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UCC
University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

Accessing the City: Exploring the Lived Experiences of Wheelchair-Users in Cork City.

Michael O Donnell

CARL Research Project
in collaboration with
The Cork Centre for Independent Living

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- provide their services on an affordable basis;
- promote and support public access to and influence on science and technology;
- create equitable and supportive partnerships with civil society organisations;
- enhance understanding among policymakers and education and research institutions of the research and education needs of civil society, and
- enhance the transferrable skills and knowledge of students, community representatives and researchers (www.livingknowledge.org).

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Abstract

People who use wheelchairs regularly encounter physical access barriers while living their everyday lives in the urban environment. Many previous studies have addressed the mechanistic details of creating an accessible environment. However, few studies have addressed the phenomenology of marginalisation and exclusion created through interaction with the built environment and the social world of which it is a product. This study focuses explicitly on the experiences of people who use wheelchairs accessing a built environment which is designed with supposedly 'able-bodied' people in mind. In this study, I uncover the power relationships built into the physical environment which serve to marginalise and exclude. I explore how, despite decades of advocacy for a social model, much social policy and legislation around disability still draw from theories of a medical model. I use complimentary participatory and phenomenological methods to carry out this research 'with' rather than 'on' participants and explore their experiences purely from their own perspective by bracketing my own biases and experiences. I draw five themes from the data which highlight how participant's experiences of the built environment in Cork city are still predominantly negative despite improvements in recent years. It is evident from the findings that much work still needs to be done to enable people who use wheelchairs to live fully independent lives and be fully included with regards to the built environment. Despite being a small study the findings in this research correspond with the findings of other similar studies. I suggest that more research is needed to explore possible gendered, racial and ethnic dimensions to this phenomenon. I also suggest that further research could focus on the experience of other groups encountering access barriers such as people with visual or other sensory impairments, older people and their experiences and to explore whether the experiences of these groups are comparatively similar or very different to those of people who use wheelchairs.

Chapter 1

Introduction

Introduction:

This research identifies the lived experiences of five people who use wheelchairs regarding access to the built environment in Cork city. Therefore, the current researcher aims to put to the test Hahn's argument that: "cities have been designed, not merely for the non-disabled but for the physical ideal that few humans can ever hope to approximate" (Hahn, 1986, cited in Imrie, 1996, p.2) and whether or not this still holds true thirty years later in Cork City. The current researcher aims to explore the lived experiences of disability in relation to the built environment in Cork City in order to find out if Barnes (1991) is correct when he suggests that discrimination and oppression of those with physical disabilities is never more obvious than the restrictions placed on physical mobility and access by a poorly designed built environment. In doing this, five themes emerge which illustrate the experiences of the participants and these are explored in detail in a later chapter. This project is carried out in collaboration with the Cork Centre for Independent Living (CIL) and as part of the Community Academic Research Links (CARL) initiative in University College Cork.

Rationale:

The rationale for this research is based on personal observation. As a Personal Assistant working with people who have physical disabilities in Cork City, I have observed a number of wheelchair-users being excluded from the use of services and public facilities such as pavements (resulting in the service-user being forced to drive their wheelchair alongside the main stream of traffic) and public transport (buses and trains have a limited number of wheelchair spaces which are often occupied by luggage/buggies or other people) as well as other public facilities.

This research will not just focus on issues of inaccessibility in the city but will also explore the use of accessible services provided in a 'piecemeal' fashion. Examples include buildings with ramps installed at rear of building for wheelchair access and elevators in new

buildings continuously breaking down, and which, arguably, give little thought to the dignity of the service-user in the provision of the service. As a consequence, the research aims to explore the phenomenological implications for wheelchair users in encountering accessibility barriers such as those mentioned above as well as the lived experience of using services which are, often, not fit for purpose.

Research Objectives:

The aim of this research is to explore the lived experiences of wheelchair users in accessing services and the built environment in Cork city. The overall goal is to highlight any major issues experienced by wheelchair-users in accessing the built environment in Cork city with a view to improving current and future access. Thus, this research assumes a transformative approach, underpinned by a philosophy of participatory research with a view to creating change.

Moreover, this research is be carried out as a core part of the B.Soc.Sc degree programme in collaboration with Community Academic Research Links (CARL) in University College Cork. CARL is a research initiative which assists civil society organisations (CSOs) in carrying out research relevant to their areas by matching students who are researching these topics with organisations who need the research carried out.

The CSO that was collaborated with in this study was the Cork Centre for Independent Living (CCIL/CIL). CIL is an organisation who "is committed to working towards the removal of barriers to inclusion and working for rights-based equality legislation for people with disabilities" whose primary aim is "to empower and enable people with disabilities to achieve independent living, choice and control over their lives and to achieve full and active participation as equal citizens in society" (Corkcil, 2011).

Research Questions:

According to Creswell, phenomenological studies need to ask two broad general questions about participants:

- What had they experienced?
- What contexts or situations had influenced or affected those experiences? (Creswell, 2007, p.62).

More specific questions that will be addressed by this research are the following:

1) What physical barriers are experienced by wheelchair-users in Cork city throughout their everyday lives?

2) What is the lived experience of wheelchair users encountering physical barriers or undignified access issues in the city?

Methodology:

The research methodology applied in this study is qualitative, manifesting as interviews and focus groups which are in-depth and semi-structured. This study is phenomenological in nature meaning it will be focused on the lived experience of the participants. This research is carried out using a hybrid between social constructivist research methods and participatory action research (otherwise known as transformative research). The participatory dimension in this research is seen as an essential element in the nature of a study affiliated with Community Academic Research Links. This research is participatory because it takes a "bottom-up" approach. This means that the research involves carrying out a preliminary interview in which broad questions are asked in order to elicit the most relevant issues for the individuals in the study. After analysis of this data, more specific research questions were generated from what was learned and further interviews took place using those questions. This method was selected because it allowed the interview format to informed by the lived experiences of a participant and not as entirely constructed by the researcher (myself) who has not directly experienced the issue at hand.

Chapter Outline:

Chapter One - Introduction

This chapter introduces the research topic. It provides a background on the research, the rationale, a set of research objectives, broad questions underpinning the research study, the philosophical paradigm within which the research will be carried out and the methodology which will be employed to carry out the research. Chapter one also introduces Community Academic Research Links (CARL) and the Cork Centre for Independent Living (CIL), each of whom are supporting this study.

Chapter Two - Theory Chapter

Chapter two focusses on the broad theories in the area of disability studies including models of disability, the selection of social-relational approach as the approach taken in this research, the power relations inherent in interactions involving people with disabilities, theories of disability in the city and disability in space.

Chapter Three - Policy Review

This chapter critiques some of the current policy and legislative context which are relevant to issues of accessibility for wheelchair-users.

Literature Review

The literature section looks at similar phenomenologies carried out on disability in the built environment. Much of this literature originates other parts of the world.

Chapter Four - Methodology

This chapter discusses the phenomenological methodological approach taken in this research and justifies its selection as an appropriate means of answering the research questions.

Ethical considerations, the description of the participants, the limitations of the research and the 'recipe' that was used in carrying out this research are also outlined.

Chapter Five - Findings and Discussion

In this chapter the findings will be outlined. The experience of encountering inaccessible environments conveyed during the research will be explored, analysed and meanings found in order to touch on the 'essence' of the phenomenon.

Chapter Six - Conclusion

In this chapter, the conclusions drawn from the interviews and key themes in the literature will be drawn together. Furthermore, recommendations will be made on the basis of the findings.

Chapter 2

Models of Disability

Introduction

This research is focused on the interaction between people who use wheelchairs in Cork city and the built environment of the city that they exist within. It should be noted that in this study, 'the built environment' does not only refer to the physical barriers and obstructions faced by people who use wheelchairs. It also refers to the inherent power relationships that are embodied within those structures. Finally, it refers to the interactions with those can be considered the 'gatekeepers' to accessibility such as bus drivers, taxi drivers and more. Thus, in this research, the built environment is understood to be a product of the social world more than simply a physical structure. While, there are no specific statistics available for wheelchair users in Cork City from the Central Statistics Office, in 2011 the number of people in Cork City of both sexes who have "[a] condition that substantially limits one or more basic physical activities" is 9,252 (CSO, 2011).

The Medical Model of Disability

As Considine and Dukelow (2009, p.392) explain the medical model of disability also known as the individual or personal tragedy model, 'approaches disability in individual terms, diagnosing conditions, impairments, etc that have the effect of defining an individual by these traits'. Therefore, the underlying philosophy of the medical model sees disability in and of itself as being the preventative force in full participation in society.

Moreover, "[u]nder this model of disability, disabled people's inability to join in society is seen as a direct result of having an impairment and not as the result of features of our society which can be changed" (Moyne, 2012). Following this model, a person might say: "I cannot go into the museum or the cinema because my disability prevents me from climbing the stairs" (Greed, 1999, p.76). Thus, as Johnstone (2001, p.16) points out: "the medical model of interpretation of disability projects a dualism which tends to categorise the

able-bodied as somehow 'better' or superior to people with disabilities".

This approach conjures an image of disabled people which is identified with pity, fear, and charity. Historically, this approach causes the term 'disabled' to be associated with ideas of abnormality, dependency and badness. These ideas have historically been used to legitimise oppressive practise against disabled people and medicalised approaches which have allowed the caring services to justify doing things 'to' disabled people rather than doing things 'with' them (Johnstone, 2001).

