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Beyond barriers:

a critical realist perspective on disability and the
meaning of the dwelling

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Abstract

This research engages with critical realism to reassess the meaning of the dwelling for physically disabled individuals. Much of the existing literature on experiences of the dwelling for physically disabled individuals has explored functional design issues. In doing so a homogenous view of the meaning of the dwelling has been presented, one that has largely neglected the influences of both agency and physiology. To remedy this neglect this research seeks to explore the possibility for difference in the meaning of the dwelling and in doing so move beyond the explanations presented in the past.

Drawing on the data generated through life history interviews with nineteen individuals with a wide range of physical disabilities, this thesis explores the range of events that can affect the meaning of the dwelling for physically disabled individuals. Moreover, by developing a critical understanding of critical realism, over the course of the thesis an analytical framework will be developed; a framework that can help explain the experiences of the nineteen participants in a non-reductionist fashion. Principally, this framework will highlight the impossibility of reducing experiences to just one cause and assert the need to recognise that a combination of structures, mechanisms and events co-determine the meaning of the dwelling.

By taking an epistemological position influenced by critical realism it becomes possible to acknowledge experiential diversity in the form of: episodic issues; type of impairment; biographical accomplishment; emotional attachments; impact of care services etc. without disregarding all important issues of design or homogenising experiences. In doing so this research not only makes a contribution to the meaning of the home literature, but to disability and housing studies in general.

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However this thesis is dedicated to Len Harris (Grandad), David Harris and Agnus Slorance (Granny), three close family members who died during the course of this research project. Treasured memories always.

Author's declaration

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree

Signed amw/achmil (candidate)

Date 05-10-2007

Statement 1

This thesis is the result of my own investigations, except where otherwise stated. Other sources are acknowledged by footnotes giving explicit references. A full bibliography list is appended.

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Table of contents

Abstract	ii
Acknowledgments	iii
Author's declaration	iv
Table of contents	v
List of figures and tables	ix
Chapter 1. Introduction: issues and intentions	1
1. 1 Introduction	2
1. 2 Identifying key concepts	3
<i>1. 2. 1 A house, a home or a dwelling?</i>	3
<i>1. 2. 2 Models of disability: what is 'disability'</i>	5
1. 3 Intentions and objectives	9
1. 4 Plan of forthcoming chapters	13
Chapter 2: Disability, care and housing design: contextualising the research	16
2. 1 Introduction	17
2. 2 From institutionalisation to community care	18
<i>2. 2. 1 'Caring' for disabled individuals: The Poor Law 1601 to the National Health Service and Care in the Community Act 1990</i>	18
<i>2. 2. 2 Community care in action</i>	22
2. 3 Housing design: a barrier to inclusion	25
2. 4 The impact for disabled people of community care legislation and design guidelines	32
2. 5 Conclusion	41

Chapter 3. Theory development: critical realism	44
3. 1 Introduction	45
3. 2 Understanding critical realism	46
3. 2. 1 <i>An introduction to the philosophy of critical realism</i>	46
3. 2. 2 <i>Understanding society and agency as ontologically distinct but interacting structures</i>	56
3. 3 Physiology, society and agency: developing a three-dimensional framework	61
3. 3. 1 <i>The missing body: bringing the physiological body 'back in'</i>	62
3. 3. 2 <i>The 'three-dimensional' framework.</i>	65
3. 4 Conclusion	71
 Chapter 4. Integrating critical realism: a critical review of the literature on disability and the meaning of home	 74
4. 1 Introduction	75
4. 2 Understanding disability	76
4. 2. 1 <i>Debates within the social model</i>	76
4. 2. 2 <i>Critical realism and disability</i>	80
4. 2. 3 <i>Discussion: re-theorising a model</i>	86
4. 3 Disability and the meaning of the dwelling	87
4. 3. 1 <i>Understanding the 'home'</i>	87
4. 3. 2 <i>Addressing the gap - Disability and the meaning of home</i>	90
4. 3. 2. 1 <i>The psychological impact of adapting the home</i>	93
4. 3. 2. 2 <i>Positive accounts of the home</i>	96
4. 3. 3 <i>Critical realism and the meaning of the dwelling</i>	99
4. 4 Conclusion	102
 Chapter 5. Methods and methodological discussion: critical realism and epistemological justification	 105
5. 1 Introduction	106
5. 2 Methodological approach	106
5. 2. 1 <i>The critical realist approach to data collection and analysis</i>	106
5. 2. 2 <i>Qualitative methods: possibilities and limitations</i>	112
5. 2. 3 <i>The life history approach</i>	114
5. 2. 4 <i>A life history approach to disability and the meaning of the dwelling</i>	116

5. 3	Conducting the research	119
5. 3. 1	<i>A commitment to disability research: The need to justify disability research as a non-disabled researcher</i>	119
5. 3. 2	<i>Negotiating access</i>	123
5. 3. 3	<i>The interview process</i>	129
5. 3. 4	<i>Analysis of data</i>	136
5. 3. 5	<i>Ethical issues and a reflection on the research</i>	138
5. 3. 5. 1	<i>Ethical considerations</i>	138
5. 3. 5. 2	<i>A reflection on the research</i>	142
5. 4	Conclusion	145
Chapter 6. A complex experience: describing the data from the nineteen life history interviews		147
6. 1.	Introduction	148
6. 2	“The thing about me is...”: describing the lives of the research participants	149
6. 2. 1	<i>Housing circumstances</i>	149
6. 2. 2	<i>Care in the dwelling</i>	160
6. 3	Discussing the descriptions: linking the description to literature and policy	163
6. 3. 1	<i>The dwelling as a biographical accomplishment “...the only way to get me out of here would be in a box</i>	164
6. 3. 2	<i>Questioning the dwelling as a source of ontological security</i>	168
6. 3. 2. 1	<i>The implications of inadequate housing design</i>	168
6. 3. 2. 2	<i>“it’s all very . . . convenient”: challenges to biographical accomplishment</i>	170
6. 3. 2. 3	<i>The impact of community care policies</i>	174
6. 3. 2. 4	<i>Trapped and isolated: the dwelling as a prison</i>	180
6. 3. 3	<i>Being ‘an outside person’: questioning the biographical accomplishment hypothesis</i>	184
6. 4	Embodied life histories: understanding the temporal dimension to the meaning of the dwelling	186
6. 4. 1	<i>“Developing” an attachment: the influence of time on the meaning of the dwelling</i>	186
6. 4. 2	<i>Ever changing meanings: the importance of a temporal dimension</i>	187
6. 5	Coding the data	189
6. 6	Conclusion	192

Chapter 7. A unique experience: understanding the meaning of the dwelling through the three-dimensional framework	194
7. 1 Introduction	195
7. 2 Understanding the research findings through the DREI schema	196
7. 2. 1 <i>Impairment effects</i>	196
7. 2. 2 <i>The inaccessible environment and inadequate housing</i>	198
7. 2. 3 <i>Discrimination and 'care' dynamics</i>	200
7. 2. 4 <i>Emotional attachment to the dwelling</i>	201
7. 2. 5 <i>Relationship with co-habitants</i>	204
7. 3 A unique experience: understanding the data through the three-dimensional framework	205
7. 4 Explaining the meaning of the dwelling: Case studies	210
7. 4. 1 <i>Case study one – Louise</i>	211
7. 4. 2 <i>Case study two – John</i>	219
7. 4. 3 <i>Case study three – Jodie</i>	224
7. 5 Conclusion	233
Chapter 8. Conclusion	236
8. 1 Introduction	237
8. 2 Addressing the research aims	237
8. 3 Contributions, conclusions and implications	241
8. 4 Critical review of the research	246
8. 5 Directions for future research	250
Bibliography	254
Appendix 1: Design specifications	283
Appendix 2: Three dimensional framework	287
Appendix 3: Sample access letter to organisations	288
Appendix 4: Specific access letter to Katy	290
Appendix 5: Biographies	292
Appendix 6: Interview schedule	294

List of Figures and Tables

Figures:

Figure 2. 1 Ramp to front door	37
Figure 2. 2 Adapted bathroom with walk-in shower and grab rails.	37
Figure 2. 3 Ceiling Hoist	38
Figure 2. 4 Through floor lift	38
Figure 2. 5 Flashing light doorbell	38
Figure 3. 1 Critical realist view of causation	53
Figure 3. 2: The Transformational Model of Social Activity	59
Figure 3. 3: The Morphogenetic sequence	60
Figure 3. 4: The emergence of personal and social identity	60
Figure 3. 5: 'Multiple determination of events as a nexus in an open system'	65
Figure 3. 6: Three dimensional framework for explanation of an experience	66
Figure 3. 7: Three dimensional framework for explanation of an experience over time.	70
Figure 5. 1: Areas of investigation in intensive and extensive research	111
Figure 5. 2: Second period of access negotiation	125
Figure 5. 3: Interconnection of interview topics	134
Figure 7. 1: Structure and mechanism underlying the event of impairment effects	197
Figure 7. 2: Structure and mechanism underlying the events of the inaccessible environment and inadequate housing	199
Figure 7. 3: Structure and mechanism underlying the events of discrimination and care dynamics.	201
Figure 7. 4: Structure and mechanisms underlying the event of emotional attachment to the dwelling	202
Figure 7. 5: Structure and mechanisms underlying the event of relationship with co-habitants	204
Figure 7. 6: Full schema of structures, mechanisms and events identified in the determination of the meaning of the dwelling	206
Figure 7. 7: Structures, mechanisms and events identified in the determination of the meaning of the dwelling for Louise	217
Figure 7. 8: Structures, mechanisms and events identified in the determination of the meaning of the dwelling for John	223
Figure 7. 9: Structures, mechanisms and events identified in the determination of the meaning of the dwelling for Jodie	231

Tables:

Table 3. 1: Three domains of the real, the actual and the empirical	51
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Chapter 1. Introduction:

issues and intentions

Chapter 1

Introduction: issues and intentions

1. 1 Introduction

Home. Home is an Englishman's castle. Home is where charity begins. Home is where the heart is. From the first scholarly article concerning the home in 1678 (McCann, 1941) to its use in popular literary fiction, poetry and music, 'home' has long been an attractive, alluring and above all, absorbing concept ¹.

A wealth of literature now exists seeking to grasp and explore the 'meaning' of home (see, for example, Hayward, 1975; Sixsmith, 1986; Saunders, 1989; Despres, 1991; Gurney, 1996; Gilman 2002). This rapidly developing body of work on the meanings associated with home has explored a range of variables including gender (Madigan, Munroe and Smith, 1990; Madigan and Munroe, 1991; Darke, 1994), age (Sixsmith, 1990; Gurney and Means, 1993; Heywood, Oldman and Means, 2002), ethnicity (Lewin, 2000), sexuality (Johnston and Valentine, 1995) and class (see Somerville, 1997: 228). However, there has been little work that explores the meaning of home for physically disabled individuals. This thesis is concerned with filling this gap, yet rather than exploring the meaning of the *home* – a term that, it shall be argued, imposes artificial boundaries - this thesis will explore the meaning of the *dwelling*.

The purpose of this chapter is to clearly set out the direction of this thesis. Section 1. 2 identifies key concepts that will be used and referred to throughout the dissertation. It begins by exploring what is meant by the term 'dwelling'. making a clear distinction between the notions of 'house' and 'home'. The chapter will then move onto reviewing the two most influential models of disability: the medical and the social model, stressing the value of the latter for this thesis. By exploring the models of disability the chapter will also explore the different ways in which the word disability is defined and offer an original definition that reflects the direction of this research.

¹ McCann notes that writings on the subject of nostalgia and home 'properly begins in 1678 with a dissertation on the subject by J. Hofer' (1941:165). However McCann does not offer a reference for Hofer's piece.

With these key ideas in mind, section 1. 3 then outlines the substantive research objectives, indicating exactly how this thesis intends to contribute to the existing literature. Specifically this section identifies what this research is and what it is not. To finish, section 1. 4 offers a plan of the forthcoming chapters.

1. 2 Identifying key concepts

1. 2. 1 A house, a home or a dwelling?

The word 'house' and the word 'home' are continually being used by both the UK government and the building industry as interchangeable concepts (Gurney, 1996; King, 2004; Mallett, 2004). However to do so is inadequate. Moreover, it is semantically incorrect. Following the definition given in Merriam-Webster's *Dictionary of Law*, the word house will be used in this thesis to refer to:

“*House* - ...a building (as a single or multiple family house, apartment, or hotel room) serving as living quarters and usually including the curtilage.”
(Merriam-Webster, 2006:230)

A home however is something different. It is more than just the bricks and mortar. The word home is defined by Dictionary.com as:

“*Home* -... the place in which one's domestic affections are centred”
(Dictionary.com Unabridged, 2006)

Whilst ambiguity surrounds the definition of the word home - indeed in exploring etymological and semantic studies of the word home Gurney (1996:57) notes that the Collins English Dictionary (Collins, 1986) provides some 33 separate meanings for the word - what becomes clear is that rather than a physical structure home is an experience. Home comes to refer to a site of emotions. Home, in short, is a verb rather than a noun, not a place or thing but a state of being (Pallasmaa, 1995:136). It is these definitions of the words 'house' and 'home' that will be used when referring to these concepts throughout this thesis.

'Dwelling' however is very much a contested concept. For some it is a house, for others a home:

“*Dwelling* – noun, formal, literary; a place of residence, a house.”
(Chambers, 1999: 410)

“... dwelling involves the process by which a place in which we exist becomes a personal world and home.”
(Seamon and Mugerauer, 1985:8)

The first quotation defines the dwelling in terms of physicality, equating dwelling with the house. The second quotation however recognises dwelling as a verb, and forms part of a broader enquiry into the nature of dwelling, as, for example, typified in the work of Heidegger (1971: 145-161). Within this latter tradition, dwelling is about more than just physical accommodation; it concerns a state of being and belonging. To dwell is to live (King, 2004:21).

Further, it has also been suggested that the word dwelling can be used to encompass both housing *and* home.

“Dwelling is not merely a concrete physical entity, but one intended to encapsulate both home and housing. Therefore can we not see dwelling as having a meta-meaning, where it consolidates all we seek from housing as a concrete entity as the nebulous associations we have toward home? Dwelling is so significant because it can take in any number of levels from solidarity to security; from fastness against the elements into an emotional sense gained through intimacy and insularity.”
(King, 2004:89)

For King the dwelling thus becomes a complex interrelationship of both the physical product of house and the emotional processes of home (2004, see also Kemney, 1992). To avoid confusion between existing linguistic understandings of home and house, it is this understanding of the dwelling – one that encompasses both home and house – that will be adopted in this thesis.

Acknowledging these definitions not only serves to avoid confusion in terminology throughout the thesis but also becomes central to the direction of the research project. Principally, through recognising these differences it becomes necessary to note that rather than exploring the meaning of the *home* this thesis will be exploring the meaning of the *dwelling* for physically disabled individuals. This is not just semantic ‘nitpicking’, for whilst looking at the meaning of the home would examine *just* the

emotions connected to the home, exploring the meaning of the dwelling goes further. Seeking to understand the meaning of the dwelling entails investigating both its physical and emotional dimensions, in doing so appreciating that emotions connected to the home can be intimately bound to the design of the house (something previously called for by Kemney, 1992). By acknowledging the role of physical design in the formation of emotional attachments it is held that a more developed, experiential understanding can be formed.

1. 2. 2 Models of disability: what is 'disability'

Like the notion of dwelling, there is no universal discourse for defining disability. How disability is defined depends upon the model of disability adopted. There are various models seeking to define and explain disability in the UK; most notably the medical model and the social model.

The medical model of disability has traditionally been the dominant model in the medical profession. The historiography and characteristics of the medical model are widely rehearsed elsewhere (for example, Oliver, 1990, 1996; Hughes, 2002; Swain, French and Cameron, 2003; Shakespeare, 2006). Crucially, the medical model holds that the physically impaired individual needs medical attention to help to 'rectify' their 'problem'. The only way of overcoming any disadvantage arising from impairment is seen to be through either treatment or cure (Crow, 1996). As a model of individual pathology the medical model places an emphasis on an individual's impairments being the cause of any disadvantages experienced. Consequently the definition of disability for those who adhere to a medical model approach centres on disability as referring to the functional limitations created by an individual's impairment. The most widely referenced example of a definition of disability which reflects the values of the medical model is that given by the World Health Organisation's (WHO) in its 'International Classification of Impairments, Disabilities and Handicaps' in 1980:

"Disability: Any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being."
(Wood, 1980: 27)

With an emphasis on impairments - and impairments only - as the cause of any

restriction or disadvantage, this definition exhibits the characteristics of a medical model approach to disability.

In stark contrast to this definition is that offered by those writing from the position that has become known as the social model. Although the term 'social model' was not coined until 1983 (Oliver, 1983), its origins in the UK can be traced back to the emergence of disabled peoples movements in the 1960s and 1970s. This emergence generated a critique of existing medical explanations of disability, with disability coming to be interpreted in a new way. Whilst this challenge was established by disability activists, the new approach of these 'organic intellectuals' to disability which drew on personal experience and sociological insights led to the rise of disability as the legitimate focus for academic enquiry outside of medicine, the beginnings of what can now be termed 'disability studies' and the development of the social model of disability (Barnes, 2004a: 28- 32).

Disability organisations such as The Union of the Physically Impaired Against Segregation (UPIAS) played a pivotal role in the evolution of the social model of disability. They asserted that it was the onset of industrialisation, and with it standardisation of design premised upon an abstract notion of what an able body is, that had constructed disability. Disability, UPIAS argued, is a capitalist creation. Of fundamental importance was the distinction between impairment and disability. For UPIAS- and writers within the social model tradition- disability is:

“Something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from participation in society.”

(UPIAS, 1975:4)

In distinguishing between impairment and disability UPIAS indicated that at a personal level we might understand that the acquiring of impairment might be a personal tragedy. However the real tragedy commentators such as UPIAS stress is at the social level where barriers in society continue to disable certain impaired individuals.

Accordingly, the central message of the social model is that it is society, not an individual's impairment, that 'imposes limitations on certain groups or categories of people' (Oliver, 1983:23). By focussing on barriers created by society rather than

individual impairments the social model becomes the antithesis of the medical model (Hughes, 2002:63). Broadly, the barriers can be understood as falling into two categories – design barriers and attitudinal barriers. Design barriers refer to the physical obstacles in the built environment that restrict access for physically disabled individuals. These barriers include steps, uneven pavements, and street furniture (see, for example Oliver, 1990; Imrie, 1996; Gleeson, 1999; Imrie and Hall, 2001). The inappropriate design features in buildings, public space and public transport come to present a substantial barrier to inclusion.

Attitudinal barriers refer to the prejudice faced by physically disabled individuals (Hunt, 1966; Oliver, 1990). These attitudinal barriers become apparent through discriminative and stigmatised attitudes towards physically disabled individuals by able-bodied people in society, something that is then reinforced through negative images of physically disabled individuals in the media (Barnes, 1992a; Shakespeare, 1994). The impact and importance of the social model and the disability rights movement in bringing about policy change (such as the amendments to the Disability Discrimination Act 1995 and the new WHO classification of disability) are undeniable and a wealth of literature now exists discussing the social model and its implications (see, for example, Oliver 1983, 1990, 1996; Barnes, 1990, 2004a; Gleeson, 1999; Barnes, Oliver and Barton, 2002; Barnes and Mercer, 2003; Swain *et al*, 2004; Shakespeare, 2006). By questioning the dominant epistemological tradition of the medical model and distinguishing between impairment and disability it has helped to shift attention away from the individual and helped to focus on tackling the way in which society excludes certain groups.

In addition to the medical and social models there are also two further models of disability, which have become known as the ‘tragedy’ and ‘affirmational’ models. The tragedy model is emergent from a medical model understanding, and is the view that dominates media representations of disabled individuals (French and Swain, 2004). It presents disability as a tragedy, something that ruins lives. Like the medical model the tragedy model defines disability in terms of an individual’s impairment. This model perpetuates the idea that physically disabled individuals cannot be happy and want to be ‘normal’ (for further discussion of the tragedy model see Abberley, 1987; Oliver, 1990; French and Swain, 2004). In contrast to the tragedy model is the

affirmation model, which itself has emerged from the social model. The affirmational model has been developed most clearly in the Disability Arts Movement (Swain and French, 2000). This model can be briefly summarised as holding a non-tragic view of disability, seeking to portray positive disabled identities (for further writings on the affirmation model see Swain and French, 2000; Benjamin-Darling, 2003). Like the social model the affirmation model defines disability in terms of attitudinal barriers created by an unjust society.

Of the four models, the social model of disability has had the most significant and profound influence over the direction of this thesis and the definition of disability that will be adopted. As a result it is important that the reader understands this model from the outset. However, whilst the social model has had a significant impact on this thesis, this does not mean that any discussion on impairment is disregarded. In fact quite the opposite is true. In Chapter 4 arguments will be presented which detail how impairment itself can have a disabling effect and how this can be integrated into a social model approach. Given this recognition of disability as encompassing both social barriers and impairment, to avoid confusion it becomes necessary to define exactly what the terms impairment and disability will refer to in this thesis:

Impairment: “is the functional limitation within the individual caused by physical, mental or sensory impairment.”
(Disabled Peoples International, 1982 cited by Oliver, 1996:31)

Disability: is the restriction of opportunity to take part in activities on an equal basis caused by - but not limited to - factors arising from social barriers and/or impairment.

The definition of impairment above is the one provided by Disabled Peoples International. The term impairment here refers to a description of limitations that arise from the physical body. The definition of disability given above is inspired by the writings of the social model of disability. However the inclusion of impairments alongside social barriers in this definition will sit uneasily with many social model theorists. Nevertheless it is this original definition of disability that describes what will be meant by the term disability in this thesis. What has to be recognised is that like home, house and dwelling, impairment and disability are not interchangeable concepts. All the same, they are interlinked and by acknowledging the role of

impairment as well as social barriers in defining disability it becomes possible to gain a greater understanding of the experiences of disabled individuals.

Whilst both the terms impairment and disability given in the above definitions cover those with learning disabilities, mental health difficulties and physical disabilities this research will **not** be investigating the experiences of individuals with *learning disabilities* or *mental health difficulties*. The reason for this is purely practical – exploration of the experiences of the wide range of different learning disabilities and mental health difficulties is beyond the scope of this time-limited research project. Given this focus, to save unnecessary repetition the word ‘disability’ will be used in this thesis to refer just to physical disability.

This research can be understood as being located within housing studies, the sociology of the home and in disability studies. The location of this research project has significant bearing on this thesis. Firstly it has affected the way in which disability has been defined as encompassing social barriers *and* impairment, a way unfamiliar in the disability studies tradition. Further, given that this research is more firmly located within housing studies than in disability studies the thesis will have a particular ‘feel’, focusing on specific literature that may be more familiar to readers from a housing studies background than those from disability studies.

1.3 Intentions and objectives

The research objectives of this thesis can be understood as follows:

1. To develop a critical understanding of the theoretical aspects of critical realism.
2. To demonstrate the methodological potential of critical realism and establish its potential within disability and housing studies.
3. To advance an analytic framework through which to understand the impact of conflicting events on the meaning of the dwelling.
4. To explore the range of events that can affect the meaning of the dwelling for physically disabled individuals.
5. To critique the social model of disability, asserting the need for a more experientially grounded understanding that is able to recognise the potentially disabling impact of impairment effects.

These objectives serve as an outline for the direction and scope of this research project. It is worth highlighting here that from the outset of this research the focus was to be on the impact the neglected variable of disability had on the meaning of the dwelling. Given this focus on understanding the impact of disability – and a belief that it may prove to be a significant variable - this research does not seek to explore the role that class, gender, ethnicity, sexuality or tenure may have on the meaning of the dwelling. All these variables have been studied in isolation elsewhere, and it was felt the time has come to address the gap in the literature and offer an in-depth account of the impact of disability on the meaning of the dwelling.

Furthermore, what also has to be acknowledged is that ethical concerns were placed at the very heart of this research project. Following existing literature typified within feminist methodology (see, for example, Oakley, 1981; Finch, 1993; Ramazanoglu with Holland, 2002), alongside the more ‘traditional’ ethical considerations of anonymity, confidentiality, informed consent and protection from harm, a commitment was placed on recognising, questioning and destabilising power hierarchies in the research (see Chapter 5). Whilst not an objective as such, ensuring that ethical concerns were placed at the core of the research most certainly was an intention.

Through the five objectives identified above this thesis seeks to make a contribution not just to the meaning of the home literature but also to disability and housing studies in general. These contributions can be understood as falling into three categories: theoretical, methodological and empirical:

Theoretical

In theoretical terms neo-Marxist and social constructionist perspectives have dominated the literature on the social model and within disability studies. Whilst housing research has been dominated by policy concerns, where housing studies has engaged with theory there has also been a focus on providing constructionist explanations (see for example Franklin and Clapham, 1997; Somerville, 1997; Gurney, 1999; Hunter and Nixon, 1999; Clapham, Franklin and Saugeres, 2000; Jacobs and Manzi, 2000).

Whilst acknowledging the significance of constructionism in extending the analytical scope of housing, there are certain inadequacies (Edley, 2001; Maze, 2001; Somerville and Bengtsson, 2002; Burr, 2003; Fitzpatrick, 2005). It is intended that critical realism will be shown to be a valuable tool through which to highlight such inadequacies and provide a platform from which to question the existing focus on society. The advantage of critical realism is that it can recognise that an experience – such as disability or the meaning of the dwelling for physically disabled individuals – involves the complex interaction of events arising from physiology and agency as well as society. The insights made through questioning the constructionist focus on events arising solely from society and recognising the importance of events arising from the structures of physiology and agency will then be directed towards informing the development of a new analytical framework for research based on critical realism.

Methodological

The distinguished disability writer Jenny Morris has previously argued that there has been a dangerous trend to present disabled individuals as a homogenous category of adults in a wheelchair (1993:155). This ‘wheelchair reductive’ position has come to dominate constructions of what constitutes disability, ignoring the wide range of different ways in which disabling barriers can become apparent (Imrie and Hall, 2001:43). Indeed until very recently forms of disablism faced by individuals with sensory impairment have been largely ignored (Thomas and Corker, 2002:24). This thesis intends to move beyond such a ‘wheelchair reductive’ view of disability and explore the experiences of individuals with a range of physical disabilities, both sensory and mobility. However as noted above whilst this thesis seeks to explore a wide range of physical disabilities this research will not be investigating the experiences of individuals with learning disabilities or mental health difficulties.

Exploring the experiences of individuals with a range of disabilities and impairments involves a number of methodological challenges. For example, particular action has to be taken to ensure that individuals with sensory and communication difficulties do not feel excluded from the research process. It is in showing how research can be accomplished with individuals who have communication difficulties that this research offers a further methodological contribution to the literature.

