instructed by the Leader to do so.

Personal Assistants do not work in day centres or nursing homes or in any similar establishment where they are responsible only to management of the said establishment. Personal Assistant's tasks are customized to the individual needs of the Leader and may include personal care, household help, assistance in the college or at the workplace, driving, interpretation etc. The major difference between a Personal Assistant and a carer is that in case of Personal Assistance the service is designed and managed by the service user directly.

DIRECT PAYMENTS

Direct Payment is cash paid to individuals to enable them to employ, either directly or indirectly, individuals to assist them with their everyday tasks.
(CIL [online])

FOCUS GROUP

a group of interacting individuals having some common interest or characteristics, brought together by a moderator, who uses the group and its interaction as a way to gain information about a specific or focused issue.

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APPENDIX

Exploring disabled people's experience of Independent Living

I am Paul Fagan and I am a student at the National University of Ireland Maynooth. I am inviting you to take part in a research study. Before you decide on your participation please take the time to read the following information carefully.

What is the purpose of the study?

This study is being undertaken as part of my requirement in fulfilling an MA in Community Education, Equality and Social Activism at the NUI Maynooth. The aim of the study is to explore the philosophy of Independent Living (IL) and its impact on the lives of disabled people. The study will examine what IL means to you, how you got involved in IL, who was your main influences, how you define the philosophy of IL and to identify changes you have experienced within the concept of IL. Finally the research will ask you to express what you feel are the new challenges for the IL.

Why have you been invited to take part? I have invited you to take part in this study because as a person involved with the IL movement your knowledge is invaluable to the research and its successful outcome.

Do you have to take part? Taking part is entirely voluntary and it is up to you whether or not you take part. If you do take part you will be asked to sign a consent form. If you decide to take part, and, subsequently, you feel unable to continue, you are free to withdraw at any stage without giving a reason.

What happens if you take part? The study is based on lived experience and so you will be asked to take part in a short interview. The interview should last between half an hour and forty five minutes. There are no risks to participation.

What are the benefits of participation? While there are no direct benefits from participation, your contribution will add to the discussion and understanding of independent living and hopefully make a difference for the future direction of people choosing independent living.

Is the study confidential? All the research material collected will be held in accordance with the NUIM's policy on Academic Integrity. The data will be kept as anonymous as far as possible; however because of the relatively small size of the community involved it would be impossible to guarantee total anonymity. It is also my intention to show each interviewee a copy of their individual transcribed interview before the final drafting of the dissertation.

Contact details. If you have any further queries about the research you can contact:
Researcher: Paul Fagan tracslaptop@eircom.net (XXXXX mob.) or Supervisor: Brid Connolly brid.connolly@nuim.ie

Consent for Participation in Interview Research

I volunteer to participate in a research project conducted by Paul Fagan. I understand that the project is designed to collect and collate interviews from people involved in the independent living movement. I will be one of approximately 15 - 25 people who will be interviewed for this study.

1. My participation is entirely voluntary. I understand that I may withdraw at any stage and that if I do withdraw it will be entirely confidential.

2. I understand that while the interview is designed towards discussion I may withdraw and conclude any aspect of the interview if I feel uncomfortable.

3. Participation involves an interview that will last between 30-45 minutes. Notes will be taken and an audio recording of the discussion will be made. I understand that if I don't wish to be taped I will not be able to participate in the project.

4. I understand that the researcher will not identify me by name at any stage from information obtained from this interview and that my confidentiality will remain secure and subject to standard data use policies at all times.

5. The only people present at the interview will be the participant and the researcher.

6. I understand that this research has been approved by NUI Maynooth.

7. I have read and understand the information provided to me by the researcher. I have had all my questions answered to my satisfaction and I voluntarily participate in this study.

8. I have been given a copy of this consent form.

Signature. ………………………………..
Date………………………………..

Name Block Capitals

Signature Researcher……………………………………………….