Traditionally, the medical model was the approach taken in Ireland with regard to treatment and care for people with disabilities until quite recently. Thus, many authors have critiqued these medicalised understandings of disability arguing that they place too much emphasis on the individual with an impairment and the 'personal tragedy' understanding of disability. This approach fails to address the significant barriers to participation in mainstream-society in areas such as access to the built environment and full participation in the educational and employment sectors that these individuals face collectively. Therefore, the medical model has been criticised for not placing enough emphasis on social structures of disablement. Enter the social model.

The Social Model of Disability

Dodd (2013, p.264) explains the social model of disability: The social model is "collective not individual, explicitly constructed to reverse individual understandings of disability and address the full range of disabling barriers". Thus, as Johnstone (2001, p.20) points out:

> the challenge and the strength of the social model for the interpretation of disability lies in its ability to reverse the emphasis of causation; away from the individual and personal towards shared and collective responsibility

This model emerged in the 1970's out of a global social movement for equal treatment for disabled people inspired by the civil rights movements in the USA. Furthermore, the social

model of disability was developed by people who were critical of the medical model's narrow focus on impairment and sought to develop a more political understanding of disablement. Advocates of the social model argued that the medical model focused too much on individual impairments and that societal standards and expectations also had a role to play in disabling people.

For many disabled people, the social model was useful because it highlighted that many of the barriers faced by disabled people, and that much of their exclusion from mainstream society was not a direct result of their physical impairments but, instead, resulted from the way society was organised (Moyne, 2012). Moreover, the social model of disability highlights physical and social barriers as key contributors to the active exclusion of people with disabilities from participation in mainstream society. These can include barriers to the physical environment and transport, employment and educational barriers as well as attitudinal barriers (Cdc.gov, 2016). Therefore, as Considine and Dukelow (2009, p.392) point out: "the social model of disability […] sees society as contributing to disability through its inability to accept and give recognition to difference". Furthermore, the social model provided the first framework for disabled people to begin critiquing the barriers they were faced with in everyday life.

However, just as the medical model had been critiqued for the narrowness of its conception, so too did the social model come under fire. In *Female Forms*, Carol Thomas (1999) argues that the Marxist or materialist perspectives which played a large role in the development of the social model caused it to focus too heavily on the socio-structural barriers and ignore the cultural and experiential dimensions of disablism. Morris explains:

> there is a tendency within the social model of disability to deny the experience of our own bodies, insisting that our physical differences and restrictions are entirely socially created. While environmental barriers and social attitudes are a crucial part of our experience of disability - and do indeed disable us - to suggest that this is all there is to deny the personal experience of physical and intellectual restrictions, of illness, of the

fear of dying (1991, p.10, cited in Thomas, 1999)

Thus there are, in fact, two common interpretations of the social model of disability which are often confused and used interchangeably; these are the relational approach and the property approach. The relational approach understands disability as an unequal social relationship between people. The property approach understands disability as any restriction or lack of ability experienced by people with impairments (Thomas, 1999, p.40). The Property Approach then has a tendency to overemphasise the objective context. As David Thomas (1982, p.12) points out: "Co-existing with this objective context is a subjective context and this refers to the subjective experiences of disabled people, their attitudes and attitudes they experience".

A Social Relational Approach?

The relational definition provided by The Union of the Physically Impaired Against Segregation (UPIAS) is the one which will be used for the purposes of this study. UPIAS were one of the driving forces behind the emergence of the social model of disability (Thomas, 1999). They formed a socio-political definition which explains disability as "the disadvantage of restriction of activity caused by a contemporary social organisation which takes no account of people who have impairments and thus excludes them from participation in the mainstream of social activities" (UPIAS, 1976, p.14).

In this definition, disability is expressing an unequal social relationship between people. Using this definition, Thomas (1999, p.40) provides a critical understanding of disability:

> disability expresses an unequal social relationship between people who are impaired and people who are non-impaired, or 'normal', in society. Thus, in the same way that the concept of patriarchy refers to the relationship of male ascendency over women, so the concept of disability refers to the relationship of the ascendency of non-

impaired over the impaired

Understandings of disability as an oppressive and relational concept allowed for the development of the term 'disablism' to be coined. This refers to the ideological manifestations which legitimise oppressive practises against disabled people solely on the basis of their impairment (Imrie, 1996). Moreover, the understanding of disability as a relational concept also provides the framework for a third dimension to be added to the existing medical and social conceptions of disability. This was the psychological dimension and was useful for disabled people to begin expressing, for themselves, a key issue which was previously ignored in the other models and which Thomas (1999) goes to great lengths to explore. This issue placed emphasis on the importance of the experiential dimension of what it means to live with a disability.

Thus, according to this approach, there are three dimensions to the experience of disablement rather than the two proposed by the medical and social property approaches. These are the bio-psycho-social dimensions (Thomas, 1999). Therefore, the key issue addressed in this approach is the emphasis which is placed on the lived experiences of the individual which makes Thomas's three-dimensional framework very useful here. For instance, the 'bio' in this model refers to the biological impairments experienced by the individual with the disability; the 'social' referring to barriers which restricted full participation in mainstream society; and the 'psycho' dimension referring to the lived experiences of the individuals caught within this dichotomy.

As Thomas suggests, the psychological dimension of disablement is key to understanding the issues faced by disabled people fully. Indeed, it was using this approach that Thomas defined disability as: "a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional wellbeing" (1999, p.60). The emphasis on the psycho-emotional wellbeing which Thomas addresses here is the key issue which the author aims to address in this research. Therefore, using this approach in this research, emphasis is

placed on the interaction between the individual with an impairment, the barriers in the environment that they exist within and, fundamentally, on the lived experiences of the individual who experiences this interaction.

Accessing the City, Independent Living and Universal Design as a Possible Solution

Martha Nussbaum argues that: "public space is an artefact of ideas about inclusion" (2006, p.116). In this research, the author wishes to explore how public space is experienced from the perspective of disability and if that experience is one of inclusivity. However, before anyone can experience inclusion in a space, place or group, organisation or society, they must be able to access it. Therefore, the author agrees with Lid and Solvang, when they say: "[a]ccessibility is a prerequisite for participation for all citizens" (2016, p.183). This means that access is a key issue for social inclusion in cities and elsewhere. Accessibility is defined as:

> the provision of flexibility to accommodate each user's needs and preferences; when used with reference to persons with disabilities, any place, space, item or service, whether physical or virtual, that is easily approached, reached, entered, exited, interacted with, understood or otherwise used by persons of varying disabilities, is determined to be accessible (United Nations, 2016, np).

Therefore, accessibility "describes a situation of congruity between individual capacities and environmental demands" (Lid and Solvang, 2016, p.183). Moreover, this definition of accessibility reinforces the understanding of disability as being a relational concept between the individual and the environment because it posits the interaction between the built environment and the individual as its central concern. Thus, with this understanding, it can be said that disability emerges only when there is a mismatch between individual capacities and environmental demands (Lid and Solvang, 2016).

Furthermore, one dimension to the lived experience of disability which is deeply

affected and hindered by inaccessible urban environments and public spaces is that of independent living. Gillinson, Green and Miller define independent living as:

> what most non-disabled people take for granted - living the life you want to live - deciding what you want to do, and then having the opportunity and, if necessary, the support, to get on and do it (2005, p.10).

This definition allows the ordinary reader to appreciate the depth to the experience of being denied access to basic services and facilities due to a poorly designed built environment, and thereby denied the right to independent living. Moreover, they had this to say about the concept of independent living:

> [it] is a philosophy; a manifesto for empowerment, self-determination and self-fulfilment; and a way of being - it is not a 'service' [and] it is equally the human right of disabled people to enjoy but this fundamental right is denied to them living within a disablist society (Gillinson, Green and Miller, 2005, p.9).

The Cork Centre for Independent Living describes the concept of independent living as "a philosophy, a way of looking at disability and society and worldwide movement of people with disabilities working for self-determination, self respect and equal opportunities" (Corkcil, 2011).

Moreover, "[s]ince the 1980's, western governments have increasingly acceded to the idea that inaccessible spaces and places in the built environment require some redress through public policy" (Imrie, 1996, p.97). A popular solution which has been proposed for issues of limited access is that of universal design of the built environment. Universal Design Ireland defines universal design as "the design and composition of an environment so that it can be accessed, understood and used to the greatest extent possible by all people regardless of their age, size, ability or disability" (Universal Design Ireland, 2014).

However, some theorists are critical of much of the research which currently informs the provision of universal design because it doesn't take into account the experiential dimension of the people for whom the design is intended such as people with physical impairments and wheelchair-users. As Lid and Solvang point out "few studies […] examine how people with impairments experience the urban environment" (Lid and Solvang, 2016, p. 182). Moreover, Imrie and Lucks (2014) "call for more studies on "substantive matters that relate to the interrelationships between design and people's flourishing and suffering in the world" (as cited by Lid and Solvang, 2016, p.183). In this study, the current researcher hopes to explore the lived experiences of wheelchair users in an urban environment in order to provide a substantive account of the experiential dimension that is often left out of this discussion.

Conclusion

In this chapter, the author introduces the popular conceptions of disability within which this study exists. Following that, the social relational approach is selected as the approach taken within this study. The social relational approach is selected because it is deemed most suitable to compliment the phenomenological nature of this study. Next, ideas such as accessibility, independent living and universal design are introduced. Finally, simplistic solutions to the problem of inaccessibility such as universal design are critiqued as they fail to address the key issue raised in this research which is the experience of disablement caused by the built environment.