The key methodological contribution however lies in the application of critical realism to disability and housing research. There remains very little published work discussing how critical realism can be utilised to inform either disability or housing studies (for exceptions see Williams, 1999; Allen, 2000; Lawson, 2001; Danermark, 2002; Somerville and Bengtsson, 2002; Danermark and Gellerstedt, 2004; Fitzpatrick, 2005). By discussing the implications of a critical realist research project this thesis intends to remedy this neglect. Of central concern will be demonstrating how a critical realist approach to data collection and analysis can open up the possibility of recognising the complexities of experience and the importance of time, as well as indicating the centrality of developing a reflexive research agenda.

Empirical

Whilst a wealth of literature has emerged within housing studies exploring the meaning of home (for example, Saunders and Williams, 1988; Saunders, 1989, 1990; Gurney and Means, 1993; Darke, 1994; Gurney, 1996, 1997, 1999, 2000a, 2000b; Somerville, 1997; Hiscock *et al*, 2001; Heywood, Oldman and Means, 2002; Bhatti and Church, 2004; Mallet, 2004), only very recently have these ideas been explored in relation to disability. In 2004 Rob Imrie's paper '*Disability, embodiment and the meaning of the home*' was published (Imrie, 2004a). This paper offered an original contribution to the meaning of home debate, for the first time explicitly exploring the experiences of disabled individuals (see Chapter 4 for detailed discussion).

Building on the innovative work of Imrie, this thesis seeks to reassess the existing literature on disability and the meaning of the home and develop an additional insight into the meaning of the dwelling for disabled individuals. This research project will contribute to the existing empirical knowledge base by taking a critical realist approach to the research question and exploring the life histories of the participants. By generating rich accounts and engaging with a wide range of disparate literatures including 'care' policies for disabled individuals in the UK, housing design regulations and writing on the meaning of home, this thesis will seek to add to the existing literature base. In short this thesis intends to add to the empirical literature by adopting a more experiential approach - one that can simultaneously acknowledge the role of physical design, explain the lengths individuals go to avoid adapting their

dwelling and provide a voice for the previously silenced positive experiences in the dwelling for disabled individuals.

From the intended contributions and the five stated objectives it should be clear that this research sets out to explore the range of events that can affect the meaning of the dwelling for physically disabled individuals, using critical realism as a lens to broaden the scope of existing understandings. In doing so the research will address the need to explore events arising from physiology and agency as well as society. It also questions the myth that disabled individuals are inevitably discontented in their dwelling, asserting the need to recognise positive feelings. Above all, what should also be clear is that this research intends to develop and apply an analytic framework that can help reveal the multi-dimensional nature of an experience.

1. 4 Plan of forthcoming chapters

To address the five research objectives, this thesis is organised into eight chapters. Chapters 2, 3 and 4 cover the contextual and theoretical background to the research. Chapter 2 presents a review of British legislation pertaining to the ‘care’ of disabled individuals and housing design regulations. The purpose of this review is to help identify the policies that frame the lives of disabled individuals, and in doing so contextualise the research. Through reviewing ‘care’ policies from the Tudor Poor Law of 1601 to contemporary community care developments, and policy guidance given on housing design over the last century the chapter will introduce concepts that will be drawn on later in the thesis. Furthermore the chapter will also explore the impact that community care legislation and housing design guidelines have on the lives of disabled individuals, and in doing so help to develop the focus of the research questions.

Chapter 3 provides a summary of the theoretical perspective of critical realism and offers the reader a detailed insight into the way in which my theoretical position influenced the direction of this research project. Building on the central tenets of critical realism, an analytic framework will be developed, one that is able to simultaneously acknowledge the influence of the three structures of physiology, society and agency in explaining an experience. The ‘three-dimensional framework’ developed in this chapter has substantial implications for the research agenda for this

thesis, and in the closing sections of Chapter 3 the methodological consequences of adopting this framework will be documented.

Chapter 4 reviews the existing literature on the debates within the social model of disability and on the meaning of 'home' for disabled individuals. The first part of Chapter 4 presents a critique of the social model of disability, and through an appeal to critical realism and the three-dimensional framework develops debates on the integration of impairment into the social model. In developing a more experientially grounded understanding of disability this part of the chapter seeks to fulfil one of the five objectives of this research.

From this understanding of disability the second part of the chapter seeks to critique the scant literature on disability and the notion of the home. Through a detailed review of a wide-ranging and disparate collection of literature, Chapter 4 works towards addressing the research gaps and establishing the possibility for a research agenda exploring disability and the meaning of the dwelling based on a three-dimensional framework.

Chapter 5 identifies and justifies the methodological approach used for the research. The chapter begins by discussing the methodological possibilities and implications of critical realism, making detailed reference to the specific demands of data analysis in critical realism and the appropriateness of using life-history interviews as a method of data collection. Following this, the chapter offers a description and critical appraisal of the research process. This includes a justification of the research in light of my non-disabled status, a review of the interview process (including the efforts taken to destabilise research power hierarchies) and a detailed discussion of ethical considerations.

Chapters 6 and 7 present the empirical findings of the research. Chapter 6 describes the results from the life history interviews conducted with nineteen participants. Through engaging with the policy and literature presented in Chapters 2 and 4 the findings raise a number of challenges to widely accepted beliefs on the meaning of the home and also reveal that the meaning of the dwelling for disabled individuals is *complex* and subject to change over time. In addition to describing the research

findings and discussing how they fit in with the existing literature base the chapter also codes the data collected. Here the suggestion will be made that from the data collected, there appeared to be seven 'events' that can have an impact on the meaning of the dwelling. These events are: inadequate housing design, impairment effects, the inaccessible environment, 'care' dynamics, discrimination, emotional attachment to the dwelling and relationship with co-habitants.

Chapter 7 seeks to explain the data presented in Chapter 6 through reference to the analytical framework developed in Chapter 3. Through retroductive analysis of the research findings and an appeal to the three-dimensional framework, the case is made that the meaning of the dwelling must not only be understood as complex but also *unique*. By operationalising the three-dimensional framework and focussing on individual participants the chapter explores the compromises, conflicts and ambiguities involved in the meaning of the dwelling. In doing so the chapter is able to attend to the remaining research objectives and understand the meaning of the dwelling in a new way.

Chapter 8 concludes the research by demonstrating how the research addressed the five research objectives and highlights the challenges to existing literature that emerge from this research. In closing the dissertation, this chapter also suggests how this research can be used to stimulate future lines of enquiry within disability and housing studies.

Chapter 2. Disability, care and housing

design:

contextualising the research

Chapter 2

Disability, care and housing design: contextualising the research

2. 1 Introduction

Policy is one of the contexts in which disabled individual's lives are framed. Given this, in order to understand the meaning of the dwelling for disabled individuals an awareness of UK policy regarding 'care' and housing design is necessary. The purpose of this chapter is to provide the reader with such knowledge and draw attention to the impact this policy has on the lives of those it affects.

To do this the chapter contains three substantive sections. The first briefly and uncritically reviews key UK legislation pertaining to the care of disabled individuals. This section begins by tracing the historical context from which current care policies developed back to the Tudor Poor Law of 1601, following it through mass institutionalisation of the Victorian era to the development of community care policies and the legislation contained in the National Health Service and Care in the Community Act 1990. The section will then progress to describe how contemporary community care works in practice. Exploring the context of 'care' policies in this way is crucial to the research as it draws attention to the removal of disabled individuals from mainstream society –and hence their dwelling- and incarceration in institutions. Furthermore, it also highlights the way in which reaction to institutional regimes led to the development of packages of 'care' that were developed to 'enable' individuals to live in the community and in their own dwelling.

The second section (section 2.3) explores UK policy guidance given on housing design since the start of the twentieth century. The intention of this review is to provide the reader with the background context that can help to explain why the British housing stock does not satisfy the needs of many disabled people. Further, it also provides insights that will be developed later in the thesis.

Having provided an overview of relevant legislation and policy developments, the third substantive section (2.4) critically engages with the policy, investigating the impact for disabled people of community care legislation and design guidelines. This section explores the way in which whilst community care policies have sought to

foster independence in practice the system has left many individuals feeling dependent, powerless and isolated in the dwelling and looks at the way inadequate housing design has presented a challenge to independence and forced the need for individuals to install adaptations in the dwelling or even move into supported housing settings.

The final section of the chapter, section 2. 5, offers not just a conclusion to what has been presented in the chapter but also discusses the integral role of this policy review to the research, indicating the way in which the material raised in this chapter – in particular that in 2.4 - underpins many of the themes that will be developed in the thesis.

2. 2 From institutionalisation to community care

2. 2. 1 'Caring' for disabled individuals: The Poor Law 1601 to the National Health Service and Care in the Community Act 1990

The displacement of disabled people from the social mainstream in the UK in effect derives from the 1601 Tudor Poor Law where workhouses were built to house those unable to earn their own living. The workhouses rapidly became repressive institutions, with a strict distinction between the able bodied poor, compelled to labour, and the disabled poor, who were considered abnormal, inferior and objects of charity (Oliver and Barnes, 1998). This practice of segregating disabled individuals from mainstream society – by moving individuals from one space into isolated workhouses and similar institutional settings – continued throughout the seventeenth, eighteenth and nineteenth centuries through a series of amendments to the 1601 Tudor Poor Law (for further detailed writings on the incarceration and exclusion of disabled individuals from society see Oliver, 1990; Barnes, 1991; Barnes and Mercer, 2003; Borsay, 2005: 17 - 112).

Although critical accounts of institutional care have existed since the eighteenth century (Coppock and Hopton, 2000:3) it was not until the second half of the twentieth century that these concerns were comprehensively discussed, most notably in the work of Barton (1959), Goffman (1961), Szasz (1961) and Foucault (1973). Arguably, it is Goffman's *Asylums: essays on the social situation of mental patients and other inmates* (1961) that has become the most influential and widely referenced

of the critical work on institutions. Whilst, as Goffman recognised, institutional effects had previously been pointed out in sociological literature under different names and guises (e.g. Rowland, 1939, cited by Goffman, 1961:16) it was Goffman who coined the phrase 'total institution' to refer to the tendency for institutions to control every aspect of an individual's life (1961:11).

Goffman argued that in the 'total institution', unlike 'normal' life in the community, all phases of daily activity became tightly scheduled by a system of precise formal rules. The institution claimed total control over patients, making privacy, dignity and independence difficult to establish. As Goffman graphically details:

"...some mental hospitals have found it useful to extract the teeth of 'biters', give hysterectomies to promiscuous female patients, and perform lobotomies on chronic fighters."

(Goffman, 1961:77)

Testimonies in the UK in the 1960s confirmed Goffman's macabre depiction of the degrading, dehumanising and depersonalising effects of life within institutions. A wealth of literature emerged detailing the detrimental effects of institutional care for various groups including the elderly (Townsend, 1962), mentally ill (Meacher, 1972) and the physically disabled (Miller and Gwynne, 1972). Furthermore, declarations also emerged from disabled people and their organisations on the abuse, cruelty and harassment present in many institutions:

"There are administrators and matrons who have had people removed on slight pretexts, who try to break up ordinary friendships if they don't approve of them. There are the staff who bully those who cannot complain, who dictate what clothes people should wear, who switch the television off in the middle of the programme, and who will take away 'privileges' (like getting up for the day) when they choose."

(Hunt, 1966:154)

In step with these criticisms of the 'total institution' - as well as concerns about their growing cost - the emergence of the welfare state in the UK in the 1940s saw a move to bring those in institutions back into their community and into their own dwellings. The responsibility to provide services to disabled individuals in the community was

first set out in Section 21 of The National Assistance Act 1948². However as Means, Richards and Smith note this Act did not achieve as much as hoped as Local Authorities (LA) were able to ‘offer minimal provision yet still meet the requirements of the Act’ (2003:22). Consequently many commentators have cited the 1954 report by the Royal Commission on Mental Illness and Mental Deficiency and the Mental Health Act 1959 as pioneering the development of community care (Morris, 1993; Oliver, 1999; Welshman, 1999; Mays, 2000; Barnes and Mercer, 2003). This Act dictated that hospital care should be reserved for acute episodes and a small number of severe cases only, with LAs being obliged to provide more residential accommodation.

Community care principals rapidly became a major policy goal (Ministry of Health, 1962, 1963; cited by Welshman, 1999: 212). However, it soon became clear that most authorities lacked the funds and consequently provisions to implement community care successfully (Welshman, 1999). To help ‘rationalize the chaos that was the reality of community care’. The Chronically Sick and Disabled Persons Act (CSDPA) 1970 was introduced (Oliver, 1999:258). This Act was to go on to become of significant importance to the lives of disabled individuals. The Act stresses that the responsibility for ensuring an effective community care system in which individuals were assisted to integrate into the community rests with LAs. Indeed under Section 2 of the CSDPA all LA social work departments have a duty to make arrangements for the provision of services to meet the needs of disabled individuals even when LA resources are tight.

Underpinning the CSDPA was a belief that disabled individuals should be able to live an ordinary life in the community. As Selwyn Goldsmith - then advisor to the Department of the Environment on housing services to disabled people - explains:

“For people who are disabled living in institutions is a bad thing. Living in ordinary housing is a good thing”.

(Goldsmith, 1976:70)

² Whilst in 1929 The Wood Report (Ministry of Education) used the expression ‘community care’ (Part IV, Chapter VI p. 42) the report also promoted a policy of segregation and even sterilisation of ‘the mentally deficient’ (Welshman, 1999: 206-7).

This doctrine became a mantra for policy makers, marking a turn towards 'normalisation'. Originating in Scandinavia in the late 1950s, normalisation became the buzz-word in 1980s UK policy-making regarding community care, in particular in regard to supporting individuals with learning disabilities. Whilst normalisation is a family of ideas and has been defined in a number of ways (Emerson, 1992) it can broadly be understood in the community care context as a move away from institutional care and towards enabling individuals 'enjoy as normal a lifestyle as possible' (Clapham, Kemp and Smith 1990:146). The principles behind normalisation were not about making people 'normal' but supporting individuals to live 'normal lives' by integrating them into mainstream society (Brown and Smith, 1992; Barnes and Mercer, 2003).

Whilst the notion of normalisation was principally used to refer to the need to support individuals with learning disabilities attain socially valued roles within the community, as Franklin notes the concept of normalisation also underpins developments in community care policy relating to physically disabled individuals in the 1980s and early 1990s (1998:167). Following criticisms of the CSDPA by academics and the media (see Barnes, 1991: 172-173; Morris, 1993:6), damning reports on community care policies by the Audit Commission (1986) and concerns about the spiralling cost of care provision, the UK government commissioned Sir Roy Griffiths (1988) to review the funding and organisation of community care and look towards ways to create a more effective community care system. Griffiths' recommendations were published in the report '*Community Care: an Agenda for Action*' (1988) and informed the subsequent White Paper 'Caring for People' (DoH, 1989). This in-turn formed the basis of the National Health Service and Care in the Community Act (NHSCCA) 1990. The Act defines community care as providing the support 'to enable people to achieve maximum independence' (NHSCCA, 1990). The physically disabled were identified alongside the old, the learning disabled and the mentally ill as priority groups in need of support to achieve independence. The principle objective of the Act was to ensure that as many individuals as possible within these groups received the support they needed to live independently in the community, rather than in institutions. This remains the key objective of community care in the UK (for a detailed review of the development of community care in the UK see Borsay, 2005).

2. 2. 2 *Community care in action*

The three stages for obtaining community care were outlined in *Community Care in the Next Decade and Beyond* (DoH, 1990). The first stage is an assessment of the needs and circumstances of the user. The user will be allocated a care manager who will oversee the assessment process. During the assessment process an individual's physical and mental condition, current housing situation, care needs and emotional needs will all be assessed alongside considerations of available support networks. Whilst this assessment is principally conducted by social services, to assist with assessment for health care and housing needs LAs also have a duty to invite housing departments and the NHS (see Greaves, 2006:146 – 155). Occupational therapists (O.T.) play a key role here, assessing the functional abilities of an individual according to what has come to be defined as 'Activities of Daily Living'. These activities generally include assessing an individual's competence on actions such as bathing, dressing, feeding, going to the toilet, preparing meals and doing housework (Office for National Statistics, 2001). The O.T. also assesses an individual's current housing situation, making recommendations on which aids/adaptations may assist the individual to live independently (see Bull, 1998 for further discussion on role of occupational therapists in assessment and the specific skills they bring). The outcome of the assessment by the O.T. is an important one as it largely determines whether an individual can live in their dwelling or whether they should move to a more appropriately designed property (for a detailed reading of the process of assessment see Davis, Ellis and Rummery, 1997; McDonald, 2006).

If an individual is assessed as needing practical help in the dwelling the second stage is the creation of a care plan in agreement with the user, carers and relevant agencies to meet the assessed needs of the user. These plans would be the basis for developing a variety of services. The list of services to be provided is outlined in Section 2 of the CSDPA and include day care and domiciliary care, the provision of aids/adaptations, and holiday provision (McDonald, 2006). LAs and in particular social workers and community occupational therapists are charged with the main responsibility for providing for arranging care services. The idea is to create a needs-led care package rather than just assessing eligibility for services already being provided by the council.

The third stage is the implementation and monitoring of services. The responsibility for the effective delivery of packages of care lies with the care manager. The requirement to assess (and regularly re-assess) an individual's needs lies in both the CSDPA (Section 2.1) and the NHSCCA (Section 47.1).

However, for some care users the practice of the second stage of care provision has changed over the last decade following the introduction of The Community Care (Direct Payments) Act 1996. This Act gave LAs, for the first time, the discretionary power to offer a *direct* payment to disabled adults assessed as needing community care services (under Section 47 of the NHSCCA 1990)³. Direct payments operate by giving the care user the opportunity to 'purchase' any services that meet their assessed needs rather than having them provided for them by social services. In most cases the direct payments are used to employ personal assistants to provide the support previously provided by care professionals. The exact amount paid to an individual varies and is determined through the same assessment process as before, with the needs of disabled individuals taken into account when calculating the exact cash amount. The individuals who receive the assessed payments become employers, taking on the responsibility of hiring and firing staff, working out insurance, holiday pay, training etc (Hasler, 2004). What is important to note is that through the direct payments scheme care users gain control over their care. They choose who their carers are, when they need them (though the amount of hours will be limited to their assessed care needs) and what the care is used for.

Direct Payments are about facilitating independent living. Consequently, the cash received cannot be used to pay in full or in part for residential accommodation. In Scotland the recipient of the payments is also unable to employ anyone who lives in the same house (i.e. family). However since April 2003 in England and Wales Direct

³ Prior to The Community Care (Direct Payments) Act 1996, some individuals were able to purchase their own services through indirect payments from The Independent Living Fund (ILF). Running from 1988 to 1993 the ILF was a major development towards what became the direct payments scheme. The principal difference was that the ILF was just a small scheme and furthermore under this scheme individuals could only receive payments *indirectly* via third party organisations (Greaves, 2004). For further readings on the development of the direct payments scheme see Kestenbaum (1996); Priestley (1999, 2004); Shakespeare (2000, 2006); Hasler (2004); Mercer (2004).

Payments can be used to pay a spouse or relative in the same house, 'if the LA is satisfied that it is necessary to do so' (Greaves, 2004:156). Originally the act was restricted to adults aged between 18 and 65, but following a number of changes to the framework the scope has been widened to include disabled individuals aged 16 and 17, parent carers of young children with impairments (Carers and Disabled Persons Act, 2000) and people over the age of 65 (Health and Social Care Act, 2001). It has now become mandatory for LAs to offer a direct payments scheme.

However following assessment some individuals find themselves in a position whereby their needs are deemed to be such that they cannot be supported in their existing dwelling. For such individuals 'supported housing' (also termed 'special needs' accommodation) provides a short- or long-term solution for those with a variety of needs that cannot be adequately accommodated for elsewhere (Franklin, 1998; Means, Richards and Smith, 2003). Supported accommodation is provided by a variety of HA and voluntary organisations as well as LAs. There are many different types of supported housing, with the term 'supported housing' being used to encompass a range of settings. To summarise the different types of supported accommodation, Franklin has offered a useful list identifying ten very different types of supported accommodation (1998:168-169). These include scatter(ed) flats ("self contained flats dispersed amongst housing stock where someone can keep an eye on the individual"); shared housing (a bedsit with communal living area, shared kitchen and staffed during the day with 24 hour on call cover); sheltered housing category 1 ("self contained bedsits, flats, houses or bungalows with an alarm call service"); sheltered housing category 2 (as category 1 plus a resident warden and more extensive communal facilities); residential care homes (single rooms with communal facilities and full personal care but not medical care) and nursing homes (as residential care homes but with medical care). Whilst residents in supported housing are usually tenants and live fairly independently as can be seen from this list some settings have more intensive levels of surveillance than others (for more on supported housing see Franklin, 1998:168-9; Cope, 1999; Means, Richards and Smith, 2003).

For many the need to move into supported housing stems from living in housing which is inadequately designed to meet their needs. Indeed a number of commentators have argued (Arnold *et al*, 1993; Arblaster *et al*, 1996; Franklin and

Clapham, 1997; Franklin, 1998) that community care goals have been held back by Griffiths' assumption that housing is just a 'bricks and mortar' issue (1988). Amongst other things, the effect of Griffiths' remark has been that the importance of ensuring an appropriate housing stock existed has been overlooked. This is a critical mistake as housing is crucial to achieving the community care objective of enabling people 'to live as independently as possible in their own homes' (Department of Health 1989, Section 1:1). Indeed Franklin has argued that whilst 'suitable, appropriate housing' can diminish the need for carers, 'inadequate, defective housing ... will render the need for support more likely' (1998:166). To explore why the British housing stock presents such a barrier to the independence of many disabled people it is necessary to review British policy guidance on housing design.

2. 3 Housing design: a barrier to inclusion

There now exists an extensive volume of research on inadequate housing design, all of which highlights the difficulties disabled individuals face and the way in which such design represents a barrier to independence (see, for example, Davis, 1981; Barnes, 1991; Kestenbaum, 1996; Franklin, 1998; Oldman and Beresford, 2000; Harrison and Davis, 2001; Imrie and Hall 2001; Imrie, 2003, 2004a, 2006a; Heywood, 2004a; Stewart, 2004; Thomas, P., 2004). Much of this literature regarding inadequate housing design revolves around the issue of spatial concerns. Size and space become an issue throughout the house for individuals with a range of impairments, both mobility and sensory. The continuing neglect about the height, width, weight and design of doors, windows, handles, electrics, plumbing, appliances, kitchen units etc embodies both the apathy the private house building industry has towards the inadequate housing design for those with a range of physical impairments and the extent to which many disabled individuals remain dependent on others to complete simple tasks. The lack of adequately designed dwellings can affect the independence of disabled individuals from childhood (Oldman and Beresford, 2000) to becoming a young adult and wishing for an independent life away from parental home (Morris, 1993), throughout adult life and into old age (Kestenbaum, 1996; Stewart, 2004).⁴

⁴ Detailing exactly how many houses in the UK are inaccessible for individuals with a range of disabilities is impossible to give. John Grooms Housing Association has estimated that to satisfy the demand of wheelchair users alone, the UK needs over 300,00 new wheelchair

The difficulties faced by disabled individuals in accessing satisfactory housing are varied and complex. One important reason for the inadequate design is that architects have continued to ignore the needs of those whose bodies fall outside the 'norm' having only a very narrow notion of 'normality' (Imrie, 2003), and indeed when quizzed appear to have only a 'vague notion' of what these needs might involve (Burns, 2004:778). Ultimately however, the housing stock of any country is the result of the regulations and policies in place at the time they were built. With the UK having the oldest housing stock in the EU, to understand why so many homes are inaccessible it is necessary to briefly explore the history of design regulations (Rickards *et al.* 2004).

The belief that disabled individuals needed to be 'cared for' in institutions allowed mainstream housing provision to ignore the needs of disabled people (Imrie, 1996:72; Kestenbaum 1996). Segregated from society and placed in 'special care' accommodation, housing design in the UK came to be based on a normative belief of absence of impairment. Indeed, The Tudor Walters Report - regarded as a landmark in the history of British Town planning leading to the development of some 500,000 dwellings - maintained the idea that disabled individuals should be housed in 'special needs' accommodation (Local Government Boards for England and Wales and Scotland, 1918, cited by Milner and Madigan, 2004: 728).

It was not until the passing of the National Assistance Act 1948 and then a decade later the Housing Act 1957 that the UK government finally outlined a commitment to the development of housing policy for physically disabled individuals. This was demonstrated in Section 91:V of the Housing Act 1957, which stressed that it was the duty of every LA to consider 'the needs of the district with respect to the provision of further housing accommodation' (cited by Rostron 1995:12). The Act emphasised that the housing needs of all were to be considered – including those who were disabled.

accessible houses (John Grooms, 2005). Such is the prevalence of inaccessible housing, that many authorities now have an 'Accessible Homes Register' to match housing wants and needs to available properties. There is no obligation for authorities to provide such a list at the time of writing.

Following this Act, in 1961 the Parker Morris report '*Homes for Today and Tomorrow*' was published (Ministry of Housing and Local Government, 1961). This report introduced space standard regulations for the first time in the UK with the aim to build adaptable houses for changing family needs. Whilst it did have its critics, most notably that it was based on a narrow definition of 'needs' (Goodchild and Furbey, 1986, cited by Madigan and Milner, 1999:402), these standards are an important benchmark for the regulation of space standards. The significance of the Parker Morris report continued into the 1970s. Parker Morris Standards were updated, and the implementation of the Chronically Sick & Disabled Persons Act 1970 and the Housing Act 1974 led to a requirement that all LAs assess the housing and adaptation needs of disabled people and work towards ensuring that a proportion of their housing stock (albeit less than 5 per cent) was accessible (Milner and Madigan, 2004). However, the development of inclusive design standards ground to a halt in the 1980s. With a turn to privatisation and deregulation the drive towards inclusive design standards became marginalised with the house building industry simply opposing any extension of the building regulations (Rostron, 1995; Madigan and Milner, 1999).

The last fifteen years have however seen a number of initiatives that have sought to reconsider housing design and reintroduce design standards. HAs have had a considerable influence in the development of these initiatives. Indeed it is worth noting that HAs have played an important part in helping to achieve community care objectives, coming to play a significant role in providing accommodation for marginalised groups since the 1960s when they become seen as the 'third arm' of housing provision alongside the private and public sector (Franklin, 2006:52-59). Whilst a large proportion of HA housing stock is unsuitable for the needs of disabled individuals – as Karn and Sheridan (1994:98) noted many HAs have been willing to sacrifice standards in the competition for allocations – some HAs such as Edinvar, Habinteg and John Grooms have played a central role in defending space standards, putting pressure on the government to reinstate minimum space standards and promoting innovative housing design ⁵.