Chapter 3

Policy, Legislative and Literature Context

Introduction

This chapter addresses the development of disability policy in Ireland. It will look specifically at social policy and legislation relating to independent living and physical accessibility to the built environment. Following that, the relevant literature is explored with a view to developing a comparative framework for this research. The policy, legislation and previous literature were compiled into one chapter in this research because it is the combination of these factors which contextualises the current study. It is only through understanding how all of these factors operate together that a full understanding of the lived experience of participants could be developed. Therefore, the policy, legislation and literature are seen as thematically linked to lived experience.

Development of Disability Policy in Ireland

Records of the earliest services set-up for people with disabilities in Ireland which began in the middle of the 19th century provide a "salient illustration of how the social construction of difference can have massive implications for the lives and wellbeing of different social groups" (Considine and Dukelow, 2009, p.391). The earliest policy development which affected people with disabilities occurred in 1838, during the famine, when they began to be institutionalised in centres such as the workhouses which were set up to house the very poor and those in need.

Throughout most of the 20th century disability policy in Ireland remained relatively static. It was not until the 1950's that the first non-religious voluntary and community sector organisations began targeting people with disabilities in Ireland. Moreover, prior to the 1990's, public policy in relation to people with disabilities was seen primarily as the role of the Department of Health (Quinn and Redmond, 2003). This began to change in the wake of new thinking about disability, such as the social model, which began to move issues of disability out of the hands of the medical profession and into society at large towards a more

inclusive policy direction. An example of this could be seen in The Green Paper on *Services for Disabled People, Towards a Full Life* "which demonstrated a broadening perspective on disability issues" (Considine and Dukelow, 2009, p.393). This paper addressed issues such as improved access to public transport and buildings, the employment sector and to increased participation in society overall (Considine and Dukelow, 2009). In time, issues such as independent living and accessibility became a central focus for people with disabilities nationally.

Recent Developments in Disability Policy in Ireland

From the 1990's until recently, Ireland bore witness to an unprecedented expansion of disability policy. Key policy and legislative developments occurred which included people with disabilities; these included: Needs and Abilities: a policy for the intellectually disabled (1990), The Green Paper on Mental Health (1992), The Employment Equality Act (1998), Establishment of the Equality Authority (2000), The National Disability Strategy (2004), The Disability Act (2005) and the Citizens Information Act (2007) (Considine and Dukelow, 2009, p.393). More recently, a policy known as "New Directions: Personal Support Services for Adults with Disabilities (2012) was published. Moreover, "the last decades of the 20th century saw marked changes in thinking about disability and the role of services in addressing the issues of people with disabilities" (Quinn and Redmond, 2003, p.2). Indeed, according to Considine and Dukelow (2009, p.392) "the emergence of a disability rights movement began to challenge the conventional assumptions about disability and promoted independence, rights and greater awareness of the segregation and exclusion experienced by people with disabilities".

Furthermore, while few policies gave significant attention to issues of accessibility in cities and the built environment, significant progress was made with regard to issues of independent living (Linehan, et al, 2014).The needs and abilities policy for the intellectually disabled was the first which aimed to transform disability services from a model of care based on congregated settings to a model of care based on people with disabilities being

support to live independently in their own communities. (Linehan, et al, 2014). Moreover, instead of congregated settings, the Needs and Abilities policy "proposed a range of community-based alternatives, including forms of adult foster care, and supports for families to enable them to maintain their family member in a home situation" (HSE, 2011, p.10). This would be one of the first steps in enabling disabled people to move out of residential treatment facilities influenced by the medical model and into the community at large.

This shift was strengthened more recently by another important document known as the "Time to Move On From Congregated Settings" (2011) whose aim it was to move individuals out of the congregated setting in to housing that is situated in the community. This would be reinforced through the provision of individualised support which would assist the person to live independently. This document states that all people departing congregated settings should be housed in regular neighbourhoods within the community with social support services specifically arranged to meet their own individual needs and wishes (HSE, 2011). Lastly, the New Directions: Services for Adults with Disabilities (2012) policy is aimed at mobilising all of the supports available within the community so that people with disabilities have the widest possible choice about how to live their lives (HSE, 2012). It should be noted that, despite these developments, in 2015, there were still 4,000 individuals living in institutional care in Ireland (HSE, 2015).

The Role of the Centre for Independent Living

The independent living movement grew out of the international disability rights movement in the second half of the 20th century. The first Irish Centre for Independent Living was initially set up in the 90's by people with disabilities as part of a pilot scheme known as "INCARE" implemented to provide a Personal Assistant service for people with disabilities living in the community. Founding members included Catherine Hickey, Declan O' Keefe, Hubert McCormack, Michael McCabe, Ursula Hegarty, Peter Moore and Dermot Walsh. The first CIL in Ireland was established in Carmichael House in 1992 (Dublincil, 2017) and today there are twenty two CIL's in Ireland. Their establishment meant that the necessary support

needed for integration back into the community after leaving a congregated setting would be available to whoever wanted it (DFI, 2014, sec. 2.2).

The developments towards independent living resulted in many people who would traditionally have been housed in congregated settings and excluded from mainstream public life now living more publicly and as part of the community. This shift towards community based living was central to a new public awareness of accessibility issues. Thus it was only when disabled people became more visible in Irish society that significant accessibility barriers became apparent and could begin to be addressed.

Accessibility Policy and Legislation

There is relatively little in the way of policy which directly addresses the issue of accessibility in towns and cities in Ireland. A few important documents have been published in the recent past which focused entirely, or partially on issues of accessibility and were aimed to improve access to buildings and services for people with disabilities. The Disability Act (2005) "places significant obligations on public bodies to make buildings and services accessible to people with disabilities, provides for sectoral plans in key service areas, requires public bodies to take positive actions to employ people with disabilities and provides for the establishment of a Centre for Excellence in Universal Design" (Fahey, 2005, foreword). However, this provision came with significant limitations. These include: cases where providing access to services would not be practicable; cases where providing access would not be justifiable by the cost involved and cases where providing access would cause unreasonable delay in making goods and services available to other people (ahead, nd).

Furthermore, some of the legislation such as Part M of the Building Regulations in Ireland has been heavily criticised for not being robust enough. Part M is intended to ensure that all buildings are constructed to a minimum standard to facilitate accessibility for people with disabilities. However, several exemptions are included in this provision on the basis of cost or sustainability issues. According to Roulstone and Prideaux:

> Irish legislation still carries a loose proviso that a Minister may exclude a public building from the scope of the requirements of Part M if he or she is satisfied that the building is being used as a public building on a temporary basis or will no longer be used as a public building after 3 years. Exemption could also be granted if refurbishment cannot be fully justified on the grounds of cost due to infrequency of use by disabled people (Roulstone and Prideaux, 2009, np).

Indeed, Part M came under so much fire from disabled people that The National Disability Authority (NDA) commissioned independent research to assess its effectiveness and concluded that there were serious concerns over the lack of vigour behind the monitoring mechanisms regarding this provision. Ultimately, many wheelchair users argue that Part M has failed to improve access to the built environment (O'Herlihy and Winters, 2005). Adams proposes that people with disabilities are excluded from consultation when decisions about the built environment are being made. Thus, he argues:

> Popular constructions of disability have established a relatively powerless and deviant status for the disabled population when compared to their able bodied peers. Regulatory controls and legislation require that builders and designers are sensitised to the needs of disabled people, but there is no legislative process to endorse disabled peoples request for a fully inclusive and accessible lifestyle (Adams, 2006, Abstract).

This paternalistic approach which grants the responsibility for creating a non-disabled environment with the designers, builders, contractors and other professionals who do not consult with any disabled people in the process is best explained by Charlton as non-disabled professionals 'knowing best what disabled people want' (Charlton, 2000).

> In other words, 'rehabilitation', 'inclusion' and 'normalisation' embodied in the more pervasive notion of 'care' [are] subject to the considered opinions of politicians,

> medical professionals and the non-disabled who [know] 'what [is] best' without any substantial consultation with disabled people over their specific difficulties obstacles, needs, wants or desires" (Roulstone and Prideaux, 2012, p.23).

Another policy which addresses accessibility in the built environment is The United Nations Convention on the Rights of Persons with Disabilities or UNCRPD (a treaty which Ireland signed in 2007 but has yet to ratify a decade later) which emphasises the need for countries to take measures to ensure that persons with disabilities can access "[b]uildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces" (UNCRPD, 2008, article 9).

Other legislation provides a key protection for the rights of disabled people to access the built environment. The Equal Status Act (2000) sets out the legal grounds upon which discrimination against a person with a disability in accessing public and private places can occur. It states:

> For the purposes of this Act discrimination includes a refusal or failure by the provider of a service to do all that is reasonable to accommodate the needs of a person with a disability by providing special treatment or facilities, if without such special treatment or facilities it would be impossible or unduly difficult for the person to avail himself or herself of the service (Irish Statute Book, 2000, sec.4).