⁵ Indeed HAs, and in particular specialist HAs, have had a pioneering role in challenging inadequate design not just for disability but for the range of diverse needs in society, such as the needs of minority ethnic communities and those with 'special needs' (see Karn and

Broadly the initiatives, proposals and recommendations aimed at developing more inclusive housing design can be seen as falling under four categories: barrier free design; Part M recommendations; Lifetime Homes; and Smart Homes and assistive technology.

1. Barrier free – Housing Associations such as Edinvar played a pioneering role in the development of barrier free housing design. Barrier free housing is about attempting to make all housing ‘barrier free’ and accessible to individuals with a range of disabilities. To define this notion of barrier free housing Karn and Sheridan (1994:71) draw on the four different categories of barrier free design outlined by The Edinvar Housing Association. These four categories can be summarised as:

- (i) ‘Negotiable’ – the most basic, with wheelchair users able to move freely around one level of the dwelling. Wheelchair users may however have to be assisted up steps to the dwelling and they may not have access to a WC.
- (ii) ‘Visitable’ – in addition to the conditions of ‘negotiable’ also allowing unassisted access to the lowest level of a dwelling, with an ‘accessible’ WC (an ‘accessible’ WC is one ‘that can be used with the door left open and possibly with assistance’).
- (iii) ‘Livable’ – Over the conditions of ‘visitable’ this category has a ‘useable’ WC and bathroom (i.e. one that ‘can be used independently with the door closed’) and a room suitable for use as a bedroom.
- (iv) ‘Universal’ – Here the dwelling is specifically designed for a wheelchair user.

Typically, however barrier free design refers to building an environment which is sympathetic to the needs of wheelchair users by providing ramps and other design modifications to help individuals gain a greater level of independence (for further details on barrier free housing design see Martin, 1992).

2. Part M regulations – Minimum space and design standards were reintroduced by the UK government in Approved Document Part M of the Building Regulations (DETR, 1998). Approved Document Part M came into force with regard to private

Sheridan, 1994; Findlay, Price and Cadwgan, 1997; Franklin and Passmore, 1998; Madigan and Milner, 1999; Franklin, 2006).

dwellings on 1st October 1999 (before this, Part M regulations only applied to new non-domestic buildings). It was later reaffirmed in the housing green paper 'Quality and Choice: a decent home for all' (DETR, 2000). These new regulations state that new homes have to be built with a level entry, a door wide enough to allow wheelchair access, switches at an accessible height, a WC on entrance level of the first habitable floor and internal arrangements to allow adequate circulation in a wheelchair (a more detailed outline of what Part M requires can be seen in Appendix 1; see also ODPM, 2004). Since the introduction of Part M accessibility has become a necessary design consideration.

3. Lifetime Homes – The concept of Lifetime Homes was initiated in 1989 by the Helen Hamlyn Foundation, a charity which seeks to develop inclusive approaches to housing design (Milner and Madigan, 2004: 735)⁶. Alongside the Helen Hamlyn Foundation the Joseph Rowntree Foundation (JRF) has been at the forefront of Lifetime Homes standards (LHS), becoming a key player in the development and influence of LHS (for JRF produced reports on Lifetime Homes see Brewerton and Darton, 1997; Sopp and Wood, 2001). In the wake of this interest surrounding LHS a wealth of literature has now emerged discussing the topic (see, for example, Carroll, Cowans and Darton, 1999; Nielsen and Ambrose, 1999; Harker and King, 2002; Barlow and Venables, 2004; Milner and Madigan, 2004, Imrie, 2006b).

Lifetime Homes are not aimed solely at disabled individuals but rather offer flexibility in housing use, simplifying the adaptation process to meet the changing needs of the occupier over their life course. Lifetime Homes are distinct from 'special needs' housing, offering a set of design standards that should be applied to all new dwellings. LHS go beyond Part M requirements offering sixteen specific design features, such as a downstairs toilet with draining to enable a shower to be fitted, space for a through-floor lift, walls in bathrooms and toilets to be capable of taking adaptations such as handrails and a reasonable route for a hoist between the main bedroom to a bathroom (see Appendix 1 for Lifetime Homes design specifications). Design guides for

⁶ However, as Nielsen and Ambrose note the idea for accessible, adaptable housing came as early as 1974 in the 'United Nations Recommendation on Adaptable Housing' and the European Commission also sponsored a European seminar on the subject in 1988 (1999: 13).

adaptable or lifetime homes are now in place in many countries across Europe (Nielsen and Ambrose, 1999:16). This includes the UK, where a number of HAs including large providers such as Habinteg, Edinvar and John Grooms have articulated their support for LHS. Furthermore, LHS are also having an influence at UK governmental level, with all new social housing in Wales having to meet LHS since 2001 (The National Assembly for Wales, 2001) and legislation for the incorporation of LHS to Part M legislation scheduled for England by 2007 (Department for Work and Pensions, 2005).

4. *Assistive technology and Smart Homes* – Technology is increasingly being used to assist and support people at home (Dewsbury *et al*, 2004). Assistive technology started with the use of community alarms which were initially developed for elderly people in sheltered social housing and were extended to vulnerable people living alone. Community alarms provide a way for vulnerable people to call for help in an emergency. Users wear a small pendant which when pressed sends a signal to a control centre which will then send assistance. The community alarm service has now evolved into a basic system of ‘telecare’ with an enhanced telephone system, gas and smoke detectors, and detectors which allow the respondent to ‘roam’ outside the home (Barlow and Venables, 2004: 802). Telecare can help increase the functionality of homes, both in new and existing housing stocks, and a target has now been set to enable all homes that need telecare to receive it by December 2010 (Barlow and Venables, 2004; for further readings on community alarms and telecare see Brownsell *et al*, 2000).

Taking assistive technology a step further, the notion of Smart Homes has developed a growing interest over the last decade (see, for example, Gann, Barlow and Venables, 1999; Pragnell, Spence and Moore, 2000; Thomas and Ormerod 2001; Dewsbury *et al*, 2003, 2004; McCreadie and Tinker, 2005; Essen, 2006). Smart Homes ‘use electronic networking technology to integrate various devices and appliances found in almost homes’ (Pragnell, Spence and Moore, 2000: 1). A detailed discussion of Smart Homes has been offered by Gann, Barlow and Venables (1999) who indicate that one control system will operate everything in the home, allowing remote control of everything from appliances to the opening and closing of windows/doors/cupboards/curtains. Equipment is designed to use as little muscular

force as possible (for example motion-sensitive tap controls) and non-skid surfaces are also present throughout the house. In creating an inclusive design that facilitates control for all users, Smart Homes and the design guidelines they assert have the potential to assist in working towards independence for individuals with a variety of disabilities (Thomas and Ormerod, 2001).

These four initiatives highlight the extent to which attitudes towards design are changing. Indeed underpinning the Lifetime Homes and Smart Homes initiatives is the notion that has become known as universal design. The aim behind this universal design philosophy is to create products ‘that are usable by people with the widest possible range of abilities’ (Barlow and Venables 2004:797). Justified as part of a rights-based approach to environments, universal design is about moving away from design as an add-on feature and about promoting flexibility, adaptability and design that does not disadvantage any users and can help facilitate independence (for a detailed description of the key principles of universal design see Imrie and Hall, 2001:15, see also Harrison, 2004; Imrie 2004b).

Whilst the notion of universal design can help facilitate independence through improving design, arguments have emerged that question the ability of such steps to bring about inclusion. Accordingly, developing on from the principles of universal design is the notion of inclusive design. The notion of inclusive design argues for more than just a technical response, requiring a need to also challenge the ‘social and institutional’ practices that underpin the housing design and building process (Imrie and Hall, 2001:18). In placing social and attitudinal relations at the centre of any concerns, inclusive design comes to be just as much about the process as products (see Imrie and Hall, 2001:19 for key principles of inclusive design). Inclusive design goes further than universal design by placing an emphasis on the need to challenge ‘experts’, stressing the importance of user feedback. Crucially inclusive design is about recognising users knowledge and appreciating the impact that inadequate design regulations/standards can have on the lives of disabled individuals.

However design guidelines/standards/philosophies only have an effect on any buildings built *after* any regulations came into effect. Given that 61% of the UK housing in 2004 was built before even the Parker Morris report was published, most

housing in the UK does not cater for the needs of many disabled individuals (Rickards *et al*, 2004). Consequently it is to exploring the legacy of inadequate housing design and the impact of community care legislation have on the lives of disabled individuals that this chapter shall now turn.

2. 4 The impact for disabled people of community care legislation and design guidelines

The importance of the development of community care policies and the emphasis accordingly placed on the ability of individuals to live independently cannot be stressed enough. The community care policies marked a substantial shift in thinking from exclusion and domination of disabled people to inclusion and freedom. Community care radically changed 'the social-spatial arrangements of social care' facilitating a move away from incarceration and back into the community (Gleeson, 1999:156). In doing so disabled individuals have been able to live with their loved ones and re-develop attachments to their dwelling.

The NHSCCA in particular had a positive impact on the lives of disabled individuals. The shift from a service-led to needs-led assessment has helped individuals live a more independent life by having a care package tailor made to their specific needs. It also helped to empower users by respecting their opinion and wishes. The increase in power helped to challenge inequitable practices that were previously accepted (Stevenson and Parsloe, 1993; for a detailed discussion of community care legislation see Rummery, 2002; Means, Richards and Smith, 2003; Morris, 2003, 2004).

However, a number of criticisms have emerged which question whether community care legislation really has had such a positive impact on the lives of disabled individuals. Indeed, critics have argued that community care has in actual- fact proved to be little more than 'institutionalisation within the community' (Morris, 1993:179; see also Scull, 1996; Mays, 2000; Morris 2001, 2004) ⁷. Central to these criticisms are concerns that under community care legislation disabled individuals now face new and different forms of social control and dependency, with the power

⁷ Describing the notion of 'institutionalisation within the community' Sinson (1993) has used the term 'micro-institutionalisation', whilst Crossmaker, 1991 (cited by Brown and Walmsley, 1997:223) has referred to it as 'trans-institutionalisation' (movement from one institution to another).

Goffman described in total institutions now extending beyond the asylum door (Bartlett and Wright, 1999).

Commentators such as Oliver (1990), Morris (1993), Kestenbaum (1996), Allen (1997), Priestley (1999) and Rummery (2002) have argued that a 'recurrent and pervasive feature of community care policy making' is that legislation has been premised upon disabling assumptions, in particular that disabled individuals are dependent and in need of 'care' (Priestley, 1999:44). The community care policies convey the idea of the powerlessness of disabled individuals, giving the professional carer all the power and control in the relationship, just as in institutions (Priestley, 1999:47). Rather than enabling individuals to take control and facilitate independence the care policies 'have been geared towards doing things to and on behalf of disabled people' (Allen, 1997:95). Indeed drawing on Illich's (1977) work on professional dominance critics of community care have argued that the system is designed to serve the interests of care professionals rather than the community care clients (Bartlett and Wright, 1999). For example, care packages are designed around the schedules of care professionals *not* the requirements of the community care client. Consequently the impact of the community care framework is that disabled individuals remain both dependent and powerless in the community.

This dependency and powerlessness is reinforced through the assessment process. The rhetoric of the NHSCCA detailed a situation where a community care package would be created through interaction between a care manager and user in the assessment process. However, as Franklin notes, the value judgements implicit in the NHSCCA 'affirms that professionals are dominant and users are subject to control' (1998:165). By taking the user out of the assessment process, professional control over the assessment disempowers disabled individuals and reinforces dependency by fostering a perception of disabled individuals as a group who need to be looked after (Morris, 1993).

In a detailed analysis of the assessment process Rummery presents the process as not only disempowering but also a fundamental threat to civil rights (2002). Through managerial and bureaucratic gatekeeping mechanisms, access to the assessment process becomes an arduous task. Once an access to an assessment is made, the

applicant finds themselves at the mercy of professionals in a system that is designed to meet the practitioner's needs. The applicant will be told the time of the assessment and from here will be passed around a variety of agencies. Rummery argues that:

“If disabled people are barred from gaining access to the arena in which to negotiate their needs (the assessment) they are banned from accessing full citizenship.”
(Rummery, 2002:97)

Concurring with such an argument Priestley argues that to establish a truly needs-led package for independence, a process of self-assessment becomes essential (1999:90-98). The assessment process comes to typify the power inequalities that many disabled individuals continue to face through community care, and represents the way many disabled individuals still face many of the same disempowering processes they experienced in institutions.

To a certain extent however the introduction of the Community Care (Direct Payments) Act 1996 has challenged the dependency and powerlessness faced by disabled individuals under community care policy. By enabling disabled individuals to decide how and when they receive 'care' individuals gained control, choice, flexibility and confidence over their care. The importance of being able to choose and have control over their own personal assistants and the familiarity and often emotional support that accompany it has become for many individuals as important as the physical assistance provided (Stainton and Boyce, 2004:449). Having been in operation for a decade now, a wealth of literature exists revealing the advantages of the direct payments scheme to users, all of which stresses the independence and power gained by the user through the system (Kestenbaum, 1996; Priestley, 1999; Maglajlic. Brandon and Given, 2000; Shakespeare, 2000; Carmichael and Brown, 2002; Hasler, 2004; Mercer, 2004; Pearson, 2004; Stainton and Boyce, 2004).

Nevertheless Direct Payments is far from a perfect scheme and still has many problems. These include difficulties in the practical side of employing carers (Priestley, 1999; Maglajlic, Brandon and Given, 2000; Carmichael and Brown, 2002; Morris 2004; Priestley *et al*, 2006; for further criticisms of the Direct Payments scheme see Shakespeare, 2000, 2006; Hasler, 2004; Pearson, 2004; Stainton and Boyce, 2004). A more damaging criticism however is that the Direct Payments

scheme remains tied to the disempowering assessment process. By remaining in a system which emphasises budgetary restrictions and means tests rather than rights, disabled individuals remain locked in a community care system that reinforces dependency and powerlessness for users.

Alongside concerns that community care leaves disabled individuals dependent and powerless are fears that the system has also left users abandoned in the community and left to face 'a bleak future of isolation and segregation' (Priestley 1999:104). As Jack powerfully asserts:

"(community care) has led not to care in the community but to abandonment and neglect, not to the extension of choice but to its erosion and to 'imprisonment' for many, not in 'total' institutions but instead in poverty and destitution in the community. "

(Jack 1998:27)

As with the old institutions, this isolation can present an opportunity for abuse (Brown and Walmsley 1997). The closure of asylums and other institutional facilities failed to recognise that the family is also an institution wherein oppressive and depersonalising processes can occur (Jack, 1998). Family care, as an alternative to institutional care, was presented as unproblematic. However, Jack offers an alternative reading citing various commentators who expose the variety of physical, psychological and financial abuse affecting elderly individuals in family care (see Pritchard, 1992; Eastman, 1994, cited by Jack, 1998:21). Rather than offering independence, safety and inclusion, for some disabled individuals community care legislation has seen isolation and abuse replicated.

A critical issue with community care legislation, as noted above, was the fundamental neglect of the role in which housing would play. Given the legacy of housing design regulations/standards that failed to account for the needs of disabled individuals, the result of this arrangement has been that housing has been a substantial barrier to independence. Inadequate design has meant that many disabled individuals cannot move freely or unaided around their dwelling. In many cases the inadequate design has enforced dependency and the need to engage with care services.

The central problem running through all design regulations is that they simply have not gone far enough. Not only are they subject to misreading and minimal interpretation, they also have a very limited definition of what the needs are to begin with (Milner and Madigan, 2001; Imrie 2003, 2006a; Thomas, P., 2004). All the regulations refer to disabled people in a reductive stereotyped fashion, equating disability with mobility impairment, and in particular wheelchair users (Imrie and Hall, 2001; Imrie 2003, 2004a, 2006a). The reality is however that very few individuals registered as disabled are wheelchair users (as little as 4%). The needs of those with sensory impairments and learning difficulties have been overlooked in design guidelines/standards in the narrow focus on disability as those individuals in wheelchairs. Whilst design guides focussing on sensory needs have emerged, (see Dodd, 1998; Harker and King, 2002: 82-94) as of yet they have had little impact on design standards. Whilst a step in the right direction, ultimately the impact of progressive housing design guidelines and standards such as Part M and LHS on the lives of disabled individuals has been minor. Indeed, Imrie and Hall have argued this will always be the case whilst design professionals are cast in the role as ‘experts’ and the structure of society remains disablist (2001, see also Imrie, 2004b). The result of this is that many disabled individuals still struggle to negotiate the barriers caused by inadequate housing design, leaving them once again powerless in their own dwelling and dependent on a less-than-perfect care system to help them live ‘independently’ in the community.

As a consequence of inadequate housing design, adaptations to the dwelling have come to take on a take on a hugely significant role:

“Getting the right adaptation can make a difference. It can make the difference between independence and dependence, dignity and indignity, comfort and discomfort.”

(Bradford, 1998:79)

“(The) impact of good adaptations reads like the restoration of life. This was the effect of adapted toilets and bathrooms restoring dignity and relationships, widened doors and extensions giving the chance to move about; and lifts and ramps giving access to the house, the garden or the outside world.”

(Heywood 2004b:140)

As Heywood notes, the effect of adaptations is such that 'good adaptations reads like the restoration of life'. Adaptations are changes to the dwelling that help individuals to live independently in their dwelling. To return to the notion of normalisation referred to above, adaptations are part of this normalising discourse in that the role of the adaptation is to help disabled individuals 'fit in' with the norm, rather than tackling the underlying problem of inadequate housing design. Broadly there are two types of adaptations works to the dwelling: minor and major. Minor adaptations include grabrails (internal and external), lever taps, flashing light doorbells, visual/vibrating smoke alarms, a shower over a bath, hoists, commodes and ramps whilst major adaptations include through floor lifts, stairlifts, extensions, widening of doorways, redesigning kitchens, electric window openers, walk in showers (see Figures 2.1 – 2.5 below).



Figure 2. 1 Ramp to front door.

Source: www.enabledsignservices.co.uk



Figure 2.2 Adapted bathroom with walk-in shower and grab rails.

Source: www.enabledsignservices.co.uk



Figure 2. 3 Ceiling Hoist
Source: www.horcher.com



Figure 2. 4 Through floor lift
Source: www.snowdropcareandmobility.co.uk

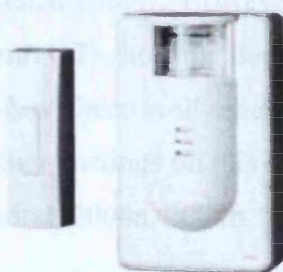


Figure 2. 5 Flashing light doorbell.
Source : www.universalaids.co.uk

Acknowledging that suitable adaptations are a key factor in enabling a disabled individual to live independently in their own dwelling, the provision of housing adaptations have become central to community care policies. Moreover, following restrictive lifting and handling practice set out by domestic and EU law (Health and Safety Executive, 1992; Management of Health and Safety at Work Regulations 1999; EC Directive 89/391/EEC cited by Disability Rights Commission, 2003), on health and safety grounds many authorities and agencies insist that where necessary adaptations such as hoists are installed in dwellings to assist care workers.

The key regulations for assistance with adaptations are set out in the CSDPA (Section 2) and the NHSCCA (Section 47) ⁸. Adaptations are means tested and an assessment

⁸ Regulations for assistance with adaptations are also set out in The Disabled Persons (Services, Consultation and Representation) Act 1986; The Local Government and Housing

of levels of need is central to the allocation of resources for adaptations. The assessment is once again needs-led. Under the Housing Grants, Construction and Regeneration Act 1996 the housing authority is required to consult with the social service authority (which in most cases will be an O.T.) in deciding what adaptations are needed. The decision is then made as to what is practicable within financial restraints (McDonald, 2006). The only mandatory grant is the Disabled Facilities Grant, though there are a number of other forms of funding available to help improve accessibility of a property (for further on sources of funding for adaptations see Heywood, 1994; Bull, 1998; Bradford, 1998; Greaves, 2006). In practice the system concerning sources of financial assistance for adaptations is complex and often confusing, with a number of different sources of funding for different tenures. A wealth of literature has already discussed the complex funding issues for adaptations and the problems associated with it. However as the topic of funding, the frustrations involved in engaging with OTs /housing departments/social services etc, and the time waiting for adaptations have been well rehearsed elsewhere they will *not* be explored in this research (for further writings on this subject see Bull, 1998; Bradford, 1998; Rummery, 2002; Heywood, 2004a, 2004b, 2005; Greaves, 2006).

What is important to note for the purpose of the current research is the impact installing adaptations can have. The adaptation process has been described as disempowering (Heywood, 2004a), stressful, frustrating and a disruption to an individual's life (Bradford, 1998). If house builders fail to appreciate the disabled householder's feelings about the adaptation process and acknowledge that the adaptations are being performed on an individual's *home*, it can leave the disabled person feeling both 'resentful and disempowered' (Heywood, 2004a:712). Heywood argues that when adaptations are done in a disempowering way which fails to consider the importance of detail on 'precious aspects of the home', adaptations may not be beneficial (2004a:724). Inadequate adaptations can also lead to more difficulties and even accidents (Heywood, 2004a). Furthermore, concerns have also been raised that the vast amounts of money spent on adaptations can also create further barriers for the disabled individual who may feel a sense of obligation or

pressure to stay in a dwelling following a large investment (Kestenbaum, 1996, Harrison and Davis, 2001). The psychological impact of adapting the dwelling will be explored in detail in Chapter 4.

There have also been similar concerns raised about the impact of assistive technology (through Smart Homes and telecare systems) in the dwelling. Of particular concern are fears that increased use of assistive technology that is insensitive to domestic design aesthetics in the dwelling can create a feeling of hospitalisation within the home setting (see Chapter 4). There have also been deeper ethical questions raised concerning the use of technology as a form of surveillance (by tracking individuals) and as to whether the use of technology in the dwelling is emancipatory or oppressive (see Gleeson, 1999:104; Imrie and Hall, 2001:17; Rauhala and Topo, 2003; Barlow and Venables, 2004; Sheldon, 2004). As a form of surveillance, the impact of assistive technology such as telecare underlines the extent to which design principles can perpetuate powerlessness and a lack of privacy for users.

Where adaptations are not possible and/or under the existing community care framework living independently in the dwelling becomes an unviable situation, as noted above moving into 'supported housing' becomes the only option. In many cases the move to supported accommodation is only necessary because society (and in particular an inadequate housing system) is not able to accommodate for diversity.

Given the range of supported accommodation, it is necessary to respect that there is difference between the various housing options. However on the whole supported accommodation retains many of the values that characterised institutional care. Distinctions remain between staff and residents, with rules for residents to follow and significant areas restricted to staff (Twigg, 2000). Authority and discipline is maintained 'albeit in a velvet glove' with residents being treated in childlike fashion (Franklin, 1998:170). Whilst individuals are free to come and go in supported accommodation, occupants lives remain monitored by support staff. Writing on this subject Morris refers to the example of one individual who said staff monitored when you left and when you returned, and a further individual who recalled the occasion when she discovered that the staff kept 'a record of when your period is due' (1993:62). Consequently, as well as perpetuating an idea that certain groups who fall

outside the narrowly defined norm need to be housed in a 'special' place, it appears that institutional practices are being replicated in supported housing settings, particularly in terms of control and surveillance. Once again, the impact of the practices in supported accommodation prevent disabled individuals obtaining independence and control over their lives. Moreover, given such accounts any attempt to depict such settings as 'home' becomes problematic (for further discussion of supported accommodation as a 'homely' setting, see Franklin, 1998; Lundgren, 2000).

2.5 Conclusion

As noted at the start of this chapter, policy is one of the contexts in which disabled individuals lives are framed. To understand this context the chapter has sought to review key British legislation pertaining to the 'care' of disabled individuals and housing design and understand the impact this legislation has.

In reviewing 'care' policies in the UK, what was highlighted was approaches to caring for disabled individuals have changed dramatically over the last sixty years. The shift in approaches has enabled disabled individuals to live in their own dwelling rather than being incarcerated in institutions. Nevertheless, the chapter has also noted that whilst the policies of community care have enabled many disabled individuals to live in the community, the 'care' given often resembles that which existed in the old institutions – with professionals and carers holding all the power in the relationship, leaving disabled individuals subordinate to their control. However, in a crucial step towards independence, the recent introduction of the Community Care (Direct Payments) Act 1996 has challenged this form of social relations, enabling disabled individuals on such a scheme to have greater control over their care package and more importantly their whole life.

In addition to policies on care, this chapter has also sought to review British policy guidance on housing design. Approaches to housing design have also changed significantly over the last one hundred years, with a shift towards recognising the needs of disabled individuals. By reviewing policies on design regulations since the turn of the twentieth century it becomes possible to realise that the British housing stock fails to meet the needs of many disabled people mainly because there was never

any real attempt made to recognise and include the needs of disabled individuals into design regulations. Part M building regulations have gone some way to improve design, and Lifetime Homes standards – which are increasingly being encouraged- go further still in integrating the diverse needs of disabled individuals into mainstream housing design. Nevertheless, these guidelines still do not go far enough and there remains a ‘wheelchair reductive’ approach to what the needs of disabled individuals are. Furthermore, echoing the writings of Imrie what has to be acknowledged is that if these improvements are not matched by wider social changes designing for disabled individuals will never be seen as integral to good quality housing design (2006a, 2006b). Given the inadequate design of UK housing, adaptations have taken on a hugely significant role in enabling disabled individuals to live in their own dwelling.

Through an awareness of these policies and many of the problems associated with them, it becomes possible to develop an understanding of the impact such policies can have on a disabled individual’s life. Recognising this, it becomes important to acknowledge that policy plays an important role in contextualising the research. From the review of the impact that community care policies and housing design regulations can have, a number of issues emerge that become crucial to explore during the course of the thesis. These include:

- Independence being threatened by the power held by professionals/ carers and whether being on the direct payments scheme changes this power dynamic.
- Feelings of isolation, segregation and confinement in the dwelling.
- Problems faced in the dwelling as a result of inadequate design.
- The impact adaptations/ assistive technology in the dwelling have on an individual.
- Institutional practices being replicated in supported housing settings (particularly in terms of control and surveillance).

Much of this thesis will develop these broad points by exploring existing related literature on these subjects (Chapter 4), utilising interview data to investigate the issues (Chapter 6) and describing how a number of different issues, including (but not limited to) these, come to interact to produce a meaning of the dwelling unique to each individual (Chapter 7). However, before this discussion can take place the next

chapter will set out the theoretical dimension of the research, exploring the notion of critical realism and developing a framework from which to explore the influence of society, agency and physiology on experience.