Of note in this act is the use of the phrase "all that is reasonable". Roulstone and Prideaux point to the contesting constructions of 'reasonableness' in relation to environmental access barriers for wheelchair users as a sticking point for progress in this area. "A key challenge in applying accessible principles to environmental planning in the EU is to find an agreed consensus on "reasonable" access and "reasonable" adjustment to the built environment" (Roulstone and Prideaux, 2009). Indeed, Male and Spiteri point out that:

> Within the context of the physical built environment tensions exists between various competing value systems about what is or is not deemed reasonable in a whole variety of situations. For example, contenders amongst the divergent value systems in the current research are those of the legislators, the disabled persons, NGOs (non-governmental organisations) and other relevant associations, service providers, building owners and tenants, and various mediating professions including architectural, legal and medical and caring professions (Male and Spiteri, 2005).

In their comparative study of four European countries, (The U.K, France, Ireland and Malta) Roulstone and Prideaux point out that:

> [The different states] can, therefore, be positioned on a continuum with notions of "reasonable", at one extreme, being attached to conservative disability policy and the need for disabled people to accept that "Rome was not built in a day"; while at the other extreme, what is seen to be "reasonable" can be read alongside broader principles of human rights for disabled people to fair and equal access and, ideally, without having to use legal action to arrive at the access that nondisabled people take for granted (Roulstone and Prideaux, 2009).

Furthermore, the authors found that much of these tensions are rooted in the historically ingrained differences of the 'problem' of disability thus concluding that the predominant views of disability in the environment are still based on a medical model which constructs the individual who is not accommodated by their environment as the problem. As a result:

> Questions relating to what is "reasonable" could, therefore, be seen as the willingness of disabled people to fit into existing environments via assistive and therapeutic devices such as the use of wheelchairs (Roulstone, 1998, as cited by Roulstone and Prideaux, 2009).

This approach contrasts with the understanding of 'reasonableness' presented by the social model which is underpinned by ideas of social justice and human rights. In this approach what seems reasonable is that which offers wheelchair users the most dignity and does not discriminate against them. However, despite a change in discourse in policy documents which purportedly emphasise the importance of inclusion, equal access and justice and dignity for people with disabilities, policy and policy making still appears to be strongly influenced by the medical model in contrast to the social model perspective evident in the disability community.

Literature Emphasising Wheelchair-Users Accessing the Built Environment in Cities

Davis (1985) argues that the spatial structure of modern cities mirror and reinforce dominant power relations which, in turn, play a part in the oppression and exclusion of large sections of the population, including those with disabilities. Indeed, The National Disability Authority in Ireland argue that: "[m]any people with disabilities are faced with barriers that exclude them from participating as equal citizens. These barriers can be attitudinal and societal as well as physical" (NDA, 2014).

Barnes and Mercer point out that barriers to physical access "underscore significant barriers to undertaking routine activities such as shopping, going to work and visiting leisure venues" (2010, p.117). These barriers result in a form of social exclusion which, ultimately, makes truly independent living impossible. Moreover, Barnes and Mercer use concrete examples to highlight the various barriers faced by wheelchair users in the city:

> to gain entry to a building may require ramps and easy-to-open doors - [w]heelchair users find that circulation areas and corridors often lack adequate turning space, while upper floors are 'out-of-bounds' due to the absence of lifts and accessible toilets (ibid, 2010, p.117)

These examples highlight the barriers to physical accessibility faced by wheelchair users on a

day-to-day basis. Furthermore, one study which focused specifically on the experiences of disabled people accessing leisure facilities such as a gym or swimming pool showed that a lack of curb cuts, height of reception desk, lack of elevators, inaccessible exercise equipment and changing rooms were all major barriers facing them as service users (Elsworth et al., 2009).

In 'The Irish Times' Kiara Lynch writes of her personal experiences in Ireland as a wheelchair user facing limited or no accessibility to services on a regular basis. Her account illustrates how the theories in the academic literature above play out in people's lives. She provides the example of a restaurant (which complies with legislative requirements under Part M) informing her upon arrival that her table and the accessible bathroom were situated up two flights of stairs and that the staff were going to lift her up. She further discusses her experiences on the train when other customers place their luggage in the wheelchair accessible space and she is forced to sit in the hallway for the journey. Other problems included staff on the train forgetting or not being informed that there is a wheelchair-users on board resulting in long waits for the ramp to appear so that she can depart the train (Lynch, 2013).

Lived Experience

As discussed in a previous chapter, the lived experiences of people who use wheelchairs in interaction with the built environment in Cork City is the central theme being researched in this thesis. This focus is being used to shed light on a minimally understood or researched phenomenon. Hahn proposes that "[j]ust as the definition of disability is determined by the interaction between the individual and the environment, the experience of a disabled person in the city is shaped by encounters with the characteristics of this urban center" (Hahn, 1986, p.280). By understanding this interaction, a better understanding of how our cities accommodate or fail to accommodate populations of varying shapes, sizes and abilities can be developed. This can be used to understand the essence of exclusion and marginalisation in the urban environment.

To begin with, Waksler points to the relation between body and world and the experience of disruption to space and time that are an "integral element" of physical disability (Waksler, 1995). She provides the example of objects such as her office or the first and subsequent floors of the building which were formerly regarded as "near" due to the ease of access with which she could reach then becoming "far" as the extent of her impairments progressed. Thus the interaction between the individual and the environment is altered.

A study in Thailand which focused on the lived experience of one wheelchair-user accessing the built environment highlights the range of limitations and problems experienced by that individual (Sawadsri, 2011). These included being forced to plan and think all day about organising her journey; the physical and mental limitations placed on her by both the built environment and attitudinal barriers and the resulting stress and impact on her psychological health from these struggles which she encounters on a daily basis is considered.

The most informative and telling study carried out was by Imrie and Kumar (1998). This study involved focus group research in the UK on disabled people's (weighted towards the experiences of wheelchair users in particular) experiences of the built environment. It revealed that people with disabilities had a wide variety of responses towards access in the built environment ranging from humiliation to anger, hopelessness and confrontation (1998).

Imrie and Kumar found that the built environment had a role to play in the experience of marginalisation for disabled people. "Inaccessible places are experienced as signifiers of difference and as material obstructions" (p.361) and create a feeling of exclusion. Moreover, they also found that disabled people experienced powerlessness in their desire to contest their exclusion due to environmental/physical barriers because of the professional nature of control over key decisions regarding land-use and building design (Imrie and Kumar, 1998).

One respondent in this research discussed their experience of feeling themselves to be of lesser value than 'seemingly' able-bodied people:

> access is something which is the realisation that you are unfortunately different … every time I go outside of my house I'm reminded that I'm in this wheelchair and I feel I've got a battle on my hands to go where I want to go … the streets are all broken up, it's like a salom course for me … it saps my strength and I feel like people are staring at me (Imrie and Kumar, 1998, p.362).

For some respondents there was a clear experience of binary divides with regard to comfortable and uncomfortable spaces in relation to the experiences of the built environment. They reported receiving often averse reactions from people they encounter in public spaces. Additionally, respondents were aware of a feeling of discomfort generated by their presence. In general, a feeling of inferiority was reported as being experienced but this came less through overt discrimination and more through subtle aversions or patronising comments of how wonderful they are (Imrie and Kumar, 1998).

Other respondents reported the "back door treatment" as an issue arguing that they are very often forced to use a back entrance, back alley, side entrance or any entrance other than the front door. This is interpreted by the authors as a general spatial signifier which separates disabled people from their "normal" counterparts. Other wheelchair users reported experiences of invisibility in social spaces such as pubs where the bar is too high for the person to be seen.

Additional issues included the lack of freedom to be spontaneous and make impulse decisions due to physical restrictions and barriers and, worst of all, one respondent said that of all of their local nightclubs only one is accessible and that one does not have an accessible toilet. They reported that "it's discreetly done under the table … it's embarrassing and degrading but what else can I do" (ibid, 1998, p.366)

Conclusion

It is clear from the evidence presented above that for wheelchair users, the city can be a place

which excludes and marginalises. As one of the respondents explained in the Imrie and Kumar study, it is similar to the experience of entering an obstacle course every time one leaves their home. Yet this experience is relational and occurs through interaction. Socially and geographically, the environment is acting as a, sometimes insurmountable, obstacle which continuously brings wheelchair-users to a stop in their tracks.

However, the interaction does not end there. The individual who experiences this blockage is regularly forced to internalise their feelings towards the event. They sit at the receiving end of a power gradient atop of which are the policy makers, designers and other professionals who make decisions on their behalf regarding these issues. In addition, these professionals rarely facilitate the input of wheelchair users in the decision making process and thus provides little opportunity for them to express their frustrations or provide feedback that may improve the situation. Thus, the interaction inevitably leads to feelings of anger, hopelessness, annoyance, inferiority and more which creates additional stress and, thus, health concerns for the individual in question.

Chapter 4

Phenomenological Research Methods

This phenomenological study utilised a qualitative research methodology to investigate the lived experiences people who use wheelchairs interacting with the built environment in Cork city. This methodology was selected because I was interested in exploring how lived experience interacts with the environment through the perspective of people who use wheelchairs. This study draws on Carol Thomas' (1999) work discussed previously which emphasises the importance of the bio-psycho-social approach. Phenomenology was selected because I believed it was the most appropriate methodology to get to the essence of that experience.

For the purposes of this research I carried out five interviews. Four of the interviews were face-to-face and these were audio-recorded on my mobile device. The fifth was carried out via e-mail. Each of the participants were wheelchair-users. The interviews each lasted approximately thirty minutes. While I had originally intended that the interviews would last in the region of forty-five minutes I found that participants began to get tired and were less inclined to provide new information beyond the thirty minute point. Two of the interviews were carried out in University College Cork. One of the interviews was carried out in the participant's home. Another was carried out in the participant's office. The final participant was meet in their home and we discussed the consent form and all it entailed before I subsequently emailed the interview questions to her and she responded to each question and returned it to me.

Phenomenological Research

The research methodology selected to gather data for this project was qualitative in nature. This methodology was chosen to allow for a deeper response from participants with regard to their experiences of the built environment and it provided the option of pursuing some issues in-depth. The specific methodology utilised was phenomenology. "A

phenomenological study describes the meaning for several individuals of their lived experiences of a concept or phenomenon…[t]he basic purpose of phenomenology is to reduce individual experiences with a phenomenon to a description of the universal essence" (Creswell, 2007, p.58) or a "grasp of the very nature of the thing" (Van Manen, 1990, p.163 as cited by Creswell, 2007, p.58). Thus, phenomenological methods were deemed the most appropriate research methodology for developing and understanding the meanings generated by participants through their experiences of exclusion generated through inaccessibility to the built environment.

Additionally, I aimed for this research to take on a transformational dimension as a complimentary methodology. Describing transformative research as 'participatory action research', Kemmis and Wilkinson propose that this approach is "practical and collaborative because it is inquiry completed "with" others rather than "on" or "to" others" (1998, as cited by Creswell, 2013, p.26). Thus, as was the case with this study, transformative authors encourage participants to play an active role in designing their research questions. Therefore, one interview was carried out as an open pilot interview and left deliberately broad and was then analysed to inform the formulation of questions for the remaining interviews. This is known as a bottom-up approach.

This was deemed an appropriate strategy because, as I am not a wheelchair user, I do not have direct experience of the interaction in question. Nevertheless, I wished to ensure that the questions I asked were based on the experiences of the participants and not only on my experiences as a Personal Assistant. Moreover, I was aware that my professional experience in this area may have positioned me with a set of assumptions around this issue which I wished to bracket and put aside so as to not interfere with the 'purity' of the responses. For that reason a pilot interview was selected as an appropriate strategy to allow me to put my values and assumptions to one side and, instead, bring an attitude of curiosity to the process. To that end, a bottom-up approach involving a pilot interview allows for the remaining interviews to address the issues which were highlighted to me by a participant, as oppose to the issues which I might have pursued were I to have constructed the questions

purely on the basis of my own experience. Nevertheless, as these interviews were semi-structured, the author did not limit the scope of the questions to only those issues mentioned in the pilot interview but used them as a guide to forming questions and, when appropriate, would veer into unexplored territory with some participants if their experience did not speak directly to that of the pilot interview.

Procedures Utilised in Conducting Phenomenological Research

Creswell provides a series of steps for conducting phenomenological research which I utilised in this study. They are summarised here:

- A phenomenon of interest - in this case: the lived experience of wheelchair accessibility in the built environment - was identified.
- I determined that this research problem is best examined using a phenomenological approach because it is a type of problem in which it is important to understand several individuals common or shared experiences of a phenomenon.
- I recognised and specified the broad philosophical assumptions of phenomenology and in this case the interaction between the objective reality of the built environment with the lived individual experiences which were 'conscious' and directed towards an object.
- I collected data from the individuals who experienced the phenomenon using five in-depth semi-structured interviews which were recorded using my mobile device.
- The participants were asked two broad general questions. 1) What had they experienced in terms of the built environment? 2) What contexts or situations had influenced or affected those experiences?
- I utilised Interpretative Phenomenological Analysis in the data analysis. "The aim of interpretative phenomenological analysis (IPA) is to explore in detail how participants are making sense of their personal and social world, and the main currency for an IPA study is the meanings particular experiences, events, states hold for participants" (Smith and Osborn, 2007, p.53). In this research, I utilised interpretive phenomenological analysis by

suspending my own preconceptions in order to get a grasp of the life world of the participants. I did this through the use of reflective journaling after each interview. A sample journal can be found in the appendices of this study. Following that, I used it in the analyses of the data (interview transcripts) by using a bottom-up approach. This involved highlighting significant statements, sentences or quotes that provide an understanding of how participants experienced the built environment and then I developed clusters of meaning from these statements into themes. Thus the use of IPA in this research meant that I was not setting out to test a hypothesis but simply to 'see what comes up'.

- These themes were then used to write a 'textural description' of what the participants experienced and a description of the context or setting that influenced how the participants experienced known as structural description. I also wrote about my own experiences and the context and situations in which they took place. These have been attached in the appendices of the research paper.
- Using the textural and structural descriptions I wrote a composite (or essence) description which focused on the common experiences of the participants (Creswell, 2007, p.60-62).

Style of Interview

For the purposes of this study, I employed semi-structured, in-depth interviews with five participants as a method of primary data collection. "An in-depth interview is a one-to-one method of data collection that involves an interviewer and interviewee discussing specific topics in-depth" (Hennink, Hutter and Bailey, 2011, p.109). Thus, some authors understand in-depth interviews as a conversation with a purpose (ibid). In-depth interviewing can be understood as process of producing meanings between participants and interviewers (Hennick, Hutter and Bailey, 2011). The in-depth interviewing approach was deemed the most appropriate for the interviews in this study because it best allowed for the expression of the everyday social world and lived experience of the participants.

Furthermore, these interviews involved a semi-structured approach. In a semi-

structured interview "the interviewer has a schedule of questions, some tightly phrased to elicit clear, simple responses and others open so that some issues can be explored more freely" (Greetham, 2014, p.224). I chose a semi-structured approach to allow for maximum flexibility in the research process and because it complimented the phenomenological nature of the study. This approach was utilised by asking broad open-ended questions and using probes such as "can you tell me more about that" whenever the interviewee mentioned something that was of significance. A typical in-depth, semi-structured interview takes on the following structure: introduction, opening questions, key questions and closing questions.

This structure is usually utilised as a means of establishing rapport with the participants. Thus, during the early part of the interviews I attempted to create feelings of trust in the relationship by introducing myself, stating my reason for carrying out these interviews and asking broad general questions about the participants lives to begin with in order for them to feel more comfortable when turning towards the more specific questions relating to their experience. In the middle of the interviews I asked key questions relevant to the topic of the research and at the end of the interviews I attempted to close them smoothly by 'fading it out' rather than ending it abruptly when I had acquired the information I needed (Hennick, Hutter and Bailey, 2011).

Recruitment Strategy

This research was carried out in collaboration with Community Active Research Links (CARL) in University College Cork and with the Cork Centre for Independent Living (CIL). CARL is a research initiative which assists civil society organisations (CSO's) in carrying out research relevant to their areas by matching students who are researching these topics with organisations who need the research carried out.

CIL is a civil society organisation organisation which is "committed to working towards the removal of barriers to inclusion and working for rights-based equality legislation for people with disabilities" whose primary aim is "to empower and enable people with

disabilities to achieve independent living, choice and control over their lives and to achieve full and active participation as equal citizens in society" (corkcil.ie, 2011).

The participation in the study was on an entirely voluntary basis. There was a small number of inclusion and exclusion criteria. The inclusion criteria were the following: a) All participants were required to be adult wheelchair-users. b) All participants were required to be based in Cork city. The exclusion criteria were the following: a) None of the participants had a significant intellectual impairment which would add an extraneous variable to the homogeneity of the sampling. b) None of the participants were known professionally to me which would create a dual-relationship with them and interfere with the nature of response received.

In order to recruit participants for this study. The Cork Centre for Independent Living made contact with their service-users via email informing them of the study and asking if anyone was interested in taking part. Six participants responded to this email and were, in turn, put in touch with me via email. After initial consultation with each participant, again, via email, five of them chose to take part. Following this, dates, times and locations were arranged through a combination of emails and phone-calls. Table 1 outlines basic details of each participant interviewed in this research.

Participant's Pseudonym	Gender	Age Range	Type of Wheelchair
Mary	F	20-30	Powerchair
Jayne	F	40-50	Manual
Liam	M	30-40	Powerchair
John	M	30-40	Manual
Susan	F	40-50	Powerchair

Collaboration

Regular contact was maintained with Nicola (the person in the Centre for Independent Living who assisted me throughout this project) and she was available to answer any queries that I had or issues that presented themselves as I was carrying out the research. Towards

the end of the research process, a draft of the completed project was sent to Nicola to ensure that it was what she (and the Centre for Independent Living generally) were expecting and to ensure that she had an opportunity to provide her insight and feedback. A draft of the completed project was also sent to Dr. Anna Kingston from the Community Academic Research Links initiative in UCC who also provided insight and feedback to the project from her perspective. The combination of these inputs with that of my supervisor's Dr. Fiona Dukelow securely positioned this project within the collaborative values espoused by CARL.

During the period of time that I carried out this research I encountered a significant access issue in the city which posed a considerable danger to the welfare of service-users and PA's alike. In light of this project I decided to raise this issue with the Centre for Independent Living and they, in turn, directed me towards the Access Group in Cork city who are responsible for raising significant access issues with the city council. As a result of my involvement with this project I was invited to attend a meeting with the access group that I would present the issue at a meeting in light of my findings from this research project. This meeting will take place after this project has been submitted.

Visual Methodology

I had originally intended on including a visual element in this research which would involve participants sending me photos of access issues they encountered in the city while living their everyday lives and a brief description of what it meant for them to encounter it. This was an optional extra dimension to the research and it was mentioned in the initial correspondence and meeting at which point only one of the participants expressed an interest in pursing it. For that reason, I decided not to include this element in the research.