Chapter 3. Theory development:

critical realism

Chapter 3

Theory development: critical realism

3. 1 Introduction

This chapter presents the theoretical standpoint taken in this research. The purpose of providing such a discussion is to introduce concepts and terminology that will be drawn upon throughout this thesis. Furthermore, it also gives a detailed insight into the way in which the theoretical position influenced the direction of the research project. By discussing the theoretical standpoint taken in this thesis before the presentation of empirical findings the intention of this chapter is to furnish the reader with an understanding of the theoretical concepts that underpin the analysis of the data.

Broadly, the theoretical position that has been adopted can be understood as that of the developing critical realist perspective. The chapter is divided into two substantive sections. In the first section the philosophy of critical realism will be introduced, offering a twelve-point summary detailing exactly what adopting a critical realist stance does and does not entail. Given the importance in critical realism of holding society and agency ontologically distinct, drawing on the writings of Roy Bhaskar and Margaret Archer this notion will be discussed in detail. This will involve a focus on identifying what is meant by the terms ‘society’ and ‘agency’ and explain the way in which society and agency have to be understood as ontologically distinct yet interacting structures – a theme that will run throughout the thesis.

The second section will discuss an issue that has been present in critical realist literature but has remained under-theorised – that of physiology. Drawing on critical realist literature and wider writings within sociology on physiology and the body, this section shall seek to redress this, asserting the need to recognise physiology as an ontologically distinct structure. In doing so, a ‘three-dimensional framework’ will be developed– one that is able to simultaneously acknowledge the influence of physiology, society and agency in explaining an experience. This framework represents my theoretical position and as such influences the research agenda for exploring the meaning of the dwelling for physically disabled individuals. Indeed the

development of this analytical framework was outlined in Chapter 1 as one of the five key objectives of this thesis.

3. 2 Understanding critical realism

3. 2. 1 An introduction to the philosophy of critical realism

This brief review of critical realism cannot offer a detailed exposition of critical realism or its philosophical underpinnings (for this see, for example, Archer *et al*, 1998; Sayer, 2000; Bhaskar, 2002:175- 196). Instead what is presented is a 12 point summary, one that can broadly be seen as falling into two parts: what critical realism *is not* and what critical realism *is*:

Misguided assumptions of critical realism

Ontologically, realism refers to a theoretical position which maintains that the world exists independent of our thought/perception. Realist epistemology supposes that because reality cannot be fully understood through perception, theory can help reveal what is not directly observable. Different forms of realism have come under sustained, and in many cases powerful, criticism. However many of the criticisms of critical realism seem to come from a fundamental misinterpretation of what it actually entails. In adopting a critical realist position, it is first necessary dispel misleading assumptions concerning critical realism's philosophy:

1. *Critical realism is not positivist.* Like social constructionism and feminism, critical realism emerged out of critiques and responses to positivism⁹. Providing a detailed criticism of positivism, Roy Bhaskar – widely regarded as the founder of the critical realist movement - suggests that believing that an event can be understood through repeated empirical observations is an 'epistemic fallacy' (see below) in that positivism confuses the ontological matter of what exists with the epistemological issue of how we can know it (1986). As Sayer succinctly explains, the amount of times that we can empirically observe an event does not help us to understand what causes it (2000:14). Whilst critical realism believes that it is possible, even desirable, to study social phenomena 'scientifically' this belief is very different to that taken in a

⁹ Positivism is a belief that holds we can only know that which we can experience and/or perceive through our senses. Positivist approaches argue that scientific knowledge can yield true and correct connections between ideas and reality.

positivist understanding. For critical realists 'epistemological caution' must be taken with respect to scientific knowledge, not a fundamental rejection as other standpoints such as some feminist positions have contended (Lopez and Potter, 2001:9; for more on the critical realist critique of positivism see Bhaskar, 1986:224- 308, 1998:124-132; Collier, 1994:101-104).

2. *Critical realism does not subscribe to a foundationalist philosophy.* Critical realism is not a naïve objectivism claiming unmediated access to the truth. Indeed critical realists would argue the notion of absolute truth is untenable. However, unlike postmodernism and forms of social constructionism who take an anti foundationalist stance, realism does not refuse all talk of truth ¹⁰. Additionally unlike the constructionist belief that all accounts are equally valid, critical realism refutes judgmental relativism, and is open to the idea of distorted perception. Holding this notion of distorted perception, because individuals can never gain a totally comprehensive view of the world (and that goes for researchers) we can only ever have a transitive view (a transitive view is our theory of what exists; see below for discussion of the transitive/intransitive dimension). Thus, a critical realist position would argue the necessity to adopt a fallibilist philosophy. Indeed Sayer (2000:91) indicates that the epistemological position of fallibilism fits more comfortably with realism than a strong version of social constructionism (a strong version of constructionism claims that all objects of knowledge are 'nothing more than socially constructions' whilst a 'weak' version only goes as far as asserting that knowledge 'often bears the marks of its origins', Sayer, 2000:90). This fallibilist philosophy adopted by critical realism must be one that is wary of a simple correspondence of truth, and acknowledge that the world can only be known in terms of available descriptions (Sayer, 2000:2).

3. *Critical realism does not refute epistemic relativism.* Accepting that the world can only be known in terms of available discourses, critical realism accepts 'the correct thesis of epistemic relativity' (Bhaskar, 1998:57). Following Bhaskar, most critical realists happily accept that knowledge is transient and that 'neither truth values nor

¹⁰ Foundationalism is an epistemological position which holds that knowledge is to be justified through reference to self-evident and infallible beliefs/truths. Accordingly anti-foundationalism is any philosophy which rejects this approach

criteria of rationality exist outside historical time' (1998:57). Willig reaffirms this belief, arguing that critical realists accept the 'inevitability of ultimate epistemological relativism by acknowledging the linguistic and historical constitution of knowledge' (1998:91). As noted above, what critical realism is unhappy with is the notion of judgmental relativism; which asserts that all beliefs are equally valid. A critical realist position asserts the possibility of distinguishing between claims.

Critical realism's notion of truth denies any notion of absolute truth, but is more than a mere notion of subjective opinion. In adopting this position, Sayer argues that although absolute truth becomes meaningless, one can still distinguish good ideas from bad ideas (2000). This position is not unique to critical realism and some feminist literature on epistemology also calls for simultaneously acknowledging an account of knowledge as historically contingent and having a commitment to a real world (Harding, 1991, 1993; Harraway, 1991; Harstock, 1997). To say a certain proposition is true is not to say the proposition is beyond improvement, it may be shown to be false or it may be partial, or incomplete. Sayer describes this as the notion of 'practical adequacy' (2000:43). By adopting a notion of practical adequacy, Sayer accepts the notion of the social constructionist nature of knowledge but holds that there is a need to distinguish between more and less fallible accounts, between those whose inadequacy is already clear and those that have so far been proved to be adequate (for further readings on practical adequacy see Sayer, 1992,65-72).

4. *Critical realism is not essentialist.* Critical realism does not take an essentialist point of view (essentialism is a perspective which claims that objects - including people - have specific essences or innate properties which can be discovered and used as an explanation for particular characteristics). Neither though, as Sayer points out, does it argue for an anti-essentialist point of view (2000). Rather an approach is adopted in which some things have essences and others do not. Sayer argues that it is necessary to 'get beyond the stark alternatives of essentialism and anti-essentialism and work with a richer ontology' (2000:82). In arguing that it is possible to be a moderate essentialist Sayer argues that some things have essence and others do not, as opposed to a strong essentialist standpoint that everything has an essence. Strong essentialism is always wrong as it holds a misguided assumption about the universality of a group. Vice versa, it is also dogmatic to take a position of strong

anti-essentialism, which argues that just because some things do not have an essence nothing has. Anti-essentialism goes too far as it goes from arguing that if things like sex and identity can have no essence, nothing can have an essence. Sayer indicates that a critical realist position should look towards a middle way of moderate essentialism, identifying essences as potentialities without presuming they must be fixed.

Sayer indicates that there might be occasions where essentialism is unproblematic. By adopting the critical realist conception of causal powers possessed by objects we can avoid the notion that an object has a single essence. People will not have one but many causal powers, not all are unique to humans, not unchanging and eternal and not all humans will have the same causal powers. A shared attribute also does not necessarily mean that is an essence, even if it occurs in 100% of the cases, avoiding the problem of attributing accidental properties as essential ones. Thus whilst individuals may share the same properties, asserting sameness need not involve denying difference. A critical realist notion of essentialism need not assert that all members of a group are identical in every respect, only that they have some features in common; thus it is not guilty of homogenising.

5. Critical realism does not discourage reflexivity.

“[w]e do not see reflexivity as undermining researchers’ commitment to realism. In our view it only undermines naïve forms of realism which assume that knowledge must be based on some absolutely secure foundation”.

(Hammersley and Atkinson, 1995:17)

As the quote above from Hammersley and Atkinson notes, adopting a form of realism which rejects absolute foundationalism (which as noted above critical realism does) need not conflict with notions of reflexivity. On the topic of reflexivity, Sayer (2000) notes that:

“Realism does not require some kind of denial of ‘subjective’ influences or standpoints and researcher’s social context. On the contrary, it requires us to examine those standpoints so as to guard against forms of projection and selection that misrepresent our objects. Realist social science requires reflexivity.”

(Sayer 2000:53)

It follows that critical realists should be reflexive when considering the influence of standpoints on the way we see and think. Indeed an emphasis upon reflexivity is central to realist challenges on relativism. As the quote below indicates, reflexivity is vital for any kind of objectivity:

“Reflexivity is conducive – we can put it no more strongly – to objectivity in the sense of the developing of true or practically adequate accounts.”
(Sayer, 2000:61)

6. *Critical realism does not demand value neutrality.* Recent years have seen a questioning in the positivistic strive for value neutrality and objectivity (see Atkinson, Coffey and Delamont, 2003). The enhanced awareness of the role of the self became most clearly revealed from the mid 1980s in the interpretive turn – Denzin and Lincoln’s fourth moment (Atkinson, Coffey and Delamont, 2003: 58). Critical realism continues in this tradition, and Carla Willig (1998:92), a self-confessed committed international socialist, has argued for a critical realist position being ‘historically and linguistically reflexive’ yet also capable of ‘guiding active intervention in ideological and material struggles’.

By identifying and distinguishing between three types of objectivity Sayer (2000:58) demonstrates why critical realism does not demand value neutrality. Objectivity₁ is the notion of value neutrality, Objectivity₂ is the search for objective knowledge and Objectivity₃ is the notion that there are objective properties of objects regardless of what we think about them. Objectivity₁ and Objectivity₂ are often combined, and it is assumed that to get true statements about the world (Objectivity₂) statements must be value free. Sayer challenges this proposition by distinguishing Objectivity₁ and Objectivity₂ and argues that we can all accept factual statements that we do not like. For example people of contrasting political value can agree on the outcome of an election regardless of whether they are happy with it or not. For Sayer (2000:59) ‘value neutrality and objectivity in terms of commitment to finding true statements are different things’. It follows that Objectivity₂ research can be value laden.

The theory of critical realism

Having identified what critical realism is not, it seems only logical to understand what critical realism is. There is not a homogenous critical realist movement in the social sciences. Like many theories there are many different perspectives and developments. Critical realism is not a closed intellectual system, and there are a 'variety of realisms' (see Lopez and Potter, 2001:19 -75). There are however key features that are shared amongst critical realist approaches:

7. *Critical realism distinguishes between the intransitive and the transitive dimension.* The properties that we study form the intransitive dimension of science. Theories and discourse are part of the transitive dimension. Rival theories about science have different transitive objects (theories about the world) but the world they are about – the intransitive dimension – remains the same. A change in theory (transitive dimension), does not change the phenomenon as well (intransitive dimension) (Sayer, 2000:10).

8. *Critical realism distinguishes between the empirical, the actual and the real.* Critical realism does not just distinguish the world and our experience of it; it also distinguishes between the real, the actual and the empirical, and thus creates a stratified ontology¹¹:

Table 3. 1 Three domains of the real, the actual and the empirical (source: Bhaskar, 1975:13)

	Domain of the Real	Domain of the Actual	Domain of the Empirical
Mechanism	✓		
Events	✓	✓	
Experiences	✓	✓	✓

¹¹ This is somewhat of a simplification. Whilst it remains a popular summary of Bhaskar's work and was used by Bhaskar himself, the distinction between the real, the actual and the empirical the empirical is in fact just a beginning way of characterising the complexity of ontological stratification. Indeed, as Nellhaus (2004:128) notes, in Bhaskar's 'later' works (1993 onwards) this domain of empirical becomes subsumed within the 'subjective' individualised self. Unpacking this distinction is beyond the scope of this discussion (see Nellhaus, 1998: 8- 12) and consequently this thesis shall continue to refer to the three domains of the empirical, the actual and the real throughout the thesis.

As can be seen from Table 3. 1, the empirical is the domain only of observable experiences, the actual denotes the domain where events are activated, and it is only at the level of the real where underlying structures and generative mechanisms reside (Bhaskar, 1975:56). By making this distinction it becomes possible to acknowledge the reality of *unobservable* structures as belonging to the domain of the real. The refusal to collapse all domains into one through a belief in three stratified domains allows a rejection of a reliance on surface data alone, giving ontological depth to thought (Williams, Birke and Bendalow, 2003a). By appealing to this existence of unobservable structures and their causal powers at the level of the real, critical realists argue that it becomes possible to explain any observable effects at the empirical level with reference back to these underlying unobservable structures.

In keeping a distinction between the empirical, the actual and the real, and through asserting the existence of mechanisms in the domain of the real, Bhaskar is refusing to conflate the ontological (what there is to know) with the epistemological (what we know and how we know it) (Williams, 2003a:28). To collapse epistemological and ontological issues, Bhaskar argues, is to commit the ‘epistemic fallacy’ (1998:171). In refusing to conflate ontological and epistemological issues a critical realist standpoint is able to assert that whilst there is relativity of knowledge in the epistemological dimension, a belief in the reality of causal mechanisms can still be maintained in the ontological dimension (Williams and Bendalow, 2003).

9. *Critical realist notion of causation: structures and mechanisms.* One of the most distinctive features of realism is its analysis of causation. Critical realists are fundamentally opposed to the positivist cause and effect model of causation, seeking to understand an experience/event (see following discussion for definition of the terms experience and event) through an appeal to underlying structures and mechanisms. The critical realist model of causation can be seen in Figure 3.1:

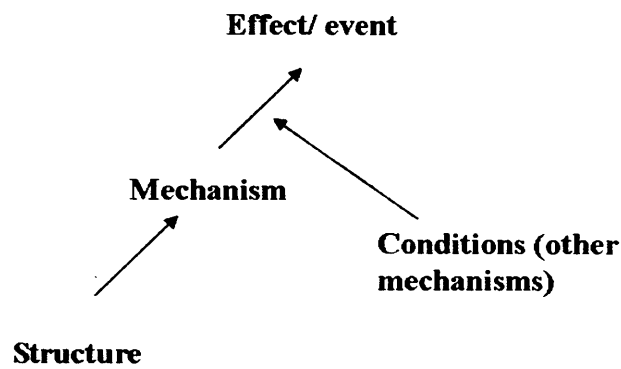


Figure 3. 1 Critical realist view of causation (source: Sayer, 2000:15)

Before explaining Figure 3. 1 it is first necessary to understand the terms being used. There appears to be substantial confusion within critical realist literature on the terms ‘structure’ and ‘mechanism’, resulting in the terms being used as if they were interchangeable. Bhaskar himself notes that ‘I often use the term structure and generative mechanisms as if they were synonyms’ – but then indicates that they are not (1998:170). The notion of a *structure* in critical realism is taken to refer to something with causal powers and that given certain conditions these powers will emerge. The effects of the causal powers from the structure become manifested in the form of generative mechanisms. A *mechanism* is not necessarily ‘mechanical in the sense of Newtonian mechanics’ (Collier, 1994:43) but rather refers to a force that emerges from the structure and ‘makes something happen’ (Danermark *et al*, 2002:206). A mechanism will exist whether it is triggered or not. However it is only when it is ‘triggered’ that it gives rise to a certain event.

Efforts to explain this process using examples have been fraught with difficulty (Saunders, 1989: 354-358; Collier, 1994:43). One way of explaining it is through reference to the event of the built environment as inaccessible to disabled individuals. The mechanism in this example is that of ‘design based on notions of the able-body’. Given that the built environment is premised on a vague notion of the ‘able bodied’ user, this mechanism of ‘design based on notions of the able-body’ will exist whether it is triggered or not. Design – at this moment in time - will always be based on notions of the able body. However this mechanism is only ‘triggered’ when an individual falls outside the narrowly defined notion of the ‘able-body’. When triggered (i.e. an individuals who falls outside the notion of able body interacts with

the built environment) this mechanism will then give rise to the event of the built environment as inaccessible to disabled individuals.

Figure 3. 1 illustrates the way in which an event has to be understood through discovering the underlying structure(s) and their emergent mechanism(s). What is of crucial importance is that causality is multi-faceted and complex, with numerous mechanisms coming together to create an event. Some mechanisms may act in a complementary fashion, others in opposition to one another.¹² Thus, the same mechanism may produce different outcomes depending on the existence of other mechanisms. As Sayer (2000:15) explains, events depend on ‘spatio-temporal relations with other objects’. By recognising the existence of multiple mechanisms – and multiple *structures* –, it becomes possible to avoid charges of reductionism and move away from a positivist cause and effect model of causation¹³.

10. Structures and mechanisms can be understood via retroduction and abduction.

The objective of critical realism is to explain experiences and events by identifying the underlying structures and causal mechanisms responsible. This is achieved through the process of retroduction and abduction. Both retroduction and abduction are thought processes. Abduction involves interpreting and recontextualising a phenomenon in a new way within a new conceptual framework with the help of general concepts/categories (Danermark *et al*, 2002:80). Habermas (1972, cited by Danermark *et al*, 2002:94) believes that abduction can help develop a broader, deeper knowledge by building on creativity and imagination. This is the essential difference between abduction and deduction. Retroduction involves advancing from empirical observation to arrive at something different (‘a conceptualisation of transfactual conditions’ Danermark *et al*, 2002:96). By looking to go beyond the empirical, transcendental argumentation is placed at the core of retroduction.

¹² This notion of competing mechanisms pays more than a passing resemblance to Berger and Luckmann’s (1967) notion of conflict between different legitimations and socialisations (the problem of logical coherence) and the resistance amongst ‘sub-universes’. For Berger and Luckmann, appearance of a sub-universe poses a threat to an existing discourse, with conflict occurring between rival groups of experts on definitions and understandings.

¹³ For a more detailed account of causation in critical realism I refer the reader to Elder-Vass (2005).

Consequently critical realism is based on transcendentalism. Transcendentalism is a philosophy which asserts that our knowledge of reality is to be found beyond the concrete and observable. One of the best-known philosophers of transcendental philosophy is Kant. However Danermark *et al* (2002) argue that Bhaskar's transcendental realism is different from Kant's transcendental idealism, as Bhaskar does not claim universal and unchangeable conditions for our knowledge of reality. Transcendental knowledge, like all knowledge is fallible.

11. *Critical realism seeks discursive and extra-discursive understandings.* Identifying structures need not necessarily involve studying language or discourse. If discourse does not play a major constitutive role in the production of forms of events then unlike social constructionism, a critical realist analysis does not need to study them (Burr, 1998:20). Actions cannot just be reduced to discourse, as Marsh *et al* (1998, cited by Sayer, 2000:25) indicated in a discussion on globalisation. Here they argued that at least in part, the discourse is dealing with something real. Realism insists on the presence of a non-discursive, material dimension to social life: a reality outside of discourse (Sayer, 2000:18). Reality lays down important restrictions on the variety of ways open to us to construct the world. Restrictions include not only the physical properties of our bodies and bodily life, but also the properties of the physical and social world we live in. Physical process can affect us extra discursively even when we come to know of them discursively.

12. *Critical realism holds society and agency ontologically distinct.* Critical realism looks to overcome the 'false opposition' between agency and society. Generally in social science the term society refers to the principles that govern behaviours, relationships and values within a particular group; principles which exist 'beyond the individual subject' (Marshall, 1998:625). Agency meanwhile refers to the 'undetermined nature of human action', that is the capacity for human agents to make voluntary choices and act upon them, as opposed to actions being pre-determined by genes/society (Marshall, 1998:10). In Bhaskar's account, the social world consists of two types of being: society and the individual. Both are real with causal powers. For critical realists this causal power means structures can either enable or constrain action. Whilst the structure of society has an influence over individuals, people's actions are never determined by a certain structure, they are just conditioned and

people can choose alternatives. Indeed Danermark *et al* (2002) indicate that society can only socialise an individual if a manifold of social relations are already in place. By adopting such a position, Bhaskar keeps society and agency ontologically distinct and in this way differs from Giddens structuration theory (1979, 1984), which collapses society and agency together (Archer, 1995: 93-134).

These twelve points offer only a very brief summary of the central tenets of critical realism. Nonetheless, as this research project has taken a critical realist perspective recognising these features will be fundamental to understanding the direction of the research. Indeed, such is the importance to this research of the last point - understanding society and agency as distinct ontological structures - that it is necessary to explore these notions in greater depth.

3. 2. 2 Understanding society and agency as ontologically distinct but interacting structures

The way in which critical realism seeks to identify accounts through the ontologically stratified dimensions of society and agency is crucial to this research that seeks to understand the meaning of the dwelling for disabled individuals. Consequently, this section shall explore exactly what is meant by the terms ‘society’ and ‘agency’ and through the work of two key critical realist theorists – Roy Bhaskar and Margaret Archer- investigate the way in which these structures are said to interact.

Society

Whilst, as Bhaskar notes, methodological individualistic accounts explain society purely as resulting from individual action, a critical realist position demands the recognition of societies as irreducible to people (1975:30)¹⁴. People and society are not related dialectically they are two different ‘kinds of thing’ (Bhaskar, 1975:40).

“The model of society/person connection I am proposing could be summarized as follows: people do not create society. For it always pre-exists them and is a necessary condition of their activity. Rather society must be regarded as an ensemble of structures, practices and conventions which individuals reproduce or transform, but would not exist unless they do so. Society does not exist independently of human activity (the error of verification). But it is not the product of it (the error of voluntarism).”

(Bhaskar 1975:42)

¹⁴ Methodological individualism refers to a philosophy which seeks to explain everything via ‘statements about the competent individual’ (Flew, 1979:230).

For Bhaskar society is not created by humans, although it is reproduced and transformed by them, as shall be discussed later. However society always pre-exists humans with causal powers which manifest as tendencies. These tendencies are then exercised through human intentionality. Consequently, as the above quotation identified, whilst society does not exist independently of human activity it is not the product of it. Exploring the materialization of society, Archer also asserts that society has deep underlying causal powers that pre-exist and are irreducible to agency (1995:71). **It is such an understanding of the notion of society that shall be adopted when referring to and using the term in this thesis.**

Agency

Whilst accepting society as a causal power, critical realism is critical of over-dependence on the power of society and discourse, and seeks to recover a notion of agency. To attempt a complex discussion on exactly what agency 'is' is beyond the reaches of this short discussion¹⁵. Nonetheless, whilst anti-realist accounts such as postmodernism and variants of constructionism have asserted that there are no emergent properties pertaining to human agency (Archer, 2000:188, notes Harre's dictum that there is 'nothing in the mind that was not first in conversation') critical realism looks towards recognising the emergent causal powers of human agency as irreducible to either society or physiology (Archer, 2002:12). This is exemplified in the works of Bhaskar who argues that people possess properties irreducible to matter that are *sui generis* real (see Bhaskar, 1998: 80- 119):

"Agency whether in the shape of mowing a lawn or in what I shall call the transformed transformative *trustworthy* totalizing transformist *transitional* praxis which would unite the interests of the human race in nature, is a species-specific in eliminable *fact*. "

(Bhaskar, 1993:210, italics in original)

For Bhaskar agency exists as a deep underlying structure. At the core of each of us (lying at the level of the real) we have a 'ground state' (2002). This 'ground state' exists prior to society and is informed and inside each and every human, comprising our true and authentic self (for further discussion see Bhaskar, 2002). Echoing

¹⁵ For critical realist writings on this subject I refer the reader to the detailed writings of Archer (1995: 247—293, 2000); Bhaskar (1993: 167-169, 1998: 80-119, 2002: 69- 116) and Nellhaus (2004).

Bhaskar's sentiments, Archer has also explored the existence of agency as real, arguing the need to assign causal powers to agency that refuse to reduce it to either society or physiology. Archer insists that agency is not a construct and has powers identifiable to itself (Archer, 1995:258-259):

“There is much more to the human being than a biological bundle of molecules plus society's conversational meanings. In fact, between the two, and reducible to neither, emerge our most crucial human properties and powers – self consciousness, reflexivity and a goodly knowledge of the world, which is indispensable to thriving in it.”

(Archer 2000:189)

From this passage, it is possible to appreciate Archer's belief that there is a sense of self 'who is sufficiently strong to resist collapsing into the social' (1995:292). By exploring the problem of agency through drawing on the emergence of self consciousness in pre-linguistic work on children by Piaget, Archer demonstrates how our sense of self is necessarily prior to our sociality (see 2000:121-153, 2002:12-15). As Moll notes, accepting human agents as possessing and exercising irreducible emergent causal powers is one of the most fundamental claims of critical realism (2004). **It is this understanding of agency as a deep underlying structure, irreducible to society and containing causal powers that shall be adopted when referring to and using the notion of agency in this thesis.**

Interaction of mechanisms

Although ontologically distinct, society and agency are inter-connected. Seeking to adopt a non-conflationary approach Bhaskar and Archer have explored the interplay between society and agency across time. Indeed understanding this interplay between society and agency becomes central to comprehending the work of Bhaskar and Archer. Bhaskar holds that whilst society and agency are distinct ontological domains, there is a mediating process interlinking the dimensions of agency and society. Bhaskar contends that whilst society would not exist without human agency, agents do not create society they just reproduce it. By the same token whilst agency is always socially situated agents have causal powers that cannot be reduced to society (1998). Society thus does not create the individual any more than the individual creates society (Harvey, 2002:168). This work corresponds to Bhaskar's

‘first’ phase in which he describes the interrelationship between society and agency through his ‘Transformational Model of the Society/Person Connection’ (1998:36).