Ethical Considerations

As this was social research, it was important to acquire ethical approval before beginning. For that reason, I sought ethical approval from The Social Research Ethics Committee in order to carry it out. To acquire this, I was required to submit an application with all the

details of the research project, the approval of my supervisor and a copy of the consent form that I would use when interviewing participants.

There were a number of ethical issues which were of concern for this project. One of these was the issue of anonymity. As the results of this thesis were to be published through the CARL website in UCC, it was important that the participants in this study were not identified. This was explained to the participants in full so that they had no concerns with regard to their identities being published or used as part of the dissertation. Additionally, I informed participants that any data collected from the interviews would be stored securely on a password protected device, and stored in the appropriate UCC storage facility in line with UCC policy for a minimum of ten years.

Furthermore, I acquired informed consent from each participant by requesting that they read (or I read to them aloud in the event that their own reading is incapacitated through disability) the pre-prepared consent form and ensure that they understood and gave their informed consent to participate. I informed participants that they were free to back out of the research at any point before it began, during the interview or after it had taken place (this was also stated explicitly in their consent forms). In the event of this occurring during or after an interview, I explained to participants that their data would be securely destroyed. I ensured that no interviews were carried out with participants with whom I had worked previously in my capacity as a PA. I deemed this an appropriate method because I wished to avoid the formation of any dual relationships with participants.

Finally, in the interests of clarity for participants, I stated explicitly to them that this research was being carried out by an independent researcher in collaboration with the Cork Centre for Independent Living. However, participants were informed that choosing to take part or not take part in this interview process would not impact on their relationship with the Cork Centre for Independent Living in either a positive or a negative capacity or in any other way whatsoever.

Limitations

In the interpretation of all qualitative data there is a risk of the researcher introducing their own bias into the material. Van Manen argues that in using an interpretive approach to a phenomenology it is impossible to bracket one's own experience (Van Manen, 1990). Instead, I chose to suspend my own understandings in a reflective move which cultivates curiosity as suggested by LeVasseur (LeVasseur, 2003 as cited by Creswell, 2007, p.62).

Some of the participants found it difficult to reflect on their lived experiences of the phenomenon and were more inclined to provide mechanistic details of the built environment instead. While this was interesting in its own right, it did not speak directly to the focus of this study. While I did my best to compensate for this through the use of probing and other means, the fact that this was a third year undergraduate research study was a significant limitation. For example, the interviews were once off and each was relatively short.

Chapter 5

Lived Experiences & Discussion

In order to understand the lived experiences of wheelchair-users accessing the city, I set out on this study with two broad general questions in my introduction which I will reiterate at this point. These are:

1) What physical barriers are experienced by wheelchair-users in Cork city throughout their everyday lives?

2) What is the lived experience of wheelchair-users encountering physical barriers or undignified access issues in the city?

I attempted to answer these questions using the interview methodology set out in the previous chapter. In this chapter, I present the findings of the study and discuss the themes that emerged. These themes are sequenced spatially in an attempt to give the reader a tangible experience similar to that of the participants. I opted to order the themes sequentially in space in order to give the reader a framework for understanding their own experience of living their everyday lives comparatively. Thus I attempted to give the impression of 'being in their shoes'. The themes that emerged in order are the following:

1)Painstaking Forethought

2)Getting to Places – Transport and Mobility

3)Getting Inside of Places and Undignified Access

4)Being Marooned Once Inside

5)Access Distress

Two other issues emerged from the data very significantly. These were 'lack of awareness' and that 'different wheelchair-users have different needs'. While these are very important issues that need to be researched in their own right, I opted not to include them in this research because this study is explicitly focused on the lived experiences of the participants and, therefore, these issues were not specifically relevant to the topic at hand.

1) Painstaking Forethought

Participants described their experiences of having to plan their lives around the built environment when living everyday life in the city. They highlighted how this was necessary in order to ensure that they could access a service, street, building etc. when going anywhere in the city. Jayne, for example, points to the issue regarding lack of and abuse of accessible parking spaces when attending entertainment venues:

Now I'd be looking let's say I'd want to go to the cinema or the opera house… I would have to look the day before at parking or let's say I'd go to town and there's one parking spaces up there outside the metro but often it's gone

- Jayne

Liam, argues that planning is involved in the vast majority of activities that he takes part in everyday:

Ah there's planning I suppose involved in more or less 80% of what I do everyday

- Liam

Susan points to the limitations and fears involved in going to places she hasn't been to before due to the potential for lack of accessibility.

It is important to be aware of the area to make things as easy and safe for you as possible and for others… Yes, I stick to my same pubs and restaurants, shops, cinema

- Susan

This suggests that Susan actually expects the environment to be limiting in any place that she has previously not been to and that this seems to be the norm for her. When asked if she

often finds herself experiencing isolation due to lack of accessibility in the built environment Susan said:

I try not to let this happen but sometimes it's inevitable [so] it's disheartening you don't [feel like] part of society

- Susan

Susan exemplifies how the environment can play a part in the exclusion and marginalisation of wheelchair-users and people with disabilities generally.

2) Getting to Places – Transport and Mobility in the City

Participants raised the issue of transport in the city in every interview as a significant problem in their personal lives and discussed the impact that this has on them. In this instance, transport and mobility refers to both public and private transportation services as well as privately owned vehicles and even using the streets and pavements an individual transport options. Modes of transport specifically raised included buses, coaches, trains, taxis and privately owned vehicles. Problems raised included issues of inaccessible city buses and inaccessible coaches, too few accessible taxis and under provision. Some participants owned their own cars and issues for them included the inadequate or abuse of parking spaces.

Taxis:

Mary highlights issues she experiences due to the lack of wheelchair accessible taxi availability in the city:

Taxis are my big bugbear, it's impossible to get a wheelchair taxi…

- Mary

Susan also points to issues in getting a taxi:

Taxis are not accessible to all wheelchair-users and are rarely available

- Susan

These issues highlight the shortage of accessible taxis available for wheelchair-users in Cork. Moreover, Liam discusses the difficulty in getting a taxi to pick him up when the taxi driver could collect a group of others without any access issues instead:

I know for a fact that wheelchair taxis are the hardest thing to organise in Cork because of the lack of wheelchair taxis… Like, wheelchair taxis are there but they're not being used for wheelchair-users. It's quicker for the taxi driver to drive up to the door… and lob in like six to eight people who have no accessibility issues.

- Liam

Additionally, Liam describes his experience of taxi drivers discriminating against him with regard to picking him up:

But there are drivers out there who just couldn't be bothered to use the ramps… you ring a Dublin taxi company and you say I've a wheelchair am going to say the I dunno train station… if I rang individually they'd say sorry we don't have one but if I got a hotel to ring they'd say "oh yeah, no problem"

- Liam

Coach and Train:

Mary points to coach and train transport as highly problematic for a number of reasons:

if you want to go on a long haul bus journey you have to give forty eight hours notice same with the train… And that's really really annoying

- *Mary*

This illustrates one of the reasons that planning might play such a large role in participants'

lives. Additionally, Mary describes her experiences of being stuck on the coach for hours because the staff were inadequately trained to deal with a wheelchair accessibility issue when it occurred:

the Bus Eireann bus staff are completely inadequately trained. Like (…) am, I go to Waterford regularly because a friend of mine is living in Waterford… and there's a hydraulic lift and none of them know how to use it… am, it's constantly breaking down because they're inadequately trained and their answer when it stops working is to kick it… I was stuck up on a bus for two hours about nine months ago because they couldn't get me down. My friend has had to leave her wheelchair on the bus and call her mother to bring a manual wheelchair to get her down off the bus.

- Mary

Staff who lack training and awareness play a large role in the lives of wheelchair-users who, as a result, are left dependent on people who do not know how to help them.

City Buses:

Liam discusses how city buses only take one wheelchair thereby forcing him to travel individually if he and his friend who also uses a wheelchair want to go somewhere together.

I mean nowadays for instance the bus service ehrm is pretty good…in terms of wheelchair-users it's not as reliable as it should be… because of the fact that they can only carry one chair per bus so it's a bit annoying if you're like want to go to town with friends or something… so if that happens one person has to get the bus and then the other person has to wait for the other bus

This type of individualised service has a large impact on social relations and everyday lived experiences by preventing wheelchair-users from travelling together if they so wish. Moreover, this is an issue which many able-bodied people take for granted when using city buses.

Parking:

Jayne points out that parking is a big issue when her Personal Assistant takes her into the city. Her experience highlights the implications it has for wheelchair-users when the accessible spaces are taken:

the disabled parking twas already full so we'd to find when we parked in the normal parking there was no space for the wheelchair then… So [my personal assistant] had to back the car out, get me in the wheelchair, hold up the traffic until I was in the wheelchair safely and then she pulled in her car

- Jayne

In this instance, the shortage of parking spaces causes significant disruption to the participant's everyday life as well as the lives of their personal assistant and the general public who were present during this process. Furthermore, John points out that some spaces which are designated as accessible are not designed with a wheelchair-user who drives their own car in mind:

instead of dipping the curb all along the the driver side they'll have a full you know footpath there and so you can't put your chair. So you can't transfer in so I've had time where I've had to park the car a few feet from the curb and then have someone else park my car in on the road-back in next to the footpath

- John

These points also illustrates the under provision of accessible spaces and point to a need for further investment in parking spaces to enable equal access in the city centre for both wheelchair-users who drive and those who do not drive.

Pavements:

This was the last issue of mobility in the city that emerged through the data. Participants reported having to backtrack regularly due to obstructions in the environment which would

result in them having to find new ways of getting to the same destination.

Actually like footpaths, yesterday I was in the cemetery in Saint [Saint's Name] and my carer's marvellous and up and down the footpath she went… but the eh dipping down they call it ditching was away up the other side and to take a shortcut I need dipping or dishing on both sides

- Jayne

I hate wheelie bins and dread the way they are thrown on the footpaths. Footpaths are narrow enough without trying to squeeze past a bloody wheelie bin. I have actually had to go backward so that I could get off the footpath and drive on the road where I have been shouted at by motorists

- Susan

3) Getting Inside of Places and Undignified Access

Participants reported their experiences of getting into places once they have arrived. Issues raised were those of segregated entrances such as entrances through the kitchen in the case of some bars and restaurants and access which is provided but in an undignified manner. Liam explains how he just wants to see a maximum availability of accessible places:

I spose the main issues for me would be ah ah like accessibility into as many buildings as possible without having to feel like you know you're causing havoc

- Liam

Of note here is the experience of 'causing havoc' mentioned by the participant. Social spaces such as bars and restaurants are often arranged with supposedly 'able-bodied' people in mind. Therefore, many spaces arrange chairs and tables in such a way that they may not be passable for a wheelchair and, therefore, need to be moved. This experience can cause disruption which naturally could lead to feelings of embarrassment, frustration, anger disappointment and more for the person involved. Moreover, Liam also points to his experience of being segregated regarding entrances as an issue:

They had a side entrance door which was electronic for wheelchair-users… I ah kind of have an issue about being segregated

- Liam

In this instance the participant self-reported being segregated from mainstream society due to an entrance as an issue which was unacceptable. Regularly, entrances for wheelchair-users are provided separately to the rest of the population in order to provide accessibility. However, segregated entrances are also spatial signals of difference which leaves participants feeling marginalised and excluded. Next, Liam discusses his experience of having to 'go around the back':

I'd have to go around the back of the Building to come in because the accessible door was locked and then you'd find the entrance was locked because the switch wouldn't work or the switch was damaged due to water-log and then the security guards wouldn't realise I was there because no one would look at the camera so like dya know

'Around the back' has implications of second class citizenship and is another example of how the environment can produce spatial signifiers of difference. Finally, Liam discusses the experiences of having to use entrances to bars or restaurants which are designated for the delivery of goods and other products.

there are other buildings slash restaurant or pubs or whatever that will say "oh yeah we have an entrance through the kitchen or we have an entrance through the side of the building" and you're there kinda going "pffft fair enough" like do you know… it's important for [us] to feel that you know we're not segregated or we're not pushed in the corner like in the 60's or 70's

- Liam

Again this represents a spatial signifier of difference and a form of second class citizenship. Moreover, it also has implications of undignified access. Forcing people with disabilities to use the same entrance as the stock entering and exiting premises exposes the values inherent in the construction process which prioritise the access of products over people. Finally, the participant's own response 'pffft, fair enough' suggests a reluctant resignation to conform and speaks volumes in its own right. While some places provide undignified access, participants also discussed their experience of being altogether excluded from a range of places due to a lack of accessibility. Some places are simply impossible to get into due to accessibility barriers as illustrated by these participants:

even crossing a road and you have a large curb to navigate which be it can be physically impossible for some wheelchair-users

- John

If for instance I was in the ehm… [building]. *I can't use those buildings because there isn't access for wheelchair-users. And plus they're too small*

- Liam

Ehm for instance [a shop] on Patrick Street they have ehm small lift but it's too small to carry my chair and plus nobody who's employed there knows how to use it

- Liam

Clearly the environment can play a crucial role in the lived experience of wheelchair-users in the city when it forces them to be confronted with spatial signifiers of difference continuously while they interact with it.

4) Being Marooned Once Inside

A range of issues are also highlighted regarding the experience of participants once they have successfully accessed a building. These issues included undignified access to bathrooms and

being marooned and unable to exit. Mary discusses her experience of accessing bathrooms in nightclubs:

It's more am (…) social environments like nightclubs…They say they're accessible and you can get in the door but there's no bathroom for you to go to…And most of them are upstairs and they're like "oooh we can get a bouncer to carry you up"

- Mary

This also highlights the issue of undignified access. If a person must be carried into a bathroom in order to use it when enjoying a night out, that could have significant implications for their psycho-emotional wellbeing and their desire to socialise whatsoever. Jayne points to problems accessing bathroom even in public buildings:

There was somebody from C.I.L. in the toilets up in the hospital C.U.H… [they] could not close the door

- Jayne

Similarly, John discusses his experiences of having his access blocked by mops or buckets which are placed on the route to the accessible bathroom:

Well it would happen regularly whereby I would go to use a wheelchair accessible bathroom and am they're often used as storage areas for so there'd be mops and stuff like that ammm and am buckets in the in the side in the within the bathroom itself so when you get there you can't close the door because there's a mop bucket or… there's you know cleaning facilities like it's like it's do you know the bathroom is just a storage area for whatever. There was one particular I was in a pub and am I went to use the bathroom and the the laneway to the bathroom was actually full of kegs of beer which made the pathway to the bathroom totally inaccessible. So even though the bathroom when you did actually get there that was accessible the pathway to it was inaccessible

- John

This example illustrates a lack of awareness on behalf of staff providing a service. Moreover, it also speaks to the undignified access experience of the participant who was could not use the bathroom because cleaning equipment was placed in his way. Next John describes his frightening experience of being trapped in a bathroom because a fire-door was too heavy for him to move:

Am another issue which is very regular is they will put a very heavy hinge on the door. It's like a fire safety I don't know what it is but like am that means that you have to pull against the door push against the door and for a lot of wheelchair-users then that might have other impairments like in their hands and stuff like that like I have impairments in my hands and ah if I was to try and pull the door backwards with a heavy hinge I probably wouldn't be able to do it. I've been stuck in toilets on occasions because I can't actually get out

- John

Several stories from participants emerged from the interviews regarding the experienced of being forgotten about or marooned by security guards or other figures of authority who were to be providing them with assistance. Participants explain:

then there was issues about the door door it wouldn't open and I'd have to get the security guards to open to and am sometimes then I'd be left out in the rain because they'd forget that I'd be coming in … and there'd be no security guards there

- Liam

I remember they used to have a temporary ramp but then people in power-wheelchairs would be out in the rain while the men would be getting it

- Jayne

Most striking is the following experience of Jayne who remained marooned in her house for a number of weeks due to the fact that her neighbour had gone on holidays while leaving their car parked on the footpath which resulted in it being inaccessible for her:

I mean for example now this car parked outside on the road the road is not mine but it's parked there for nearly four weeks and I can't it makes me going out in the road and I risk a car coming on the road so with the result I don't go out with my wheelchair

- Jayne

Many of these experiences are distressing for participants and in some cases quite frightening. Fittingly, the final theme that emerged from this research was the emotional experience of accessing the built environment.

5) Access Distress

Access distress is a term I've coined to describe the emotional experience of encountering accessibility issues for wheelchair-users. All of the participants tended to respond to questions of the emotional experience with brief or one word answers. The term 'frustration' came up in every interview. Feelings of 'anger', 'fear', 'disappointment', 'embarrassment', 'loneliness', 'devaluation' and 'loss of confidence' were all the feelings mentioned. Interestingly, one participant also said the following when asked how he felt when encountering an accessibility issue:

It kinda makes me feel like want to do something about it in terms of like (…) like I've gained a lot of experience from spending time in [education] ehm I just turn around and go 'sorry that's not good enough' you know, you have to be willing to take the ball and run with it

- Liam

Conclusion

To conclude, this study elicited participant's lived experiences of the built environment in Cork city. It therefore represents a successful effort to enter into the participant's world. Participants provided a detailed description of the physical barriers that they encounter living their everyday lives in the built environment. Moreover, they offered a rare insight into their own lived experiences of this reality and provided a tangible look at what this is like. Ultimately, it seems that participants experiences of the city are predominantly negative. This is evidenced by the themes which emerged, and are listed above, which give a clear impression of the experience of exclusion and marginalisation manifesting through the built environment.

Discussion

Several of the themes identified were particularly relevant in light of previous literature with similar findings. For example, the theme of Getting to Places and Undignified Access which is raised in this study is mirrored in Davis (1985), the National Disability Authority (2014) and Barnes and Mercer (2010) when they point out that physical barriers in the environment can play a role in oppressing and excluding people with disabilities from undertaking routine activities and preventing them from participating as equal citizens in society.

Waksler's (1995) analysis of the disruption of space and time caused by obstructions for people with physical disabilities shares similar threads with the theme of Mobility and Transport raised in the current study which explored how participants attempting to access the environment are often forced to go the long way due to obstructions. Waksler proposes that spaces which were previously near become far as a result of impairments which takes them longer to be reached or accessed. This is similar to the experience of participants in the current study where individuals are forced to take convoluted routes in order to reach the location that they are aiming for due to obstructions and barriers in the environments. While this study and Waskler's study share similar threads, it should be noted that in the current study, the cause of the obstacle course lies not in the individual with impairments but rather

in the environment which produces barriers that hinder access, thus placing this study firmly within the social model. However, in contrast, Waksler's study seems to emphasise the impairments themselves as the disabling force which positions that closer to the medical model of disability.