In his ‘second’ or ‘later’ phase, i.e. from 1993 onwards, this notion is re-presented as the ‘Transformational Model of Social Activity’ (TMSA) (Harvey, 2002:172):

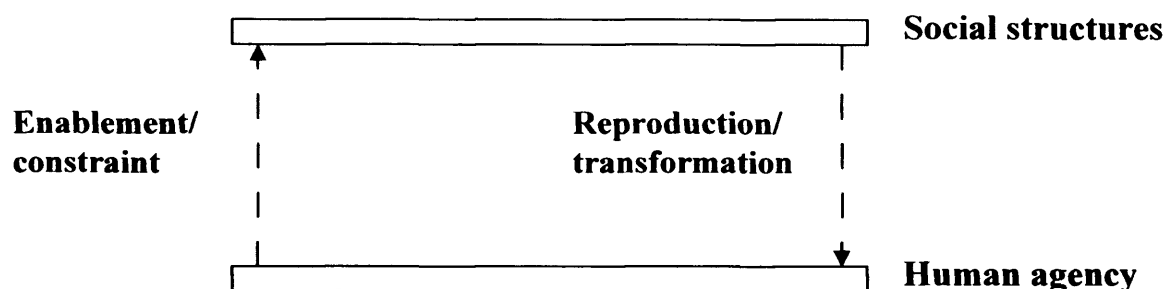


Figure 3. 2: The Transformational Model of Social Activity (source: Bhaskar, 1993:155)

From this Figure it becomes possible to understand the relationship between society and agency. Agency and society can be accorded the status of ontologically distinct generative mechanisms with their own causal powers but remain intertwined, with one impacting on the other, enabling and constraining, reproducing and transforming over time. Although agency (replacing the ‘individual’) in the TMSA is accorded a more important role. Bhaskar asserts that the message remains the same as his earlier work:

“Society is thus both the condition and outcome of human agency (the duality of structure to use Anthony Giddens’ terminology) and human agency both the production and reproduction (or transformation) of society. ”
(Bhaskar, 1994: 92, cited by Harvey 2002:172)

Archer’s Morphogenetic/Static approach complements this assumption presented in Bhaskar’s TMSA. Again, whilst society and agency have their own distinct emergent properties, they exist in relationship to one another. Archer’s Morphogenetic argument demonstrates the way in which society and agency operate over time. Society pre-exists agents but agents pre-exist the society that they maintain/transform through interaction with society over time. Consequently society is both real and

shaped by agency. The interplay and reshaping of society over time can be seen diagrammatically in Figure 3. 3:

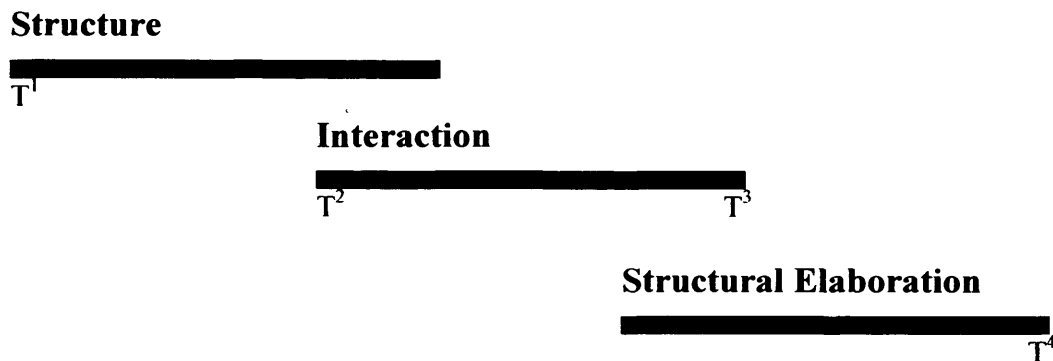


Figure 3. 3: The Morphogenetic sequence (source: Archer, 1995:76)

In Figure 3. 3 structure refers to society, interaction refers to the interaction of society and agency and structural elaboration refers to the modified society as a result of the interaction between society and agency over time ($T^1 - T^4$). Exploring the interrelationship between society and agency further, Archer insists on the irreducibility of personal identity (PI) and social identity (SI). Drawing on the notion of ‘interior conversations’ Archer explains the way in which PI is never purely social and that it cannot be just the gift of society (see Archer, 2002). However whilst PI is the basis of a sense of self, SI affects who an agent can become. The emergence of our social selves, Archer explains, ‘occurs at the interface of structure [i.e. society] and agency’. Once again Archer demonstrates the interaction of society and agency over time through the morphogenetic sequence:

The conditioned ‘Me’ – Primary agent

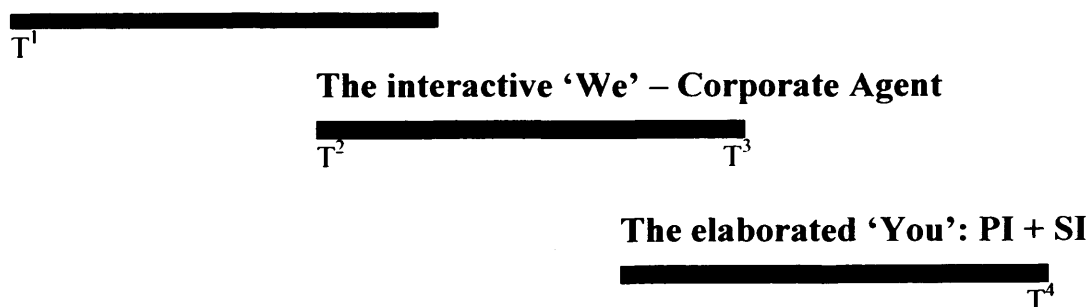


Figure 3. 4: The emergence of personal and social identity (source: Archer, 2000:296)

As with the previous section exploring the central tenets of critical realism, understanding notions of agency and society and the way in which they interact becomes crucial for later discussions; avoiding the need to have to explain terms, and allowing unbroken discussion and analysis of the meaning of the dwelling. In addition to giving a detailed understanding of agency, society and the process of interaction, what also becomes apparent is the decisive role of *time*. Acknowledging the way in which society and agency - and their emergent mechanisms - change and develop over time will become an important dynamic when seeking to understand the meaning of the dwelling for participants interviewed in this research in Chapter 7. However, the case can be made that a fundamental structure is missing from these accounts of human action, one that Archer and Bhaskar both refer to but do not develop: the influential role of **physiology**. It is to this concept of physiology that the chapter shall now turn.

3. 3 Physiology, society and agency: developing a three-dimensional framework

The role of physiology has been marginalised not only in critical realism but in sociology in general. However, understanding the impact of physiology is of significant importance to sociology, and is particularly pertinent for this research which explores the experiences of individuals who have faced dramatic changes in their physiology. This section begins by briefly noting that whilst the dualist legacy of Descartes has led sociology to abandon the body in favour of a sociological focus on the mind such a position is now being challenged. From here the way in which critical realism has continued this debate is outlined, asserting the need to acknowledge physiology as an ontologically distinct structure. However, despite this, physiology has remained absent at the analysis stage in critical realism, no where more so than in the work of Bhaskar and Archer. Seeking to redress this, in the final part of this section a 'three-dimensional framework' will be developed, one that is able to acknowledge the role of physiology, society and agency. In exploring the meaning of the dwelling for physically disabled individuals, recognising the concurrent impact of the different structures of physiology, agency and society is essential in order to avoid charges of reductionism. As such, the emergent framework

not only influences the research agenda for this thesis, but will also become of significant importance when analysing the data.

3. 3. 1 *The missing body: bringing the physiological body 'back in'*

The role of physiology in sociology has been a contested one. Descartes' proposition *Cogito ergo sum* ('I think, therefore I am'), encouraged a position whereby mind and body were separated. Following Descartes' reasoning, it seemed that whilst we *have* a body we never *are* the body. This dualism came to dominate both Western philosophical thought and medical practice; with the mind the subject for philosophy and the physical body the sole property of the medical profession (Haddow, 2005). Maintaining an uncritical acceptance of this Cartesian dualism, through work such as Parsons (1951), Zola (1972), Foucault (1973) and Illich (1975, 1976) sociology began to investigate the person as purely a social, as opposed to physiological, phenomenon. From Foucault's emphasis on the productive effects of knowledge/discourse/power, a position emerged whereby the physiological constitution of the body was no longer an issue and the body came to be understood as wholly constituted by discourse (Shilling, 2003:65). Under the weight of interest in discourse the body as a physiological phenomenon seemed to disappear, becoming nothing more than an interesting condition of social action (Shilling, 2003:28).

There are a number of writers now however, who would assert that the body is more than just 'an interesting condition of social action'. Whilst writings on the body and physiological considerations can be found in the classic texts of Marx, Simmel, Weber and Durkheim (Turner, 1996:63; for discussion see Turner, 1992; Williams, Birke and Bendalow, 2003a), it is Merleau-Ponty who appears to have done the most in overturning the Cartesian dualist legacies and bring the body 'back in' (Williams and Bendalow, 1998:51). In his 1962 work, '*Phenomenology of Perception*' Merleau-Ponty provides the foundation for a non-dualist ontology of the body. Using the notion of embodiment Merleau-Ponty indicates that we are neither purely mind nor purely body, rather the self and the physical body are complexly intertwined. For Merleau-Ponty it is through this notion of embodiment that it becomes possible to explain the essential link between the two seemingly separate entities of mind and body (Crossley, 2001). Building on the phenomenological writings of Merleau-Ponty there is now a wealth of literature that has sought to challenge the mind-body dualism

and facilitate a stance capable of bringing the body 'back in' to sociology (see, for example Turner, 1984, 1992; Freund, 1990; Leder, 1990; Featherstone, 1991; Shilling, 2003 and edited collections by Rose and Rose, 2000 and Williams, Birke and Bendalow, 2003b).

Critical realist literature continues in this tradition of asserting the need to recognise the important role of the physiological in explaining human behaviour. Indeed, Bhaskar 'takes for granted that human beings are characterised by a biological basis' (1986:171). In the work of Bhaskar, Archer and Sayer amongst others, an emphasis has been placed not only on bringing the physiological body 'back in' but also in doing so to assert its status as a real entity with ontological depth and its own causal mechanisms and emergent properties irreducible to either society or agency. As Archer notes:

"... living persons must possess bodies, which bodies being human are those animal bodies whose properties constitute the real essence of *homo sapiens*. Although this body does not constitute the person, it defines *who* can be persons and also constrains *what* such people can do ... the characteristics of *homo sapiens* (as a natural kind) cannot be attributed to society, even if they can only be exercised within it. On the contrary, human beings must have a particular physical constitution for them to be consistently socially influenced (as in learning speech, arithmetic, tool making)."

(Archer, 1995:287-8)

In addition to the need to recognise the reality of the physiological body, what also becomes apparent from this quote is that just as the interplay of society and agency affects what each ontologically separate dimension can achieve, so too does the interplay of the physiological. The body is not just a passive container; the physiological has causal powers and can limit what agency and society can accomplish. Echoing Archer's belief that the body limits what an agent can do, Sayer posits that some individuals could not do certain things even if they tried, 'because they were not born with, or have lost or not acquired the necessary causal powers' (1997:453). Bhaskar also takes a similar position. Bhaskar argues that we are all embodied agents, and it is 'in virtue of our complete biological constitution' that we have the power to do what we as humans can do, yet to reduce an individual to just their physiology would be to say that 'the acceleration of a car is the same as its engine' (Bhaskar, 1993:51; see also Moll, 2004 for further discussion).

What is crucial to note here is that for Bhaskar and Archer physiology interacts with society and agency and that explanations of experiences require reference to the simultaneous interaction between physiology, society and agency. However, despite asserting the need to recognise the physiological as a structure with causal powers, both Bhaskar and Archer respectively in their formulation of the TMSA and Morphogenetic approach (see above) do not integrate the important role of the physiological. In doing so they miss the opportunity to develop a truly embodied understanding, something that Archer claims a commitment to (1995, 2000). This is all the more surprising in the case of Bhaskar given his commitment to the importance of the physiological dimension and natural structures.

As part of the move to bring the body 'back in' to sociology, there have been attempts to simultaneously accept the importance of society, agency and physiology outside of critical realist literature. This exists in bio-psycho-social approaches (see, for example Schilder, 1950; Freund, 1990; Lyon 1996, 1997, 1998; Hughes, 2000) and in Turner's notion of 'having' (physiological characteristics) 'being' (agentic control) and 'doing' (socialisation) a body (1984, 1992, 2003). However, it could be argued that all these approaches have been overly focussed on the importance of society, without exploring the role of agency to the same extent. Furthermore a critical problem is that these approaches have adopted phenomenological or constructionist theoretical positions. In doing so physiology as a real entity with emergent causal powers remains ontologically groundless, leaving it exposed to the possibility of being reduced to discourse. By giving the physiological ontological status, such a problem can be avoided in critical realism.

The need to develop a stratified three-dimensional framework able to recognise these three structures of physiology, society and agency within a critical realist research agenda has already been called for in the work of Allen (2000) and in the writings of Williams (1999, 2001a, 2001b, 2003a; Williams and Bendalow, 1998; Williams, Birke and Bendalow, 2003a). However whilst they both refer to such a framework, neither Allen nor Williams actually develop such a framework. In the remainder of this chapter such a 'three-dimensional' framework will be developed. In doing so this framework will become crucial to the development of the research agenda for this

thesis, asserting the need to explore events emerging from the three structures in a non-reductionist fashion.

3. 3. 2 The 'three-dimensional' framework.

Building on the work of Bhaskar and Archer, and drawing on the writings on the importance of the physiological body, it becomes essential to understand experiences through reference to the three interacting, yet ontologically distinct, structures of physiology, society and agency.

In looking to describe the way in which any 'phenomenon' is the result of a number of 'mechanisms' (though it seems he actually meant structures and mechanisms) Bhaskar provided a supporting diagram:

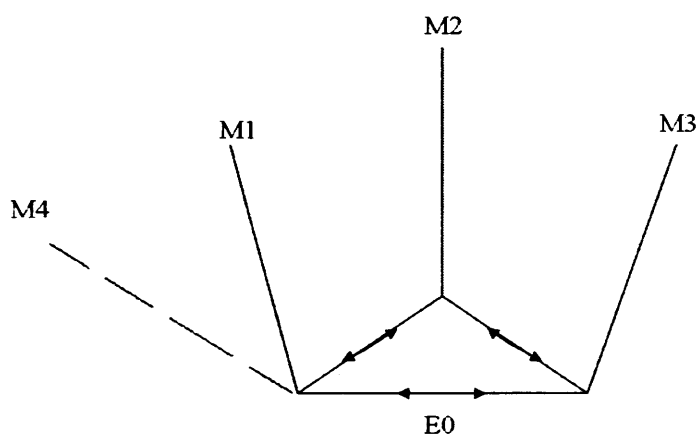


Figure 3. 5 - 'Multiple determination of events as a nexus in an open system'
(source: Bhaskar, 1986:110)

However, Bhaskar gave very little by way of explanation of this Figure, saying only that the diagram can be used to show that 'the codetermination of events within a system will result in their constitution as a nexus'. 'M' may refer to mechanism (no explanation was offered as to why each M has a different number or why M4 is a broken line) and 'E' may refer to an event (again why it is E0 is not explained). By conflating structures and mechanisms and by making it unclear as to whether the mechanisms become a nexus to produce an event or whether it is the events themselves that become a nexus to produce a 'phenomena', this diagram - as with the

majority of Bhaskar's diagrams - leaves a lot to the reader. Given the swiftness with which Bhaskar moves on from this inadequately explained diagram it comes as little surprise that he does not refer to or reproduce this diagram in any further work. Nevertheless, when supported by illustrative text, an adapted version of this Figure can aid in presenting some complex concepts. Accordingly, building on Bhaskar's diagram, to assist with the explanation of the 'three-dimensional' analytical framework used in this thesis, a diagrammatic representation is offered in Figure 3. 6:

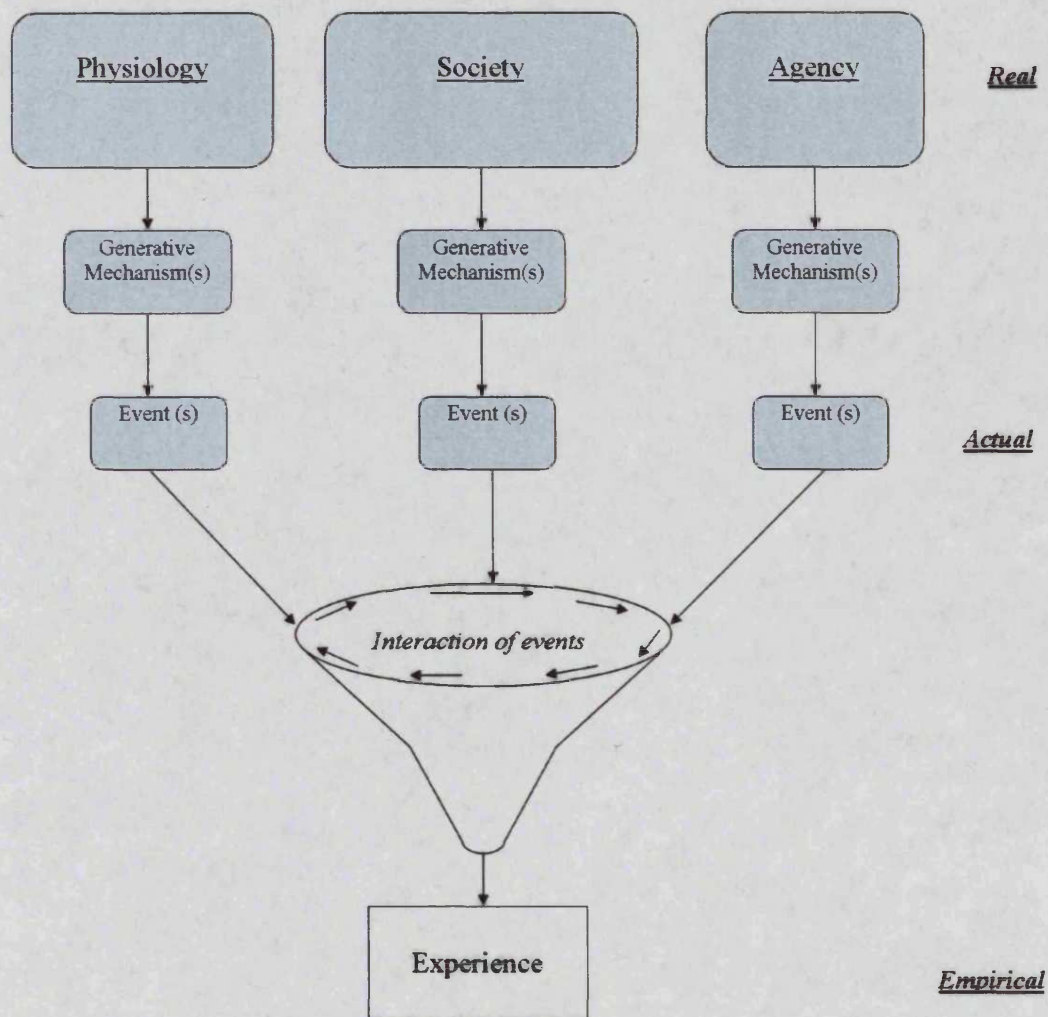


Figure 3. 6: Three dimensional framework for explanation of an experience

The ability to represent concepts graphically is fraught with difficulty and Figure 3.6 is no exception. The differences between Figure 3.5 and 3. 6 are more than just cosmetic. Figure 3.6 specifically aims to show the way in which the three structures of

physiology, society and agency give rise to particular generative mechanisms and events which interact to produce a specific experience.

The first thing to note is about Figure 3.6 is that it adopts Bhaskar's stratified ontology (not included in Bhaskar's diagram presented in Figure 3. 5) and can be broken up into the three domains of the empirical, the actual and the real. The refusal to collapse all domains into one through a belief in three stratified domains allows a rejection of a reliance on surface data alone, giving ontological depth to thought (Williams, Birke and Bendalow, 2003a).

The top layer comprising of the three ontologically distinct structures – *physiology*, *agency* and *society* - equates to what Bhaskar describes as the real. These three structures have been discussed in detail above. Nonetheless, to briefly recap, *society* refers to the 'practices and conventions which individuals reproduce or transform', but at the same time practices which are irreducible to people (Bhaskar 1998:45), *agency* refers to 'properties irreducible to matter', that is properties which emerge from persons and are irreducible to either society or physiology (Bhaskar, 1998:124) and *physiology* refers to the body as a real entity, with ontological depth and its own causal mechanisms and emergent properties irreducible to either society or agency. Whilst internal relations exist between the different structures the structures are irreducible to one another. To use the words of Bhaskar, the structures are 'existentially interdependent but essentially distinct' (1986:124). By keeping each structure ontologically distinct and assuring the reality of each structure the framework allows the possibility of bringing the physiological body back in without 'stripping agency of agency' or society of society (Williams, 1999:798). As noted above, each structure gives rise to particular generative mechanisms which also exist at the level of the real. Whilst there could be a number of mechanisms arising from any one structure, to not over-complicate the diagram Figure 3.6 shows only one mechanism.

The structures and their emergent generative mechanisms at the level of the real then give rise to particular events at the level of the actual. In this thesis the term event will be used as Flew does, referring to an occurrence that happens at a particular point in space and time and does not necessarily have to involve the participation of human

agents (Flew, 1979:115). Again, whilst there could be a number of events arising from specific structures and generative mechanisms for simplicity only one event is shown. The different events from the structures of physiology, society and agency and their generative mechanisms then interact with one another. This interaction between events also occurs at the level of the actual. In Figure 3.6 the interaction of the events is represented by a funnel. The arrows lying within the funnel represent the way in which the events arising from the different structures interact with one another.

Finally, at the level of the empirical is the observable experience. Here a significant difference appears between Figure 3. 5 and 3.6. Alongside offering very little by way of explanation, Bhaskar's figure makes no attempt to show that whatever it is that is interacting actually leads to anything. 'E0' floats ominously underneath the triangle, leaving it up to the reader to determine exactly what it is, what it is there for and why. Figure 3.6 looks to remedy this puzzle. As noted above the funnel represents the interaction of events. The result of this interaction (at the level of the actual) leads directly to a particular experience (at the level of the empirical). Experience, in short, becomes the result of the interaction of events which in turn arise from structures and their emergent generative mechanisms.

Experience has historically been a difficult term to define in philosophy (Honderich, 1995:26). Nonetheless, the term experience will be used to refer to the totality of events that have been lived through and what an individual has come to know through direct observable encounters. As such, it incorporates meanings and beliefs as well as particular instances of 'personally encountering or undergoing something' (Dictionary. com Unabridged, 2006). This experience is the result of the interaction of the events at the level of the actual which emerge from the structures and generative mechanisms at the level of the real. In distinguishing between events and experience the three-dimensional framework differs from Sayer's description of causation presented in Figure 3. 1, where the word 'event' was used to describe both events and experience. Events and experience are not the same thing and should not be conflated, and in Figure 3. 6 efforts have been taken to keep them distinct. Indeed, it could be argued that in presenting events as including experiences Sayer is collapsing the domains of the actual and the empirical, something this research will keep distinct.

Centrally the framework helps to explain experience in a non-reductionist fashion. Through a renewed application of the central tenets of critical realism, it becomes possible to understand experience as a joint determination of a number of events arising from the three structures of physiology, society and agency. As the previous discussion on Bhaskar's TMSA and Archer's Morphogenetic approach noted, unlike dualist approaches critical realism asserts that acknowledging one stratum does not involve denying another. Thus, it follows that acknowledgement of, for example, the physiological structure does not involve denying the influence of either agency or society (see also Allen, 2000:58). Moreover, as discussed in the critical realist notion of causation above, critical realism does not seek to 'find an ultimate, singular, 'first cause'' (Sayer 1997: 473). Rather it is necessary to explore the simultaneous existence of a number of causes on experience. Through the three-dimensional framework presented in Figure 3. 6 such a position is facilitated.

Furthermore, following Bhaskar what also has to be acknowledged is that the three structures, and their resulting powers, are only 'tendencies' or 'potentialities', not determinants (see above). There is no deterministic cause and effect relationship between the existence and influence of a structure and a particular outcome/experience. Once again what becomes crucial to recognise is the mutual interplay of events arising from the different structures. In doing so, the three-dimensional framework enables a situation whereby it becomes possible to move beyond the essentialist and deterministic positions presented in the past.

In short, the three-dimensional framework helps to move beyond the either/or distinctions and replace them with a more detailed both/and. However the framework presented so far has been rather crude, even 'one-dimensional'. What has been missing is how such a framework is located in time. This is addressed in Figure 3. 7.

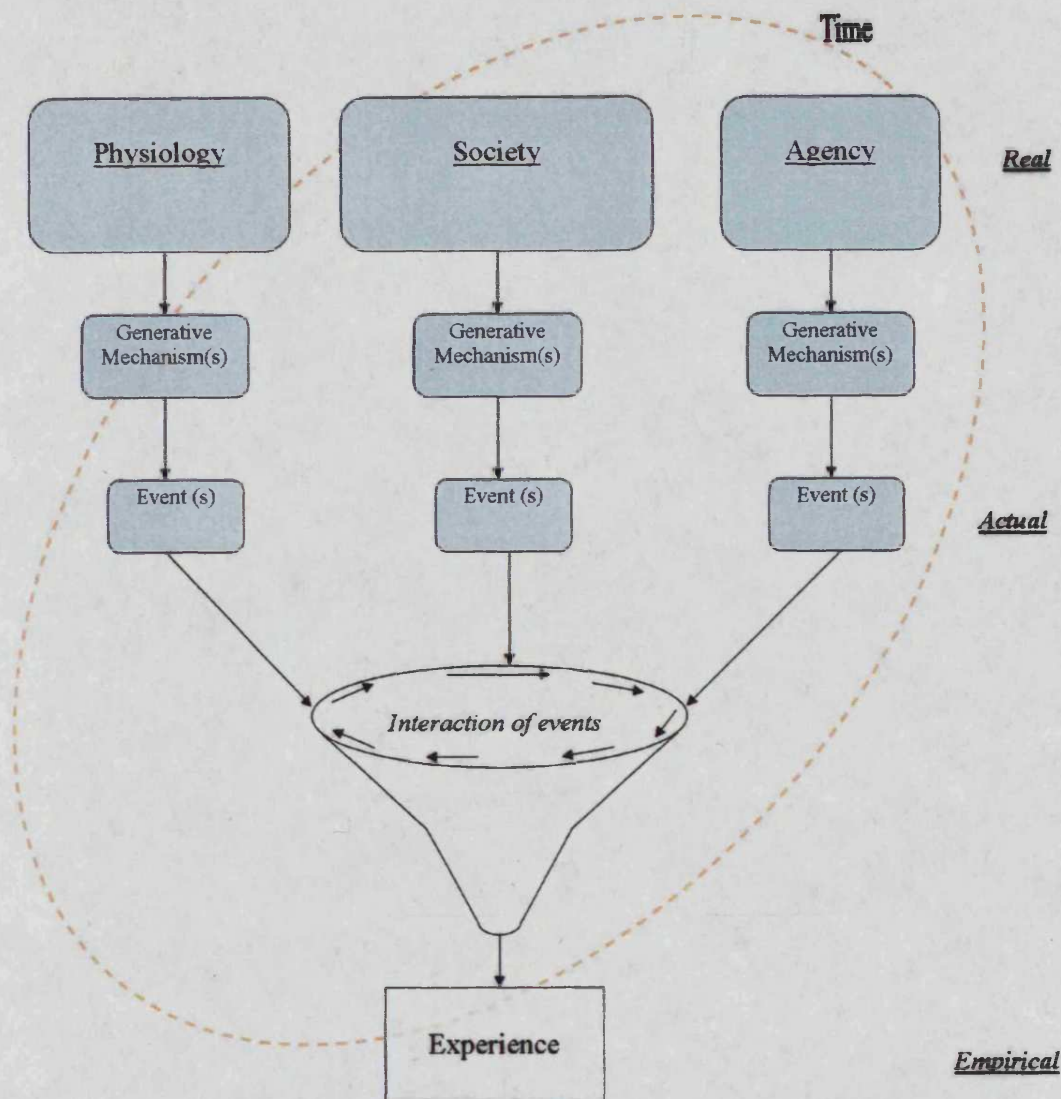


Figure 3. 7: Three dimensional framework for explanation of an experience over time.