Next, the theme of painstaking forethought was also seen in the literature review. Sawadsri (2011) raised the issue of planning as a major component of the experience of someone with a disability which places significant limitations on their experience. Similarly, in the current research a number of participants raised the issue of having to plan their lives out as a result of the limitations placed on them by the built environment with one participant saying that there's planning involved in 80% of what he does on a daily basis.

In addition, Imrie and Kumar's (1998) study carried out in the UK shared a significant number of thematic threads with the current study. For example, with regard to participant's emotional experiences of the built environment, the feelings mentioned were similar to those in the theme of Access Distress in the current study. Participants in Imrie and Kumar's study expressed feelings ranging from humiliation to anger, hopelessness and confrontation with one participant raising the issue that their experience of accessing the built environment resulted in them feeling of lesser value than able-bodied people. Feelings mentioned in the current study included embarrassment, frustration, anger, fear and devaluation.

Moreover, the experience of the 'back door treatment' discussed in the Imrie and Kumar study corresponds with the theme of undignified access in the current study. Indeed the understanding of the environment as a spatial signifier of difference proposed by Imrie and Kumar fits accurately with the experiences highlighted by participants in the current study who raised issues of segregation and the importance of not feeling segregated.

Thus, several of the themes raised in this research are consistent with those raised in previous similar studies. Finally, other issues emerged from the data but were not strong enough to be considered themes. For example, when asked about what comes up for them in response to mention of the built environment, both male participants in the study responded

that issues which able-bodied people take for granted were significant. Interestingly, none of the female participants gave this response. I did not pursue this theme because there was not a gendered dimension to this research. However, differences of lived experience based on gender would be an interesting follow-up study. Indeed, differences of lived experience based on race and ethnicity would also make an interesting follow-up.

Another issue which came up was that of frequenting the same places regularly when out during everyday life to avoid running into accessibility barriers. For some participants this experience is a normal part of their everyday lives. Others refused to be restricted in this way.

A number of participants expressed their frustration with the regularity at which social venues such as bars, restaurants, nightclubs and cafes would claim to be accessible but, despite complying with Part M, in practise would have a range of issues such as a small step at the entrance, a table situated up a set of stairs, a blocked corridor, a bathroom which was situated upstairs or an accessible bathroom which was too small to close the door when being used. This raises the issue of Part M of the Buildings and Regulations Act and the ambiguity of its meaning and application.

In addition, an issue which was brought to my attention in a number interviews was that different wheelchair-users have different needs. Manual chair users reported that they felt they had fewer challenges in accessing the environment than their counterparts with power chairs. This is because power chairs are larger and take up more space and manual chair users tend to have greater mobility in their upper bodies. This highlighted a further issue with Part M regarding the definition of wheelchair accessibility. If different users have different needs and requirements then what exactly constitutes accessibility?

Chapter 7

Conclusion

In conclusion, the two broad general research questions which I began with are the following:

1) What physical barriers are experienced by wheelchair-users in Cork city throughout their everyday lives?

2) What is the lived experience of wheelchair-users encountering physical barriers or undignified access issues in the city?

With regard to the first question, participants provided extensive details of the barriers that they face in the built environment such as parking issues, issues accessing transport, obstructions on footpaths, issues accessing social venues and others. Significantly, participants also outlined their lived experiences of this phenomenon raising themes such as exclusion from places, undignified access, access distress, painstaking forethought, being marooned and others. Moreover, on that basis, the current research has successfully provided a rare insight into the lived experiences of the participants. Overall, the participants provided a predominantly negative picture of their world with regard to the built environment in Cork city and the interaction that they have with it on a daily basis. For example, the theme of access distress highlights the emotional component of this research and shows how participant's lived experiences are 'frustrating' and 'disheartening' as described by participants.

Other themes such as exclusion from places reinforce Davis' (1985) idea that the built environment can be an oppressive and exclusionary force which serves to reinforce dominant power relations and indeed shows that the experiences of participants in Cork city correspond with Carol Thomas' idea that disability expresses an unequal relationship between people and the ascendency of the non-impaired over the impaired (1999) which, in this case, manifests through the environment.

Participants' account of their experiences suggest that, as proposed by Thomas,

disability occurs in the relationship or interaction between an individual who experiences an impairment and the social world that they exist within. In this case, the built environment acts as part of the social world which represents the unequal power relationships between non-impaired and the impaired. Thus, this relationship does not occur simplistically in either one of the experience of impairments or the social environment. Although the data in this study are exploratory, they may have implications for policy and legislative development in this area in the future. As it stands, it seems that policy and legislation such as Part M and the United Nations Conventions on the Rights of Person's with a Disability are either largely ignored or have been deemed failures to effectively address the issues regarding access to the built environment and services in the city. This reality is reflected in the experiences of participants in this study.

Furthermore, although this was an exploratory study which is not necessarily generalizable in the way that a larger study might be, it is significant that the five participants in this study reported similar experiences which correspond to the previous literature in the area and that should not be dismissed. Moreover, I would argue that even one person's experience is important and can provide insight. What was made clear from the phenomenological nature of the study is that the effects of social policy are not abstract or distant from people but rather its effects trickle down into the lives and everyday experiences of the people at whom it is aimed. Therefore, this study raises more questions than it answers. For example, further research might investigate the experiences of wheelchair-users with an emphasis on gender or race/ethnicity; older adults with reduced mobility in accessing the built environment; the experiences of people who have visual loss; and explore whether these experiences are comparatively similar or different to the findings in this research; and, consequentially, what are the implications for social policy as a result?

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Appendices

INFORMATION SHEET



Purpose of the Study. As part of the requirements for the Bachelor of Social Science Degree at UCC, I have to carry out a research study. The study is concerned with exploring the lived experiences of wheelchair users encountering physical accessibility issues in Cork City.

What will the study involve? The study will involve 45 minute to 1 hour interviews where I will ask questions regarding the nature and experience of encountering physical accessibility issues for wheelchair users.

Why have you been asked to take part? You have been asked to take part because your experience as a wheelchair user in Cork City is specifically relevant to the area study and will provide helpful insights.

Do you have to take part? No, you do not have to take part. In signing a consent form you agree to take part for now but are always free to withdraw from the study before it commences or after data collection has begun. You will also be given a copy of the consent form to keep. You will also have a two-week period after the interviews are concluded within which you will have time to withdraw and have your data destroyed if you so wish.

Will your participation in the study be kept confidential? Yes. I will ensure that no clues to your identity appear in the thesis. Any extracts from what you say that are quoted in the thesis will be entirely anonymous.

What will happen to the information which you give? The data will be kept confidential for the duration of the study, available only to me and my research supervisor. It will be

securely stored on the relevant UCC database. On completion of the project, they will be retained for minimum of a further ten years and then destroyed. Any physical data pertaining to the project will be kept in a locked filing cabinet in a secure place and consent forms and all other identifying information will be kept separate. This data can be destroyed after analysis. All electronic versions will be stored for the minimum ten year period as per the university policy and will be stored in a laptop which is password protected.

What will happen to the results? The results will be presented in the thesis. They will be seen by my supervisor, a second marker and the external examiner. The thesis may be read by future students on the course. The study may be published in a research journal. They will be published on the Community Active Research Link (CARL) website as part of the community research initiative that this project is a part of.

What are the possible disadvantages of taking part? I don't envisage any negative consequences for you in taking part. It is possible that talking about your experience in this way may cause some distress. It should be noted that, while this study is carried out in conjunction with the Cork Centre for Independent Living, this is an independent piece of research and choosing to take part (or not take part) will not impact on you (the service-user's) relationship with the Centre for Independent Living either positively or negatively or in any way whatsoever.

What if there is a problem? At the end of the procedure, I will discuss with you how you found the experience and how you are feeling. If you subsequently feel distressed you should contact your GP.

Is there anything else? A further dimension of this research is for participants to provide photographs of accessibility issues that they encounter in Cork city if they so wish. These photos will not be linked to the participant in the study and will anonymized like all of the other data.

Who has reviewed this study? Approval must be given by the Social Research Ethics Committee of UCC before studies like this can take place.

Any further queries? If you need any further information, you can contact me: [*Michael O*

Donnell, 114409152@umail.ucc.ie. My research supervisor is Dr. Fiona Dukelow in the Department of Applied Social Studies. She can be contacted at F.Dukelow@ucc.ie.

If you agree to take part in the study, please sign the consent form overleaf.

[Over…

CONSENT FORM



I……agree to participate in Michael O Donnell's research study.

The purpose and nature of the study has been explained to me in writing.

I am participating voluntarily.

I give permission for my interview with Michael to be audio-recorded.

I give permission for any photos I provide and their descriptions to be included in the study.

I understand that I can withdraw from the study, without repercussions, at any time, whether before it starts or while I am participating.

I understand that I can withdraw permission to use the data within two weeks of the interview, in which case the material will be deleted.

I understand that anonymity will be ensured in the write-up by disguising my identity.

I understand that disguised extracts from my interview may be quoted in the thesis and any subsequent publications if I give permission below:

(Please tick one box:)

I agree to quotation/publication of extracts from my interview

I do not agree to quotation/publication of extracts from my interview

Signed: …… Date: ……..

PRINT NAME: ……