In Figure 3. 7, an oval shaped ring passes through the diagram, running through the three structures of physiology, society and agency and also through experience. In doing so it is important to note that the ring passes through all three domains of the real, actual and the empirical. The oval shaped ring represents the temporal dimension of the three-dimensional framework. In Bhaskar's original diagram there was no mention of an experience being temporally located, and as a result Figure 3.7 should be seen as a significant advancement on Bhaskar's original diagram. As with Bhaskar's TMSA and Archer's Morphogenetic approach, time in the three dimensional framework is crucial. Whilst over time the structures remain ontologically distinct, they are also complexly intertwined; constantly impacting on

one another (see above discussion). Any experience is located at a particular moment in time and given that structures and their emergent generative mechanisms and events are subject to the possibility of change over time, so to may any experience. By moving away from a static view of experience and acknowledging the decisive role that time plays, as with Archer's and Bhaskar's theoretical models, the three-dimensional framework is freed from charges of over-determinism, accepting the possibility of change.

Figure 3.7 clearly marks a substantial departure from the unexplained diagram offered by Bhaskar shown in Figure 3. 5. By building on the original idea of Bhaskar a sophisticated model of causation can be presented. It is this framework, and all it entails, that will be adopted in this thesis. As this framework will be referred to on a number of occasions it is available as a fold out in Appendix 2 so that the reader can have it running alongside the text.

3. 4 Conclusion

The purpose of this chapter was to present the theoretical standpoint adopted in this thesis and introduce concepts and terminology that will be drawn upon throughout this thesis. As noted at the start, the theoretical position adopted can broadly be understood as that of the developing critical realist perspective. The twelve points highlighted in the summary of critical realism are all lines of reasoning that have influenced this thesis. Furthermore this thesis continues in the tradition of Bhaskar and Archer in recognising that society and agency are interacting yet ontologically distinct structures with their own emergent causal mechanisms.

Where the research differs is in seeking to ascribe physiology ontological status. However as was argued, giving physiology ontological status is actually integral to both Bhaskar's and Archer's arguments, nonetheless the role of physiology in their analyses has remained mysteriously underdeveloped. In developing a three-dimensional framework this chapter has sought to redress this and in doing so present a framework that is able to understand experience as simultaneously influenced by mechanisms and events arising from the three structures of physiology, society and agency in a non-determinist, non-reductionist fashion. Furthermore, as with the models of Bhaskar and Archer, the three-dimensional framework incorporates a

temporal dimension. In doing so the framework acknowledges that any experience will be temporally located and subject to change over time.

Adopting this three-dimensional framework and with it a critical realist position inevitably has substantial implications for both the research agenda and the way in which the research for this thesis was conducted. Building on the general discussions presented in this chapter, the methodological consequences of the theoretical standpoint for this research can be understood as:

- Rejecting a positivist belief in obtaining knowledge *just* through empirical observation and seeking to understand underlying mechanisms through retroduction,
- Recognising the three domains of reality and in doing so seeking to explain the meaning of the dwelling for disabled individuals through reference to events at the level of the actual and deep underlying, unobservable structures and mechanisms at the level of the real,
- Taking a reflexive approach to the research,
- Exploring the impact of the three ontologically distinct structures of physiology, society and agency on the experiences of disability and the meaning of the dwelling for disabled individuals,
- Moving beyond a deterministic understanding of the influence of either physiology, society or agency, acknowledging that the experiences of disability and the meaning of the dwelling for disabled individuals will be internally complex with structures and their emergent generative mechanisms and events interacting to co-determine the experience,
- Accepting that experiences of disability and the meaning of the dwelling for disabled individuals are temporally located, and in doing so recognise the need to explore past events and an individual's biography.

The first three of these points will be addressed in Chapter 5. Here the way in which the research process was conducted will be discussed alongside the significant influence of critical realism on this process. The remaining points have more

immediate implications. Indeed they hold a significant influence over the entire research agenda, signalling the need to develop multifaceted understandings.

In the next chapter, existing understandings of the experiences of disability and the meaning of the dwelling for disabled individuals will be explored through the lens of critical realism and the three-dimensional framework. Here emphasis will be placed on recognising the way in which the last three points noted above force a radical rethinking of what needs to be explored in order to understand experiences of disability and the meaning of the dwelling. In doing so significant gaps in the literature will become apparent, gaps that this research proposes to fill.

Chapter 4. Integrating critical realism:

a critical review of the literature on disability
and the meaning of home

Chapter 4

Integrating critical realism: a critical review of the literature on disability and the meaning of home

4. 1 Introduction

With an understanding of critical realism and a three-dimensional framework in mind, this chapter reviews the existing literature on the debates within the social model of disability and on the meaning of 'home' for disabled individuals. By doing so gaps in the existing literature can be identified, from which a research agenda for this thesis can be developed.

In the first substantive section the chapter will explore the criticism that the social model has marginalised the role of impairments, and review attempts to integrate impairment into the social model by writers within poststructuralist, feminist and phenomenological traditions. What is missing is the insights that can be achieved through an engagement with critical realism. This chapter will contend that critical realism can provide a useful framework for exploring the reality of impairment alongside the importance of recognising the disabling role of barriers in society. Moreover, here the argument will be made that the three-dimensional framework developed in Chapter 3 –which stresses the need to recognise physiology, agency and society - can provide a framework to develop a richer account of what disability is, one that is grounded in an understanding of the complexity of individual lives. Recognising the role of impairment and understanding the experience of disability in this multi-dimensional way becomes central to this research; highlighting the necessity of exploring events emerging from the structures of physiology, society and agency.

Building on this understanding of disability, the second section explores the notion of the meaning of home. However, given the abundance of literature on this topic, only a brief summary of the key contributions can be presented here. The central thrust of the section will be on exploring the way in which the disabled experience can be situated within this literature on the home, focussing on the contribution by Rob Imrie in this area (2004a, 2006a). From a critical reading of this work, it will be asserted

that a number of gaps remain, and the understanding of the meaning of the dwelling for disabled individuals remains under-theorised. In the final part of this section, the way in which an understanding of critical realism and the three-dimensional framework can help move beyond ‘functional reductionist’ arguments which focus on design issues will be presented, stressing the need to recognise a multifaceted understanding of the meaning of the *dwelling*. The intention of this review is not only to highlight the gaps that exist in the literature, but also to show the way in which critical realism can be applied and the way in which it influences the research agenda of this research project. As such this chapter offers more than just a scene-setting review of the literature.

4. 2 Understanding disability

4. 2. 1 Debates within the social model

The impact and importance of the social model (see Chapter 1) is immeasurable. Indeed the principles that form the foundation for the social model have been hailed as ‘a blinding flash on the road to Damascus’ (Zarb, 1992:127).

Despite this a critique of the social model began to appear during the 1990s, centring upon a belief that the social model was categorising all disabled people as one homogenous group. Alongside concerns that the social model was ignoring social categories such as class, race, gender and sexuality, one aspect of this criticism was that the social model had failed to look at bodily differences; be they physical, social or mental. As a result much research on disability in the social model had become ‘wheelchair reductive’ focussing on barriers that affected individuals who are wheelchair bound (Imrie and Hall, 2001:43).

Related to this critique of homogenising experiences, a more damaging criticism emerged. Critics argued that in focusing on structural issues the social model was downplaying the importance of representing the personal experience of disability – and in particular the very personal experience of impairment (Morris, 1991; Crow, 1996; Shakespeare, 1996; Vernon, 1997; Shakespeare and Watson, 1997). With the social model cast as the binary opposite to the medical model, impairment was relegated to the sidelines, with social model theorists focussing on highlighting the culturally constructed social barriers (Hughes and Paterson, 1997:379; Hughes, 2002).

Typifying this focus, Oliver has argued that in his experience 'disablement has nothing to do with the body' (Oliver, 1996: 41).

However, this statement runs counter to the personal experiences of many other disabled individuals. As Crow indicates:

"Many of us remain frustrated and disheartened by pain, fatigue, depression and chronic illness, including the way they prevent us from realising our potential or rallying fully against disability (our experience of exclusion and discrimination); many of us fear for our futures with progressive or additional impairments; we mourn past activities that are no longer possible for us; we are afraid we may die early or that suicide may seem our only option; we desperately seek some effective medical intervention; we feel ambivalent about the possibilities of our children having impairments; and we are motivated to work for the prevention of impairments."
(Crow, 1996:58)

In neglecting to explore the reality of everyday lives, as so vividly exemplified by Crow, it could be argued that the biological essentialism of the medical model is simply being replaced with a form of discursive essentialism. What has to be recognised is that the experience of living can be unpleasant or difficult in itself and that even after disabling barriers are dismantled many disabled people will still face a personal struggle related to their impairment (Crow, 1996; Zarb, 1997). Disability and impairment are not mutually inclusive, and change in one does not necessarily change the other. Whilst the need to tackle disabling barriers is crucial, the personal experience of impairment has to be acknowledged.

Alongside wider debates in sociology which have challenged the biomedical control over knowledge of the body (Turner, 1984, 1992; Featherstone *et al.*, 1991; Williams and Bendalow, 1998; Shilling, 2003), there has recently been a growing chorus of calls within disability studies to bring impairment 'back in' (Barnes and Mercer, 2003: 67). Broadly, the move to consider impairment within disability studies can be seen as falling within three theoretical positions: post-structuralism, feminism and phenomenology (Hughes, 2004:63-67).

Post-structuralism

Drawing on the work of Foucault, poststructuralist writers have sought to bring impairment in to disability studies by asserting that it needs to be reclaimed from biomedicine and understood as a cultural construct, the body itself a discursive

construct (Corker and French 1999; Tremain, 2002, 2005; Allen, 2005). For post-structuralists impairment has to be understood - like barriers in society - as a social construction in that the label of impairment just 'serves to divide, govern and control disabled people' (Tremain 2002:34).

Feminism

Whilst many feminist scholars writing in disability studies have spoken passionately on the importance of the social model, they have also asserted that it should explore the experience of disability and impairment at a personal level (Morris, 1991, Crow, 1996; Wendell, 1996; Thomas, C. 1999, 2004). Unlike poststructuralist arguments, feminist approaches have argued that whilst disability is a product of culturally constructed barriers, the experiential realm of impairment is something that cannot be reduced to simply a cultural construction.

Seeking to explore the notion of impairment, Thomas has developed a very useful concept of 'impairment effects'. For Thomas, impairment effects refer to 'restrictions of activity which are associated with being impaired but which are not disabilities in the social relational sense' (Thomas, 1999:43). Drawing on the personal, and graphic, lives of disabled women, Thomas asserts the importance of recognising the variety of experiences, impairment being one of them, necessary to truly understand the 'lived experience' of disability (see also Williams and Bendalow, 1998). Physical, sensory or intellectual impairments effects have to be understood as disabling. Thomas stresses however that the impairment effects are not purely biological and seeks to theorise the body as a biosocial phenomena:

"What is required is a materialist ontology of impairment and impairment effects an ontology that is neither biologically reductionist nor culturally determinist (Thomas, 1999). To put it another way, we should not give the bio-medics exclusive rights over the concept of impairment, nor should we perform a 'vanishing act' by relegating what are *real bodily variations from the average* to the realms of 'purely linguistically constructed difference'."

(Thomas, C., 2004: 25; italics in original)

In asserting that impairment requires engaging with the social/cultural, Thomas reaffirms Haraway's (1991) earlier calls on the need for feminist writing to explore the social/culture dimensions when considering the biological. However, when

talking about impairment Thomas maintains that this should not entail a return to discourse reductionism.

Phenomenology

The need to understand impairment as simultaneously a social and biological phenomenon is also found in phenomenological writings on impairment by Hughes and Paterson (Hughes and Paterson, 1997; Paterson and Hughes, 1999; Hughes, 1999, 2000, 2002). Unlike poststructuralist thinkers, Hughes and Paterson do not want to deny the 'reality' of impairment but do not seek to completely reject the notion of impairment as social. Drawing on the phenomenological work of Merleau-Ponty (1962) who sought to transcend the mind/body dualism through an understanding of the body as simultaneously experiencing and creating the world, Hughes and Paterson seek to develop a sociology of impairment that moves beyond the 'disembodied' social model, and like the work of Thomas offers an understanding of the body that is as 'much a cultural phenomenon as it is a biological entity' (Paterson and Hughes, 1999:600).

In developing the sociology of impairment Hughes and Paterson draw on the writings of Bendalov and Williams (1995) on the sociology of pain. Work within the sociology of pain has challenged the belief that that pain is exclusively a physiological phenomenon, indicating that it emerges at the 'intersection of bodies, minds and cultures' (Morris, 1991 cited by Williams and Bendalov, 1998:155). Consequently whilst medical discourse on pain is of great value it is 'just one amongst a number of valid voices' (Williams and Bendalov, 1998:7). Through seeking to move beyond the traditional Cartesian dualism, writers within the sociology of pain have asserted the need to reclaim pain from biomedicine and combine physical and cultural dimensions of pain to understand pain as a 'lived, embodied, physical and emotional experience' (Williams and Bendalov, 1996:38). Hughes and Paterson indicate that their case for a phenomenological sociology of impairment mirrors this reasoning, seeking to recognise impairment as both a (subjective) culturally constructed and (objective) biological experience.

The literature within these three theoretical positions has helped to integrate experiences of impairment into disability studies. Recognising impairment is crucial

for this research project which seeks to understand the range of events which affect the meaning of the dwelling. Furthermore one of the main objectives of this research is to help develop a more experientially grounded understanding of disability. However, it is my argument that none of these theoretical positions can adequately integrate the experience of impairment into the social model. By revealing impairment as a social construct, post structuralist writers incorporate impairment without attributing it an ontologically real status. However, as Houston has previously argued, bringing impairment back in through according it the status of a social construct will continue to deny individuals with severe physical impairments the reality of their condition and the needs that may accompany it (Houston, 2004:319). Whilst challenging bio-medicine's stronghold over the body through exploring impairments as a cultural construct, it can be argued that in doing so theorists within a post-structuralist tradition are writing out the reality of personal experiences, a voice that is already struggling to be heard in disability studies.

Both the feminist and phenomenological positions develop attractive positions from which to recognise the reality of impairment and the disabling effects impairments can have. Indeed Thomas' concept of 'impairment effects' is a very useful tool for exploring the effects brought about by impairment and this concept will become integral when discussing the research findings in Chapters 6 and 7. However despite these discerning insights, it can be argued that in failing to appeal to ontological realism and ground the *reality* of impairments, the enlightening work of Thomas in the feminist tradition and that of Hughes and Paterson in the phenomenological tradition can still not adequately account for the personal experience of impairment.

What is currently missing from this debate is an account of impairment drawing on the theoretical position of critical realism. It is towards broadening the debate and filling this gap - and in doing so highlighting the important implications of this new understanding for this research - that this chapter shall now turn.

4. 2. 2 Critical realism and disability

With the exception of a small number of writers (Williams, 1999; Danermark, 2002; Danermark and Gellerstedt, 2004), disability studies has by and large neglected the philosophical writings of critical realism. However, critical realism has much to

offer disability studies, in particular in relation to the contested role of impairments. This section will seek to show how critical realism can be used in this area. Specifically, it will explore the work of Williams who has used critical realism to bring the body - impaired or not- back into disability studies; expand on the shortage of literature by showing how a reading of Sayer's work on critical realism can be applied to disability studies; assert the need to recognise a number of structures and mechanisms in understanding disability and, in doing so, return to the three-dimensional framework developed in Chapter 3.

Drawing on the work of Bhaskar, Williams argues that the body is a real entity with its own structures and causal mechanisms (1999:806, see Chapter 3). Accordingly, Williams asserts, the body has 'an ontological depth independent of epistemological claims' (1999:806). To understand this claim it is useful to revisit Bhaskar's notion of epistemic fallacy identified in Chapter 3. Williams argues that by conflating the ontological with the epistemological disability theorists have until now reduced the physiological body to what is known about it (1999:805). However, as noted in Chapter 3, Bhaskar argues the epistemological and ontological cannot be conflated in this way. The social and natural world, Bhaskar asserts, need to be recognised as consisting of three domains - the empirical, the actual and the real. The body belongs to the realm of the real and consequently contains mechanisms independent of our knowledge about them. By refusing to conflate the ontological (what there is to know) with the epistemological (what we know and how we know it) Williams is able to appeal to a faith in the reality of the body and with it the reality of impairment.

Through this notion of epistemic fallacy Williams highlights the need to recognise the existence of a reality beyond discourse. In appealing to a reality outside of discourse and assigning the body ontological status Williams is able to assert the disabling impacts that impairments and symptoms of chronic illness can bring. Indeed in stressing the need to acknowledge the reality of impairment he comments that:

“endorsement of disability solely as a social oppression is really only an option, and an erroneous one at that, for those spared the ravages of chronic illness.”
(Williams, 1999:812)

Williams's remark meaningfully illustrates the difficulty in overlooking the reality of impairment in favour of a focus on the disabling barriers in society. Following Williams, by appealing to critical realism with its commitment to structures and generative mechanisms it becomes possible to go beyond the discursive focus on barriers in society and demonstrate that disability, grounded within an understanding on the real body, can equally be a product of non-discursive impairment effects (Williams, 1999:797).

However, responding to feminist appeals to impairment effects, poststructuralist writers have made the case that the call to recognise the non-discursive effects of impairment is essentialist (Hughes, 2004). A critical realist position however reveals that it is somewhat more complex than a crude distinction between essentialism and anti-essentialism (Sayer, 1997, 2000). As noted in more detail in Chapter 3, whilst Sayer is not arguing for an essentialist point of view neither is he arguing for an anti-essentialist point of view. Rather Sayer argues that it is necessary to 'get beyond the stark alternatives of essentialism and anti-essentialism and work with a richer ontology' (2000:82). This richer ontology involves an appeal to what Sayer calls moderate essentialism, a middle way between essentialism and anti-essentialism, in which some social phenomena do not have essences but other phenomena may have essences (Sayer, 1997:453).

Through rejecting strong essentialism, a moderate non-determinist essentialism seeks to identify essences as potentialities, with an essence not deterministically linked to a particular outcome. In appealing to a notion of moderate essentialism it becomes possible to maintain that impairment may have a disabling effect without arguing that all individuals with impairment will have the same experiences. To use an example by Sayer:

"There are also of course individuals who could not do some of these things even if they tried, because they were not born with, or have lost or not acquired the necessary causal powers. Thus, whereas 'essence' implies a sameness that can be problematic, we can talk of causal powers without implying that every individual has exactly the same ones."

(Sayer, 1997:472)

To repeat, a critical realist position is not looking to biological reductionism/determinism. But by holding onto a stratified ontology, in maintaining

the importance of physiological powers a critical realist approach is able to avoid biological reductionism and homogenising life experiences (Sayer, 1997).

Concurring with Sayer, by adopting the critical realist conception of causation and causal powers possessed by objects it becomes possible to avoid the notion that an object has a single essence. People will not have one but many causal powers, not all are unique to humans, not all unchanging and eternal and not all humans will have the same causal powers. Thus whilst individuals may share the same properties, asserting sameness need not involve denying difference. Drawing on a quote also used by Williams (2003b:53), Sayer notes:

“If we couple this stratified ontology with a realist analysis of causation, in which the existence of a causal power is not uniquely and deterministically linked to a particular outcome, then it becomes possible to see that the acknowledgement of a biological (and other physical) substratum of social life need not be seen as denying diversity and agency at the social level.”

(Sayer, 2000:100)

By exploring the complex relationship of structures and generative mechanisms it becomes possible to avoid reductionist and determinist presumptions. By recognising variety and agency at the social level and appealing to a stratified ontology that recognises that there may be more than one structure and/or generative mechanism involved in causation it is possible to maintain that whilst an impairment may have disabling effects, the role of agency will affect not only how the impairment is experienced but also recognise that the impairment does not determine the individual's identity. As Sayer notes ‘asserting sameness need not involve denying difference’ (1997:456).

In asserting that impairment does not determine an individual's identity, using critical realism provides a platform to rethink questions of identity and explore the role of other structures and mechanisms (Williams, 1999:797). A key theme within the sociology of chronic illness has been Bury's (1982) notion that chronic illness is biographically disruptive. This premise, although useful in highlighting *some* experiences of chronic illness, has also faced passionate and powerful disagreement. Drawing on the work of Pound, Gompertz and Ebrahim (1998), who remarked that amongst elderly working class people in the East End of London suffering a stroke was seen, contra common conception, as something ‘not that bad’, Williams seeks to

problematise the reductionist ‘biographical disruption’ hypothesis in contending that illness is not always biographically disruptive (2000; 2003a: 95-110). By recognising the role of other structures, such as agency, Williams is usefully able to stress that rather than being a foregone conclusion, the impact of chronic illness/ impairment will vary (2000, 2003a). The additional importance of recognising the role of agency is something that shall be noted throughout this chapter.

Expanding on this, Danermark explores the impact of hearing impairment (2002, Danermark and Gellerstedt, 2004). Danermark argues that whilst impairment may be the result of changes in mechanisms at the physiological level; given the influence of other structures and their mechanisms this does not entail sameness of experience:

“How the person experiences the impairment through different psychological mechanisms differs from how another person with the same kind of impairment experiences it. The outcome at the psychological level (the experience) differs because of mechanisms working at that level. ...Hence, how the impairment is experienced is not caused by biological mechanisms, although they affect it. The outcome, the experience of the impairment, is produced by psychological mechanisms. From an ontological perspective there is an important difference between neurobiological mechanisms generating the impairment and psychological mechanisms producing the experience of the impairment. ”

(Danermark, 2002: 57)

Here Danermark succinctly states the way in which psychological structures (i.e. agency) will affect an individual’s experience of impairment. Moreover Danermark asserts that in the case of hearing impairment, in contemporary Western society it will reduce our ability to communicate. The resulting stigmatisation cannot be explained by physiological or psychological structures and hence the experience of hearing impairment also becomes ‘produced by mechanisms at the social level’ (2002:58). Further, class, gender and cultural contexts will all affect the stigma experienced (2002:59). However, physiological and psychological structures are still involved here, in the intensity of the impairment itself and how the person experiences it (2002:58). What becomes clear is that in understanding impairment a non-reductive ontology which recognises that causality is multi-faceted and complex is necessary. As Danermark argues ‘impairment... is caused by a *set* of clearly identified mechanisms’ (2002: 61, *italics added*). By doing so it becomes possible to acknowledge the physiological importance of impairment but, crucially, also go beyond biological reductionism and essentialism.

In recognising the existence of structures working simultaneously at the three levels of physiological, agency and society, and the impossibility of reducing it to just one level, we return to the non –reductionist three-dimensional framework as developed in Chapter 3 (see Appendix 2).

Applying this framework the experience becomes the experience of disability with physiology referring to the body as a real entity (which may be impaired), society refers to practices or conventions (from which disabling barriers emerge) and agency refers to the individual's ability to engage to a certain degree with the other two structures so as to not homogenise experiences. To understand the experience of disability it becomes necessary to explore all structures and the emergent mechanisms (which may or may not have any affect on the experience) and appreciate that the experience will be internally complex with a combination of structures and mechanisms co-determining the experience (Bhaskar, 1986:109). Whilst internal relations exist between the different structures despite this joint action the structures are irreducible to one another. To use the words of Bhaskar, the structures are 'existentially interdependent but essentially distinct' (1986:124). By breaking free from a mono-causal explanation of an experience and recognising the way in which each structure interconnects it becomes possible to understand the experience of disability as potentially comprising of multiple interlinking but independent causes. Furthermore, what also has to be recognised is that the experience is temporally located and will be subject to change over time.

By adopting such an ontologically stratified framework, in which instances of essential sameness at one level do not preclude difference at another, the ontological reality of the impaired body can be recognised but biological reductionism condemned; agency at the social level recognised and homogeneity and a uniform group identity rejected; and the disabling effects of barriers in society can be acknowledged without slipping into determinism. Echoing Williams (1999) and Danermark (2002), by emphasising a non reductionist perspective and by refusing to privilege any one level, a three-dimensional critical realist position is able to recognise that disability is an emergent property, neither solely a product of socio-cultural or physiological mechanisms (Danermark and Gellerstedt, 2004:350).

Through critical realism disability can be understood as a multidimensional complex phenomenon involving the interplay of physiology, agency and society. In short, to paraphrase Shakespeare and Erickson, such an approach can go beyond the 'unimaginative' either/or distinction and replace it with the 'rich complexity' of both/and (2000:193).

4. 2. 3 Discussion: re-theorising a model

The intention of this section was not just to present a hostile attack on the social model, but rather to help develop a more experientially grounded understanding of disability. Indeed in questioning the dominant epistemological tradition of the medical model and focussing on barriers created by society rather than individual impairments this research accepts that the social model has transformed previous inadequate and overly-determined understandings of disability. However in focussing on inaccessible environments the social model has fallen into the trap of conceding the body to medicine and in doing so, perpetuated a reductionist discursive essentialism devoid of understanding of impairment effects (Hughes and Paterson, 1997; Williams, 1999).

What needs to be reasserted is that the social model is exactly that – a model. It is not a theory. Indeed more recently Oliver has indicated that the social model was only ever meant to be a 'working model' (2004:8). The social model itself does not reduce the focus to discourse and barriers in society; applying constructionist, post structuralist and Marxist theories to the social model do this. Whilst the feminist and phenomenological perspectives highlighted above offer an interesting departure from these perspectives, shedding new light on a mistreated area of disability studies, this thesis asserts that a more fruitful way can be achieved through exploring critical realism.

By adopting an ontologically stratified framework recognising the distinct yet interrelated realms of physiology, society and agency it becomes possible to bring the body 'back in' without sliding back into an essentialist medical model, acknowledge the variety and agency of experience and maintain the importance of recognising the disabling barriers created by society. To use Williams' phrase it becomes possible to recognise 'real bodies, real selves, real lives, real worlds' (1999:815). An appeal to

critical realism, this research maintains, can avoid the extremes of both biological determinism and social constructionism.

As well as being of benefit to disability studies in general, understanding the experience of disability in this way has important ramifications for this research. In recognising the reality of impairments and of agency alongside the existence of disabling barriers in society it becomes necessary to develop a research agenda which allows space for the consideration of all these areas. Understanding the meaning of the dwelling for disabled individuals thus involves exploring the interaction between any events that may arise from the three structures of physiology, society and agency. With this understanding of disability in mind, it is to reviewing and identifying the gaps that exist in the literature on the meaning of the home that this chapter shall now turn.

4. 3. Disability and the meaning of the dwelling

Having identified the way in which a three-dimensional framework can help to broaden an understanding of disability the task of the second major section of this chapter is to illustrate the way in which this three-dimensional framework can also assist in seeking to understand the meaning of the dwelling. The first part of this section will briefly highlight some of the existing literature on the meaning of the home, noting that by and large this literature has neglected the experiences of disabled individuals. From here the section will then look at the literature that has sought to redress this imbalance, notably in the work of Rob Imrie (2004a, 2006a). However, from a critical reading of this work it will be argued that a number of gaps remain and that the understanding of the meaning of the dwelling for disabled individuals continues to be under-theorised. The final part of this section will once again return to the work of Bhaskar, highlighting the way in which an understanding of critical realism can help move beyond functional reductionist arguments and towards recognising a multifaceted understanding of the meaning of the dwelling.

4. 3. 1 Understanding the 'home'

It was not until the late 1980s, in the work of Saunders and Williams (1988) and Saunders (1989, 1990), that debate on the importance of the notion of 'home' was investigated in housing studies. However, as noted in Chapter 1 interest in the home

has a long history. In terms of academic interest, it can be argued that it was the phenomenological work of writers such as Husserl (1931) and Schutz (1944) that helped to develop a scholarly concern in the notion of 'home' (see Gurney, 1996:84). The phenomenological perspective, to briefly summarise, is a philosophy that seeks to understand the subjective meanings people use to give the world order, and its adherents seek to uncover these meanings through qualitative methods such as ethnographic and in-depth interviews. Applying a phenomenological approach to understand the home involves exploring the meanings people give to the home and identifying the significance of particular properties (Mallett, 2004). It is from such understandings in this tradition that the research for this thesis emerges.

From this phenomenological starting point, a wealth of literature now exists seeking to grasp and explore the meaning of home to individuals. This ranges from the seminal texts of Bachelard ([1958]1994), Rapoport (1969, 1995), Cooper (1974), Hayward (1975), Rakoff (1977), Dovey (1985), Rybczynski (1986) and Sixsmith (1986), to the more recent phenomenological accounts building on the writings of Bachelard on the meaning and importance of certain items of furniture in the home including the window, the table, the cupboard, the bookcase, the bed (see Pallasmaa, 1995), the chest of drawers (Cooper Marcus, 1995:57-59) and the mantelpiece (Hurdley, 2006a) as well as the importance of the garden (Bhatti and Church, 2004).

Reviewing this literature on the meaning of home, Gurney notes that there has been a tendency to generate lists on what the home *means* to individuals (1996, further comprehensive reviews of the meaning of home literature can be found in Despres, 1991; Somerville, 1997; Gilman, 2002; Knight, 2002 and Mallett, 2004). Echoing such a statement, Despres has provided a particularly useful list summarising what she believes are the ten categories most commonly present within the non-sociological literature on the meaning of home (1991:97-99):

1. Home as security and control
2. Home as reflection of one's own ideas and values
3. Home acting upon and modifying one's dwelling
4. Home as performance and continuity (home as a temporal process)
5. Home as relationship with family and friends

6. Home as centre of activities
7. Home as a refuge from the outside world
8. Home as indicator of personal status
9. Home as material structure
10. Home as a place to own

Whilst, as Rybczynski (1986) explores, many of these categories have only fairly recently been associated with the home, the psychological importance of the home as a site of security, control and privacy has now become well established ¹⁶. The home, it is argued, offers substantial psychological benefits.

Seeking to combine these intertwined and overlapping categories, Saunders (1990) offers the concept that the home provides us with 'ontological security'. This term 'ontological security' first appears in the writings of the psychiatrist Laing (1965) and was then later appropriated by Giddens (1984). The notion of ontological security, for Giddens, is about having trust in the world, about having a sense of continuity and reliability in people and things (Hiscock *et al*, 2001:50). Saunders (1990) has subsequently suggested that the home, with its categories of meaning such as security and control, can become a source of ontological security.

Central to Saunders' ontological security argument is that the home not only offers a space in which to feel in control, but also a space in which we can express and derive identity. This idea that the home is central to an individual's identity is one that has since become well rehearsed in the literature, with Cooper's paper '*The House as Symbol of the Self*' having become one of the most frequently cited (1974, cited by Gurney, 1996:65). Cooper argues that individual's present their identities through their choice of furnishings, décor and possessions in the home setting (Cooper, 1974; Cooper-Marcus, 1995). Developing this concept by adding a temporal dimension, Gurney notes how the home becomes a store of memories – a 'psychic warehouse' – where experiences are continually formed and deposited (1996:69). For Gurney the home becomes a daily reminder of identity, embodying past memories, experiences and emotions. The home, in short, becomes a 'biographical accomplishment'. That

¹⁶ Rybczynski notes that it was well into the seventeenth century before the ideas about privacy, intimacy and comfort were coupled with domestic spaces (1986).

is, from the photos on the mantelpiece to the way in which certain spaces evoke particular memories, the highly personalised meanings within the home come to embody an individual's biography.

However the home should not always be understood in a positive light. Critics have indicated that the assessment of home as a site of ontological security does not 'reflect people's diverse experience and understanding of home' (Mallett, 2004:69). As a number of feminist writers have noted, rather than a refuge the home can be a site of abuse, repression and exploitation (Oakley 1974; Dobash and Dobash, 1980; Darke, 1994; Gurney, 1997; Hill and Tisdall, 1997; Wardhaugh, 1999; McGee, 2000; Gilman, 2002; Gregory, 2003) and rather than a centre of activities the home can become a site of insecurity, isolation and loneliness (Madigan and Munro, 1991; Cooper Marcus, 1995; Gurney, 1996; Valentine, 1998). Indeed as King notes, for the vulnerable the home becomes not a place of intimacy and desire but a prison and a hell (2004:123).

Furthermore all of the literature has presented an understanding of the meaning of the home from the perspective of able-bodied individuals. Given this focus, what becomes important for this research is to fill this gap and explore whether the home is also a site of security, control, privacy and identity for disabled individuals, and in doing so question Saunders' assertion that the home is necessarily a source of ontological security. It is to the literature that has begun to investigate this area, in particular that of Rob Imrie, a key academic on disability studies, that the chapter will now turn.

4. 3. 2 Addressing the gap - Disability and the meaning of home

Recognising a gap in the literature, Imrie has recently conducted research into the meaning of home for physically disabled individuals (2004a, 2006a). By exploring the experiences of twenty individuals who are dependent on the use of a wheelchair Imrie contends that the body and its interaction with domestic design will produce specific meanings of home. As a consequence of inadequate design, the domestic experience of a disabled individual becomes 'potentially, at odds with the (ideal) conceptions of the home as a haven, or a place of privacy, security, independence and control' (2004a:746).

The central argument of Imrie's work is that houses are not designed in a way that is attentive to bodily needs and consequently such spaces can become disembodied. Contra the work highlighting the positive meanings associated with home, Imrie asserts that the disembodied design will have a negative impact on an individual's association with their home:

"In this sense a person's feelings about, and experiences of, the home cannot be dissociated from their corporeality or the organic matter and material of the body...such spaces, for many disabled people, are potentially disembodied in the sense that they deny the presence or possibility of bodily impairment and, as a consequence, are likely to reduce the quality of their home life."

(Imrie, 2004a:760-761)

Imrie notes that for individuals with mobility difficulties the home can become difficult to use, becoming 'a series of disembodied spaces' with whole areas of the home 'off limits' (2004a:748). The domestic design of the home draws attention to an individual's impairment with the body becoming out of place. This is exemplified in the traumatic experience of one participant in Imrie's research who was forced to shower 'in the back garden with a hose pipe' because she was unable to access the shower room upstairs (2004a:752). Compounding these problems Imrie also notes that the inadequate design of the built environment and other houses confines individuals to their own homes. Far from being a sanctuary to return to, the home becomes a place an individual is trapped in (this will be explored in detail in Chapter 6).

Given the inadequate design which makes the home difficult to use, Imrie notes that individuals create 'useable spaces' by adapting the house and 'clearing up the clutter' (2004a:756, 759):

"For Jenny, the solution was to sell the furniture, or, as she said: "I've just chucked everything out and we're now in a situation where there's not even any chairs for anybody to sit on". Others have done similar things and Heather, living in housing association property, "got rid of the big furniture and put up grab rails everywhere".

(Imrie, 2004a:759)

Changing the micro architecture of the home, Imrie notes, can help give individuals an increased level of independence and control in the home. However Imrie argues that for the individuals who could not adapt the dwelling the subsequent need for

assistance in the form of carers not only undermines control but jeopardises the notion of privacy. Imrie highlights how the thought of carers 'invading' the home left them feeling 'on edge', uncomfortable and insecure (2004a:755).

This issue of care in the home is also taken up by Twigg (2000). Twigg too argues that individuals can lose control of their house to carers, drawing on the experience of one participant who indicated that they sometimes had no sense of who would be in the house (2000:81). In addition to compromising control and security, having someone 'intrude' on your home clearly has important ramifications in terms of loss of privacy. Whilst Imrie notes the way in which the home as haven hypothesis can be threatened through care staff invading on privacy, his work here can be strengthened by exploring Gurney's (2000a, 2000b) interpretation of Goffman's (1959) work on 'impression management'. Gurney argues that even within the private space of home we have a 'front space' i.e. a space where certain rules of etiquette apply, and a 'back space' i.e. a space where we may conceal items in fear of judgement by others. Applying this work to the intrusion of carers into the home, what becomes apparent is that disabled individuals lose this 'back space' in the home – everything is on show for judgement. By overlooking this work, Imrie's paper is missing an important insight into the notion of 'privacy' (for more on invasion of privacy in the home by outsiders see also Cooper Marcus, 1995; Johnston and Valentine, 1995; King, 2004).

Twigg also raises another interesting theme in relation to carers and privacy through her exploration of the uncomfortable relationship between carer and client in relation to bathing (2000). Bathing and washing involves nakedness and the help from a care worker can involve touching intimate areas. This has a profound emotional significance, and receiving help with bathing can be a source of unease, vulnerability and embarrassment (Twigg, 2000:56). Moreover Twigg notes that nearly all care workers dictated the duration of the bath and used gloves when bathing clients. Issues also emerged over the sexual orientation of the carer, with one male noting that he did not want a gay worker. Clearly the loss of dignity, power, privacy, respect and control involved in bathing and washing by a carer will have grave consequences upon any feelings about the home, and in particular the bathroom space. Whilst the need for assistance with bathing can be seen as embodying inadequate design, Twigg's work demonstrates there is clearly more at play here.

In highlighting the need to recognise the impact of inadequate design on the meaning of home Imrie stimulates the development of an added dimension in research into disability and housing. However, there are a number of issues that Imrie's work leaves open for investigation. In addition to expanding research beyond disabled individuals reliant on wheelchairs, centrally this involves moving beyond design issues and understanding the home as exactly that *a home* - a place where one's domestic *affections* are centred. By drawing on a range of disparate literature, the gaps that emerge from Imrie's original work can broadly be seen as falling under two categories: the psychological impact of adapting the home and positive accounts of the home. It is to exploring these gaps in order to develop a research strategy from which to proceed that the chapter will now turn.

4. 3. 2. 1 The psychological impact of adapting the home

The inadequate design of housing means that for some disabled individuals the onset of disability forces a move out of their dwelling. As has been noted elsewhere an imposed move under any circumstances can cause much resentment, anxiety and sadness, becoming a disruption in biography and a poignant reminder of what has been lost (Cooper Marcus, 1995; Bull, 1998). However, for many disabled individuals the need to move can be avoided through adaptations, and Imrie describes the way in which individuals create 'useable spaces' by adapting the house and 'clearing up the clutter'. However in describing this process, Imrie does not explore the problems associated with adaptation, including the psychological impact of adaptation and the need to dispose of furniture.

The items that fill the dwelling are not value neutral rather, as noted above, they are filled with emotional attachment. With regard to rearranging furniture in the home Taam notes:

"Home furnishings are part of the family identity, and the furniture in the home is a kind of *sine qua non*, without which one does not wish to show one's home to others. The arrangements that the family is asked to make are perceived not as a simple rearrangement, but as something essential being disturbed and partly lost."
(Taam, 1999:51)

Rearrangement of the family home may make family members feel they have lost certain personal attachments. Taam goes on to note the reluctance with which

individuals accept the replacement of the bed, and in particular the marital bed with a hospital bed (1999:51). From the work of Cooper Marcus it becomes possible to appreciate the way in which individuals see their homes as a reflection or extension of themselves, with a loss of the familiar in the home representing to some extent a loss of identity (Cooper Marcus, 1995; Somerville, 1997). This loss of familiarity could occur when adaptations are installed and consequently could have an effect on the home as a 'biographical accomplishment'. As Heywood argues:

"When unwelcome adaptations are installed, the recipient sees their helplessness reflected, both by the object that reminds them of their disability and by their inability to prevent its being put in. "

(Heywood, 2004b: 138)

Well-designed adaptations can have beneficial effects on both physical and mental health and help an individual to achieve a greater degree of independence (Bull, 1998). However as evidenced in the quote above it is necessary to recognise that adaptations can also become disempowering, in that they personify what the disabled individual can and cannot do. Elsewhere Heywood has also noted the upset and resentment that ugly, intrusive adaptations can cause when erected in areas of the home (2004a: 717, 2005). This again raises clear questions about the way in which adaptations can have a negative impact on the biographical accomplishment of the home. Furthermore it has also been noted that adaptations can be accompanied by an increase in costs and associated anxiety, clearly running at odds with the idea of home a site of refuge (Heywood, 2004a, 2005; Harrison, 2004).

The intrusive nature of adaptations also raises wider questions about trade offs between functionality and aesthetics in the home, as well as issues about 'ideal homes'. That adaptations can be intrusive and ugly with no regard to the emotional needs of individuals is crucial in looking to understand feelings associated with the home. The intrusion of adaptations on an individual's home has been explored by Teeland (2002, cited by Heywood, 2004a). Teeland echoes the idea that home reflects the self and goes as far as to assert that intrusive objects such as adaptations if forced on an individual can do more harm in invading privacy than any good in terms of physical assistance.

Handrails, level thresholds, ramps, hoists can all appear institutional rather than 'homely' (Madigan and Milner, 1999; Hawkins and Stewart, 2002). Adaptations can make the home seem like a machine. Whilst Le Corbusier may have described the house as 'a machine for living in' many individuals do not want to live inside a machine (1927:4, cited by King, 2004:71). Indeed the idea of the home as just a machine is a far cry from notions of the home as a biographical accomplishment. By redesigning a home in such a fashion that functionality is desired above all, there is a danger that the home may become like an institutional setting (Taam, 1999; Heywood, 2005).

The tendency towards institutionalisation is perhaps even more apparent when new technology is introduced (see Chapter 2 for discussion on issues regarding surveillance/control and technology in the dwelling). This has, for example, been noted by those evaluating Smart Homes projects (Dewsbury *et al*, 2004; McCreddie and Tinker, 2005) ¹⁷. Dewsbury *et al* noted the extent to which the Smart Home projects run at odds with domestic design aesthetics. For example doors in the home had 'PRESS TO OPEN' signs on them and hoists were bright yellow (see Dewsbury *et al*; 2004:821 for picture of an 'ugly' piece of technology in the dwelling). Such an institutional appearance could clearly influence people's experiences of the home and threaten any biographical accomplishments. The home is rarely a standardised, ordered environment. This is something the designers of adaptations and in particular the designers of Smart Homes seem to have forgotten. With so many switches and controls there is little space left in the home to arrange furniture etc (Dewsbury *et al*, 2004). Consequently whilst Smart Homes may offer many advantages to disabled users (see Chapter 2) by focussing on structural issues and neglecting the non-physiological needs, individuals are unable to assert any sense of biography into the home. It is this sense of biography in the home that becomes crucial in understanding the meaning of the dwelling.

The creation of institutionalisation within the home setting will impact not only on the disabled individual but the whole family and inevitably could seriously threaten the

¹⁷ Smart Homes, as discussed in Chapter 2 use electronic networking technology to integrate various devices and appliances around the home

biographical accomplishment of the home. The fear that the home would have to be compromised to accommodate changes in design has been highlighted by Jensen *et al*:

“I don’t want the house to become only for me. They (family) have to live here as well. My wife likes a bath and she would like to keep a bath. If you put a stair lift in you’re going to mess the house up.”

(Jensen *et al*, 1998:239)

In focussing on the importance of physical design it can be argued that Imrie misses the opportunity to explore importance of emotional attachments and biographical accomplishments. The home embodies highly personal meanings, many of which are tied to important memories, memories that with the instillation of adaptations may be shattered. In highlighting the reinterpretation of space within the home by ‘clearing up the clutter’ Imrie does not critically assess the impact this would have on an emotional level and in doing so disregards the importance of the home as a biographical achievement. Whilst only ‘clutter’ these items may have held fond personal attachments. Similarly the disposal of certain items of furniture which embody negative emotions and represent what an individual can no longer do may be a good thing, empowering an individual to feel more confident in their home now such biographically charged items have been removed.

Writing on the sociology of emotions, Williams argues that emotional attachments can ‘transform’ a given situation, making it ‘somehow more ‘tolerable’, ‘liveable’ or ‘bearable’ (2001a:58). The emotions connected with home could therefore conflict with negative impact of design making the home more liveable. Consequently what becomes crucial to recognise is the significance of emotions as a mechanism in the creation of meanings associated with home and, as will become apparent, that despite inadequate design positive accounts of the home can exist.

4. 3. 2. 2 *Positive accounts of the home*

The vast majority of literature on disability and housing only reports negative experiences, and consequently portrays the home as a site of tragedy. Crudely the disability and housing hypothesis has indicated that design is inadequate, and disabled individuals are unhappy in their home. Whilst this may be a reality for many disabled individuals it is crucial to recognise this is not the situation for everyone. What



appears to be missing are any positive stories of happiness in the home: stories that indicate that disability is not necessarily a tragedy.

Central to the idea of home is that it is not just about design but more subtle feelings of emotions and experiences. Any consideration of the meaning of home then must consider the emotional attachments and experiences that occur there. However in focusing on experiences of design in the home such emotional attachments have been overlooked. Indeed there has been a dangerous trend to present disabled individuals as a homogenous category of single adults, and in doing so to neglect the fact that many disabled individuals are part of a family structure, caring for and sharing their lives with people they love. Crucially there is also a gap in the literature exploring whether there are positive accounts of individuals' lives and the way in which *their* homes have become a biographical accomplishment.

Furthermore, what has to be recognised is that the meaning of the dwelling is not a static concept but rather is essentially temporal in nature. As Gurney and Means have previously noted, experiences and meanings attached to the home may change during different stages of the life course (1993; see also Heywood, Oldman and Means, 2002). Such a change could occur through the onset of disability. Bury has argued the emergence of chronic illness can bring about a period of 'biographical disruption' with individuals forced to rethink their biography and re-negotiate what they can and cannot do (1982). Whilst this period may affect the relationship with the dwelling, after a period of adjustment, relearning and 'coming to terms' with the disability the meaning associated with the dwelling may change once again (for work on 'adapting' to disability see Frank, 1984; Corbin and Strauss, 1987; Becker, 1993; Carricaburu and Pierret, 1995; Pound, Gompertz and Ebrahim, 1998; Perry and McLaren, 2003; Ville, 2005)¹⁸.

What is needed, as Harrison argues, is a need to recognise the 'multidimensional nature of the home environment' (2004:691). Harrison notes 16 factors that affect

¹⁸ It is worth stressing here that this is not to say that disabled individuals should just learn to 'put up' with inadequate housing design. They should not, and fundamental design changes need to take place. However what has to be noted is that in recognising the temporal nature of the meaning of the dwelling, acknowledging the emotional nature of the onset of disability and the need to emotionally 'adjust' is essential.

how an environment is understood, ranging from capacity to exert control in the home to cultural factors within the neighbourhood (2004:702-703, see also Allen, Milner and Price, 2002). What becomes crucial to appreciate is that the dwelling can be a site of positive experiences as well as negative ones. The dwelling, like disability, becomes a complex multi-dimensional experience. As with able-bodied individuals the dwelling becomes a biographical accomplishment bound with emotions. Indeed there are cases of positive experiences with workers within the dwelling. This is most notable in relation to individuals who employ personal assistants via the direct payments scheme. With disabled individuals promoted to the role of employer rather than client they are able to dictate who and at what time assistants come into the dwelling, and how they act. In many cases personal assistants are encouraged to appreciate that their job is not just about fulfilling tasks but also involves complex issues about trust, respect and relationships in the home (Kestenbaum, 1996:19). As explored in Chapter 2 the role of the personal assistant becomes very different to the care worker, as does the relationship. As one individual on direct payments explains:

“The advantages are that you can start to relive your life in the way that you want to. You can, say, pick your own clothes, where when you have got an agency you can't do that; you are in a wheelchair and you are messed up in your brain. You get a lot of companionship. You get a lot of understanding. I found girls that work for me far more understanding. I have got freedom now which I felt for years I didn't have. I have got control. I can control my own life now. I have got the biggest say in it as I used to have before, and that is all so positive.”

(Stainton and Boyce, 2004:450)

In seeking to recognise the multidimensional nature of the dwelling it becomes apparent that it is necessary to question previously fixed terms such as privacy and control. Whilst it is assumed that with carers entering the dwelling privacy will inevitably be compromised, when disabled individuals are given the opportunity to employ their own assistants (often through the direct payments scheme) the hypothesis of home as a site of tragedy where privacy and control can not be attained can be challenged.

Recognising the full range of social encounters in the dwelling, from workers to family members, becomes central to understanding the experience of the dwelling. Contra functional reductive writings that reduce disabled individual's experiences of the dwelling to just design – something Harrison has referred to as ‘physical

environmental determinism' (2004:697) - a dynamic approach is necessary which recognises the dwelling as a site of emotional attachment, as a biographical accomplishment infused with personal experiences. What becomes clear is the importance in recognising that the meaning of the dwelling is created by a number of events within it (Gurney, 1996:70).

In short what can be argued is missing from much of the existing literature on disability and the meaning of the 'home' is a recognition of the important role of emotions and personal experiences, be it from agency or physiology. One way of moving beyond a focus on the barriers created by inadequate housing design is to recognise the multi dimensional nature of disability – as presented above - and explore the theoretical writings of critical realism.

4. 3. 3 Critical realism and the meaning of the dwelling

It is indisputable that inadequate house design has an impact on the meaning of the dwelling for many disabled individuals. However it is necessary to go reject any mono-causal conception of causality which might suggest that the meaning of the dwelling is determined principally by design and to move towards a more stratified ontology that looks towards multiple structures and mechanisms. This reflects the discussion in Chapter 3 which recognised that there may be more than one generative mechanism involved in causation and which drew on the theoretical writings of Bhaskar and critical realism in general to develop a multi-dimensional framework for understanding the meaning of the dwelling.

Whilst housing research has been dominated by policy concerns, in the years since Kemney (1992) noted the atheoretical nature of housing studies there has been a wealth of housing research engaging with social theory, and the use of a critical realist perspective in housing studies is now slowly expanding. The topics of research drawing on a critical realist perspective differ in their focus, ranging from understandings of housing networks (Lawson, 2001) and housing management (Somerville and Bengtsson, 2002) to accounts of ill health and housing (Allen, 2000) and homelessness (Fitzpatrick, 2005). Nonetheless, fundamental to each study is the emphasis placed on the importance of recognising the existence of complex multi-

causal explanations and the need to acknowledge the importance of agency as a causal mechanism as well as society. In this regard the pioneering work of Chris Allen (2000) is relevant.

In his work on ill health and housing Allen argues that a linear notion of causality has so far been in which the literature has constructed 'a simplistic one way cause-and-effect relationship' where 'bad' housing conditions, become the cause of illness (2000:50). In doing so Allen draws on Giddens' notion of a 'cultural dope' (which referred to sociological theories in which actors lack agency) to argue that the existing housing and health literature posits the human body as a 'physiological dope' with individuals having no agency over events.

In response to this Allen looks towards other mechanisms that may be involved. Utilising a critical realist ontology Allen develops a three-dimensional framework, conceptualising the body as being 'composed by sociological (doing a body), psychological (being a body) and physiological (having a body) strata' (2000:50). By appealing to the three dimensional conception of the body, Allen argues that it enables an explanation of how and why some occupants of bad housing can remain in good health by appealing to emotion as part of the 'felt experience'. The home, as a biographical accomplishment, becomes central to understanding why even when a house may be in 'poor' condition it can still offer health benefits:

"the notion of home is so emotionally significant to some people that, even where it might be considered to be in "bad condition", its ability to offer "ontological security" is a crucial "generative mechanism" (cf. Bhaskar, 1978, 1979) that can sustain health and well-being. "

(Allen, 2000:50)

The 'psychological' level of emotions and experiences attached to the home acts as a generative mechanism which can intersect with the 'sociological' level of 'bad' housing, and consequently question the taken for granted empirical relationship between housing and health (Allen, 2000:59). Allen highlights the case of Mary, where the emotional 're-bonding' to her home after a period in hospital was seen by her social worker as a significant cause of improved health despite the home being in poor condition (2000:62). Indeed Allen quotes the social worker as arguing that despite Mary living on the floor of a caravan, since returning home her health had 'improved 100%' and that 'to move her (Mary) would kill her' (2000:62).

Whilst Allen's paper has a number of issues that need to be resolved – most importantly that Allen appears to conflate mechanisms and structures and focuses just on one 'mechanism' that of agency - engaging with Allen's work, and in particular the notion of a three dimensional conception of the body, has important implications. In asserting the importance of agency Allen indicates that the problems associated with 'bad' housing may be overcome in situations where the home offers the individual strong emotional attachments. With regard to physical disability and the meaning of home, such a theoretical position facilitates the ability to critique existing explanations of the home and move beyond the functional reductive arguments that focus on design as the only cause in the creation of meanings associated with the home.

To develop a new understanding of the meaning of the dwelling it becomes crucial to explore the interaction of physiology, society and agency. In doing so, as with the discussion on disability, we return to the non –reductionist three-dimensional framework developed in Chapter 3 (see Appendix 2).

Applying the three-dimensional framework, the experience becomes the meaning of the dwelling. Before explaining the framework any further it is first necessary to explain how 'meaning' can be an experience. My attempts to present meaning as an experience lie in drawing on the arguments of Wenger (1998). Wenger reasons that a 'meaning' is not simply imposed on us by society, but neither do we just make meanings up (1998:54). Rather, meanings are negotiated and shaped by a number of different events. Meaning exists as a 'dynamic relation of living in the world', and as such is both 'contextual and unique' (Wenger, 1998:54). In presenting a meaning as not just an ascribed and given occurrence but rather the product of the interaction of different events – which seemingly could represent the structures of society and agency - , Wenger's explanation holds much in common with my presentation of experience as shaped by the dynamic interplay of events/generative mechanisms/structures. In recognising meaning as something involving a range of events and something that has to be negotiated it becomes possible to assert that meaning has to be identified as an experience.

Returning to the diagram, physiology once again refers to the body as a real entity (which may or may not be impaired), society refers to practices or conventions (from which disabling barriers - such as inadequate housing design and care policies - emerge) and agency refers to the individual's ability to engage to a certain degree with the other two structures and generate specific experiences and emotions tied to the dwelling. Needless to say these structures overlap significantly and it would be misleading to suggest that they did not. As with the previous discussion on the framework, the experience, this time the meaning of the dwelling, has to be understood as being internally complex, with a combination of structures and their emergent mechanisms co-determining the experience (Bhaskar, 1986:109). The experience, the meaning of the dwelling has to be understood in a non-reductionist fashion as having a multiplicity of causes and the existence of a particular structure/mechanism/event could have a significant bearing on determining the outcome.

What this framework reveals is the need to reassess 'the ontological and epistemological commitments to the social' when exploring the meaning of the dwelling (Allen, 2000:50). Whilst previous research on disability and the home has sought to understand the experience through reference just to societal events, the three-dimensional framework asserts the need develop a research agenda which is able to explore and identify events that emerge from the structures of physiology, society and agency. As such, alongside exploring the impact of events such as inadequate housing design it also becomes necessary to investigate whether events arising from agency (such as biography) or physiology (such as impairment effects) have an impact on the meaning of the dwelling. In short, what is needed is a move away from a mono-causal design focus and a move towards exploring the full extent of an individual's experiences in order to understand the meaning of the dwelling.

4. 4 Conclusion

This chapter has reviewed the existing literature on the debates within the social model of disability and on the meaning of 'home' for disabled individuals. It has illustrated that debates on the role of impairment in the social model of disability are not new, but application of the philosophical writings of critical realism can add something to the debate. Furthermore the chapter has argued that the limited writings

that seek to explore the meaning of the home for disabled individuals have so far focussed on physical design barriers. This however is a fundamental misinterpretation of the notion of home, omitting that the notion of home is about recognising there is more at play in its meaning than just design issues.

Through integrating alternative literatures on the meaning of the 'home' and the experience of disability and drawing on critical realism, it has been possible to identify a number of areas that remain under-explored. These gaps form the basis of the research agenda for this thesis and broadly fall into three categories:

Methodological:

- Investigating the meaning of the dwelling for disabled individuals other than those confined to a wheelchair,
- Exploring the *full* range of experiences and the range of events arising from the structures of physiology, society and agency,
- Acknowledge that experience is temporally located, and in doing so recognise the importance of an individual's biography.

Theoretical:

- Engaging with critical realism to understand the experience of disability and the meaning of the dwelling for disabled individuals.

Empirical:

- Moving beyond a reductionist focus on design barriers and recognising that the meaning of the dwelling is influenced by a number of personal experiences, be it from agency (e.g. emotional attachments) or physiology (e.g. impairments),
- Acknowledging the positive stories of happiness in the dwelling for disabled individuals.

By operationalising the three-dimensional framework this chapter has illustrated the way in which this thesis intends to engage with this emerging agenda to develop a more dynamic multi-dimensional understanding of the meaning of the dwelling. Recognising the three dimensional nature of the experience of disability and the meaning of the dwelling becomes central to the analysis of the data collected (Chapters 6 and 7) and indeed can be seen as one of the main contributions of this thesis. However before any discussion at an analytical level with the data collected, having identified the research agenda it is now necessary to explore how the research was conducted.

Chapter 5. Methods and methodological
discussion: critical realism and
epistemological justification

Chapter 5

Methods and methodological discussion: critical realism and epistemological justification

5. 1 Introduction

This chapter identifies and justifies the methodological approach that has been adopted and discusses the conduct of the research upon which this thesis is based.

The first of the two substantive sections in this chapter begins by outlining the critical realist approach to data collection and analysis. Such a review helps to reassert the goal of revealing the underlying structures and mechanisms and also highlights the way in which the choice of method is couched within this goal. Having asserted the need to use an *intensive* research method to achieve this aim, the chapter proceeds to explore the possibilities and limitations involved with using qualitative research methods. Specifically here the chapter critically assesses the appropriateness of adopting the life history research method, justifying the appropriateness of such a method to help explore the meaning of the dwelling for physically disabled individuals and reveal the deep underlying structures and mechanisms at play.

The second and main section of this chapter describes and reflects on the practical issues of conducting the research. For purposes of clarification the section is broken up into five parts covering: the ability to conduct research on disability given my non-disabled status (3. 1); the process of access negotiation (3. 2); the interview process (3. 3); analysis (3. 4); and finally a discussion of ethical considerations and reflection on the research (3. 5). In addition to making the research process more transparent, this section also serves to highlight the commitment to questioning the hierarchical nature of research and accounting for any actions that were taken to overcome this.

5. 2 Methodological approach

5. 2. 1 *The critical realist approach to data collection and analysis*

As established in Chapter 3, the research for this thesis has sought to engage with a critical realist standpoint in order to explore the meaning of the dwelling for disabled individuals in a new light. In looking to understand the methodological implications

of adopting a critical realist position it becomes necessary to briefly re-acquaint the reader with the central assumptions highlighted in Chapter 3.

In summary, the key assumption in critical realism (and hence in this thesis) is that the world is stratified into three distinct ontological domains: the empirical (experiences), the actual (events), and the real (deep underlying level of structures and mechanisms). The 'objective' in critical realism is to attempt to understand the underlying mechanisms and structures at the level of the real in order to explain experiences. However whilst natural science can do this by isolating mechanisms in artificially closed environments social sciences do not have this luxury (Danermark *et al*, 2002). Social science exists in an open environment and consequently it becomes difficult to isolate structures and mechanisms in order to test them.

Consequently, as noted in Chapter 3, it becomes inadequate to adopt a positivist perspective in obtaining knowledge through empirical observation. Empirical observations cannot in themselves identify the mechanisms behind an observed pattern (Danermark *et al*, 2002:153). As Sayer explains, the number of times that we can empirically observe an experience or event does not help us to understand what causes it (2000:14, see also Chapter 3). Rather, to discover and conceptualise the complex range of underlying mechanisms at play in an open system it becomes necessary to isolate certain aspects of reality in our mind and look towards theorising and explaining the object of study through conceptual abstraction (Sayer, 1992, 2000). The principal form of *inference* in which a phenomenon can be explained through this abstract postulation of mechanisms in critical realism is known as *retroduction* (Sayer, 1992:107).

However, following a detailed reading of the work of Bhaskar the case can be made that to understand the underlying structures and mechanisms of the object of study, retroduction must actually be understood as just *one stage* in the analysis process. As Bhaskar explains:

“Theoretical explanations are analogical-retroductive, exhibiting what I shall label the DREI schema: i.e *description* of law-like behaviour; *retroduction*, exploiting analogies with already known phenomena, to possible explanations of the behaviour; *elaboration* and elimination of alternative explanations; issuing (ideally) in the empirically controlled *identification* of the causal mechanism(s) at work. ”
(Bhaskar, 1986:68)

Moving from the concrete to the abstract and back again, this DREI model of analysis (an unfortunate acronym given that 'drei' means 'three' in German and Bhaskar outlines four stages) seems to have been entirely overlooked within the critical realist literature on analysing data. However, the case can be made that understanding this four-stage process is crucial to analysing data within critical realism, each stage involving a particular action:

1. Description

The first stage, description, refers straightforwardly to describing and coding the surface events from the data generated.

2. Retroduction

With all of the data coded it then becomes necessary to focus on retroduction¹⁹. Whilst there may be little within critical realist literature on the process of DREI, a variety of sources have stressed the importance of retroduction in analysis (Sayer, 1992; Yeung, 1997; Lawson, 1998, 1999; Danermark *et al* 2002; Kazi, 2003)²⁰. To summarise, a retroductive argument 'moves from a description of some phenomena to a description of something which produces it or is a condition for it' (Bhaskar, 1986:11). That is to say, unlike deduction and induction the process of retroduction seeks to move from observation of the (coded) surface events to discover and gain knowledge about the deeper underlying structures and mechanisms of the event/experience that may not be directly observable. In looking to achieve this, unlike positivist approaches the use of abstraction and transcendental argumentation

¹⁹ Whilst 'retroduction' is often used interchangeably with the notion of 'abduction', differences do exist. In line with other critical realist research, the notion of retroduction is used in preference to abduction in this thesis. For discussion of these differences I refer the reader to Blaikie (1993: 162 – 197) and Danermark *et al* (2003: 88- 106).

²⁰ This is not to say that retroduction is limited to critical realist projects. For example, Danermark *et al* (2002:99) argue that retroduction serves as guidance behind Bauman's (1989) post-modern explanation of the conditions behind concrete events such as the Holocaust.

became indispensable tools, and indeed these concepts lie at the very core of retroductive analysis²¹.

3. Elaboration and elimination of alternative explanations

The purpose of retroduction is to develop new and deeper insights that go beyond the empirical. Whilst the insights may not discover something that no one ever knew before, by identifying connections that are not directly observable, it becomes possible to elaborate on existing explanations. What becomes important at this third stage of DREI is a process of counterfactual thinking, questioning whether the object of study would be possible without certain structures and/or mechanisms. It is at this stage that defective explanations are eliminated.

4. Identification of structures and mechanisms

Having eliminated inadequate explanations, the final stage of DREI looks to identify the underlying structures and mechanisms, and in doing so move from the abstract back to the concrete. As Sayer (2000) has previously noted there will not be a definite, beforehand given number of structures and mechanism, and as Allen's (2000) work on the causes of ill health and Fitzpatrick's (2005) work on homelessness have shown, it often becomes necessary to acknowledge the existence of multiple structures existing alongside each other. Having identified structure(s) and mechanism(s) it then becomes necessary to return to the concrete and explain the way in which the identified structures and mechanisms reinforce or conflict with one another, and explain the impact they will have on the object of study.

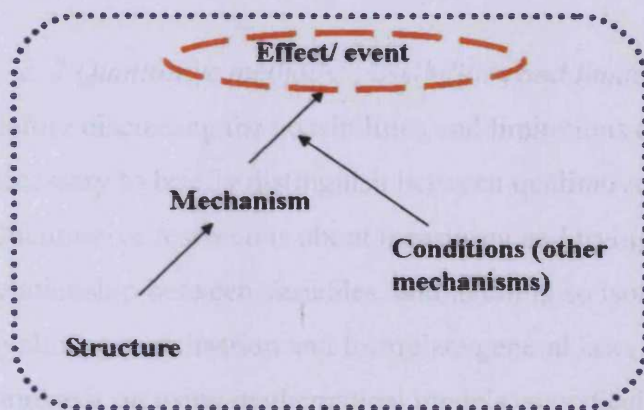
In seeking to uncover underlying structures at the level of the real in order to explain experiences at the level of the empirical, analysis thus becomes a complex process. Of course, before any analysis and retroductive inferences can be made it is first

²¹ Transcendental argumentation goes beyond the empirical seeking to explore what conditions must be necessary in order to understand a given thing as it appears. As such it is also known as transfactual argumentation. For more on transcendental arguments and in particular the way in which Bhaskar's transcendental realism differs from Kant's transcendental idealism see Collier (1994:20- 28), Danermark *et al* (2002: 96-98) and Bhaskar (1975: 21-62). For further reading on the importance of abstraction to retroduction see Sayer (1992, 1998), Yeung (1997) and Lawson (1998).


necessary to collect data from which to draw on. This process has also been discussed within critical realist literature.

Given that the number of times that we can empirically observe an experience or event does not help us to understand the deep underlying structures and mechanisms behind them, using a data collection method that simply helps to identify regularities and common patterns becomes inadequate. Rather, what is needed is a method that can help to identify causal relationships and help to understand underlying structures and mechanisms. To achieve this, it is necessary to conduct *intensive* research (Sayer, 1992, 2000).

Intensive research stands in contrast to *extensive* research. Whereas extensive research only seeks to understand regularities and common patterns, intensive research also seeks to understand 'substantial relations of connection' (Sayer, 2000:21). That is, whilst extensive research only seeks to understand concrete data, intensive research seeks to go further by producing a few detailed descriptions of concrete events in order to identify underlying causal structures and generative mechanisms (for a more detailed discussion of the differences between intensive and extensive research see Sayer, 1992). This difference is shown diagrammatically in Figure 5. 1.



KEY

Extensive research = 


Intensive research = 

Figure 5. 1 Areas of investigation in intensive and extensive research (adapted from Sayer, 2000:15)

The Figure differs from Sayer's original diagram which did not show the difference between intensive and extensive research. The dashes around just effect/event represents that extensive research only seeks to understand this level. Intensive research however seeks to understand underlying structures and mechanisms as well as effects/events and the dots surrounding the whole figure are used to represent this. The dots and dashes are used to visually show how much more intensive research explores.

Conducting intensive research involves choosing a research method that is able to produce enough detail to help not just identify but also explain events and experiences. Intensive research is not synonymous with any one particular research method. Indeed the idea of using the terms intensive and extensive was a way of addressing the qualitative/quantitative dichotomy, and in doing so try to move beyond a position where one method is ascribed a more privileged scientific position than another (Franklin, 1990:98). However whilst traditionally quantitative methods can yield intensive data, in order to obtain the depth of information necessary and expose underlying structures and mechanisms intensive research has been dominated by the use of qualitative research methods (see, for example, Porter, 1993; Yeung 1997; Danermark, 2002; Fitzpatrick, 2005).

5. 2. 2 *Qualitative methods: possibilities and limitations*

Before discussing the possibilities and limitations of qualitative methods it is first necessary to briefly distinguish between qualitative and quantitative research.

Quantitative research is about measuring and trying to ascertain the existence of any relationship between variables, and in doing so isolating cause and effect relationships to allow generalisation and formulate general laws. Quantitative methods place an emphasis on using mathematical models, statistical tables and graphs and look towards conducting research through research methods such as questionnaires, social surveys and structured interviews. Criticisms of the quantitative research approach centre around concerns that any data collected and generated amounts to little more than a 'quick fix' with little contact with people and only developing a superficial understanding of the subject under study (Silverman, 2005:7).

Qualitative research avoids such criticisms by adopting an entirely different approach to research. There are a variety of different styles of qualitative research, and what qualitative methodologies and methods involve has been widely rehearsed in the substantial body of literature on the subject elsewhere (see, for example Flick, 1998; Bryman and Burgess, 1999; Denzin and Lincoln 2000; Silverman, 2005). Very briefly, since the groundbreaking work on qualitative methodology by the Chicago Department of Sociology in the 1920s and '30s qualitative methods have played a central role in sociology (Flick, 1998; Denzin and Lincoln, 2000). Breaking away from the positivist's emphasis on quantitative and standardised methods, qualitative researchers place an emphasis on examining everyday life and capturing an individual's points of view. In seeking to capture the experiences of the individual, rather than questioning participants in a controlled environment, a number of qualitative researchers have asserted the need to conduct research in the 'natural setting' e.g. the workplace and the home (see Garfinkel, 1967:35-74).

Central to the qualitative position is the need to provide what Geertz has termed 'thick description'. To clarify what he means by this term, Geertz uses the example of the description of an individual winking their right eye (1973:6). A 'thin description' of this event would be that the individual was 'rapidly contracting his right eyelid'. However, a 'thick description' of the event would be that in winking the individual

was 'practicing a burlesque of a friend faking a wink to deceive an innocent into thinking conspiracy is in motion' (1973:7). Clearly there is significant difference in the descriptions, and it is the latter thick description that has come to play an important role in both anthropology and qualitative research in sociology. The meta-theoretical base for this emphasis on 'thick description' lies in an appeal to the phenomenological interest in the description of experience and the hermeneutic interest in interpreting texts to find deeper underlying meanings (Kvale, 1996; Danermark *et al*, 2002:158 – 161). By exploring issues in depth a richness of narrative can develop, from which the researcher may be able to discover the unexpected (see Spradley, 1979; Burgess, 1984; Kvale, 1996; Johnson, 2002; Rubin and Rubin, 2005).

There are a variety of different methods that fall under the category of qualitative research (including interviews, ethnographic methods, focus groups and conversation/discourse analysis) all of which focus on exploring an individual's experience in detail (see for example, Flick, 1998; Bryman and Burgess, 1999; Denzin and Lincoln, 2000; Silverman, 2005). One method of collecting qualitative data is the interview. Traditionally methodological textbooks have distinguished between three types of interview - the structured, the semi structured and the unstructured (May, 1997). Briefly *structured* interviews involve asking participants a list of pre-determined questions from an interview schedule which often only have a limited choice of responses; *semi structured* interviews often involve asking a series of pre determined open-ended questions, with space allowed for follow-up questions and *unstructured* interviews are conducted in a very loose framework where there is often no interview schedule at all, with participants free to bring up what they feel is important. Of course any one interview may cut across a number of interview styles.

Qualitative research is not without its critics. These criticisms include questions of representativeness and generalisability, concerns over the interpretation of other people's stories and claims that qualitative researchers are 'unscientific' and little more than journalists (for further criticisms of qualitative methods see Denzin and Lincoln, 2000; Silverman, 2005). A further issue in qualitative research is how is it possible to know if the participant is telling the truth at all? (Atkinson, Coffey, Delamont, 2003: 119). Any response may be incomplete, partial or even exaggerated.

The concern here is that qualitative research does not produce 'valid' data. Without suggesting that the participants are liars, a problem lies in that the participants may just say what they think the researcher wants to hear, only reveal certain information so as to present themselves in a particular light, may suppress certain feelings so as not to upset those within earshot, modify a story to protect themselves from certain emotionally painful memories or that the story may just reflect the individual's feelings at the present time. Drawing on the work of Goffman, it becomes necessary to acknowledge that the interview is a 'performance' (Goffman, 1959). Given these criticisms what has to be recognised is that interviews may only give a partial understanding.

5. 2. 3 *The life history approach*

Deriving from the qualitative legacy of the Chicago school, life history research has gained a growing following in sociology (see, for example Heyl, 1979; Plummer 1983, 2001; Flick, 1998; Atkinson, 1998, 2002; Chamberlayne, Bornat and Wengraf, 2000; Rustin, 2000; Atkinson and Coffey, 2001; Roberts, 2002). This approach focuses on revealing and exploring an individual's biography in order to discover what an individual sees as important in their life, doing so by exploring their past, present and future. Life history research emphasises the importance of individuals as 'creators of meaning in their everyday life (Roberts, 2002:6).

What becomes important is the need to explore accounts of an individual's life in detail and in doing so recognise the value and importance of *time* and the temporal nature of experiences (Bury, 1982; Adam, 1990; Becker, 1993, 1997; Gurney, 1996). Experiences are located at a particular moment in time, influenced both by past and future events. The past becomes an important and fertile area for exploration; being something we may be able to remember but never be able to live through again (Roberts, 2002:171). Supporters of the life history research method argue that the past is a significantly important factor and something that needs to be explored, whether it is a past gone, a past still here or a past still to return. The 'timing' of an experience is a central feature of life history research and time has to be both explored and conceptualised when adopting this method.

However, these detailed accounts do not naturally occur very often in everyday life, and accordingly the task of the researcher becomes to ‘coax’ the relevant aspects of an individual’s life story in order to shed new light on an area of study, asking specific questions (Plummer, 2001: 397). At the same time however the researcher must also allow the participant space to bring up their own themes and as such recognise the value of an unstructured approach to interviewing. To facilitate this, drawing on wider debates within qualitative research, developing rapport with participants must be recognised as a fundamental element of life history research²².

Alongside the criticisms of qualitative research in general, life-history research has also faced specific criticisms. Connected to the issue of truthfulness, a key problem facing life history research is the issue of memory (see Roberts, 2002:134-149). Memories are fallible and in addition to forgetting certain events it can become possible to ‘remember’ things that never really happened. In addition to this memories draw on cultural meanings and social acceptability and, as Atkinson, Coffey and Delamont note, what is memorable becomes ‘a function of the cultural categories that shape...what is valued, what is noteworthy and so on’ (2003:107). As such what is recalled in a life history interview may be shaped by what is deemed to be important.

Furthermore, a problem associated with life history research that is rarely acknowledged within the literature is that some people simply do not have the skills to produce rich accounts of their life, or may just be too shy to give them, preventing the collection of detailed data (Scott, 2004a, 2004b). Nonetheless despite these criticisms life history interviews have much to offer the research for this thesis. As such it is towards developing a life history approach to disability and the meaning of the dwelling that the chapter will now turn.

²² The notion of rapport has been discussed extensively in research methods literature, in particular, though not exclusively, in feminist writings on methodology and epistemology (see Oakley, 1981; Harding, 1987; Millen, 1997; Ramazanoglu with Holland, 2002). Oakley in particular has stressed the need to develop a methodology based on openness, trust and empathy.

5. 2. 4 *A life history approach to disability and the meaning of the dwelling*

Critical realism does not provide a 'cookbook' on the appropriate method to use in a given situation to generate data (Sayer, 2000:19). No method is excluded *a priori*. Rather any method chosen must be done through a careful consideration of the nature of the research question. As the aim of the research was to explore the meaning of the dwelling for disabled individuals and to seek to understand why differences exist, after careful consideration it was decided that life history interviews would provide the best method to assist in achieving the research objectives.

The life history approach has already found support within both disability studies and housing studies. In disability studies an emphasis has been placed on the importance of biographical narrative to reveal the experience of disability and chronic illness (Zola, 1982; Frank, 1995; Preece, 1996; Smith and Sparkes, 2004; French and Swain, 2006). In housing studies it has been used to understand issues about the home (Forrest and Murie, 1987; Franklin, 1990; Gurney 1996, 1997, 1999, 2000a; Wardhaugh, 1999; Knight, 2002; Gregory, 2003; Boucher, 2005). However adopting a specific research position simply because similar studies have done so does not provide sufficient grounds for justification.

The rationale behind choosing the method lies in the emphasis the life history approach places on encouraging rich responses which uncover an individual's biography. Indeed it is this notion of time and exploring life history that becomes crucial to understanding the way in which the dwelling can become a biographical accomplishment/ experiential warehouse, containing memories of past events (see Chapter 4).

Life history research can help to reveal the range of different events at play in an experience such as the meaning of the dwelling better than any other method as it gives the participant the space to discuss changes in their lives – changes in the past that may have a significant impact in the meaning of the dwelling in the present. Life history research also enables the researcher to probe particular events in an individual's life. For example the researcher is able to explore the consequences of life changing events such as the onset of disability, marriage breakdowns, children moving out of the family home or the death of a life-long partner. Once again it is

these events that occurred in the past that could have particular impact in an individual's current experience. The capacity of life history research to explore a wide range of past, present and even future events lies at the heart of any justification as to why the life history method was used in this research project.

By encouraging rich, in depth, individual accounts of experience; ones that recognise the importance of temporal issues it becomes possible to break free from explanations which seek to explain experiences by reference just to society and capture previously unexplored points of view. Subsequent interpretation of this experientially grounded, 'intensive', qualitative data can then help to reveal the underlying structures and mechanisms at play in the creation of meaning and experience of a dwelling in a way that statistical, 'extensive', quantitative data could not (Danermark *et al*, 2002). As noted above, causality cannot be understood by how often a mechanism can be empirically observed, and subsequently it becomes clear that the use of 'intensive', qualitative methods such as life history interviews are more appropriate.

Furthermore, given the sensitive nature of the data being collected and the commitment to question the power of the researcher in the research it was also vital to choose a research method that stressed the importance of developing rapport. As a technique characterised by high levels of rapport, stressing the need to break down hierarchical research relationships, the life history approach became particularly useful.

Of course, as noted above there are problems with taking a life history approach. These problems do not rule out the use of the life history interview for research into disability and the meaning of the dwelling. Nevertheless, in justifying the use of life history interviews these problems do need to be addressed.

The first limitation regards the concern that participants may not be telling the truth. To discuss philosophical notions of memory and truth is something that is far beyond the reaches of this chapter (a useful introduction to these issues is offered by Hospers, 1997). Crucially however it can be argued that it is *not* the task of the researcher to decide which statements are true and which are false but to accept that any narrative given by participants will inevitably be incomplete (Bruner 1993, cited by Plummer,

2001:400). What becomes important is not outright acceptance or rejection of stories but rather to be reflexive about the data collected and to analyse them accordingly. Consequently a substantial section on reflexivity will be included at the end of this chapter.

The second problem critics have with research collected through methods such as the life history method are that their focus on just a few individuals means that it becomes impossible to make any claims to generalizability or predictability. For many critics, this throws the validity of the data into question (Kirk and Miller, 1986; Kvale, 1996; Denzin and Lincoln, 2000; Fern, 2001; Silverman, 2005). Given that this research only has a small sample making any generalizable predictions would go beyond what is possible with data of this kind. However the inability to produce generalizable data does not equate to the data being invalid. As with all qualitative research, critical realist research is about explaining and seeking 'substantial connections' not generalizing or predicting (Sayer, 2000:27, see also Bhaskar, 1986; Sayer, 1992; Danermark, 2002; Danermark *et al*, 2002). Predictability and explanation are not the same. Within an open system an outcome becomes a complex combination of different mechanisms. Given the number of mechanisms that may be at play, reality becomes too complex to predict and seeking to find empirical regularities becomes a meaningless task. Therefore rather than looking to produce knowledge of the sort 'all cases of *a* will produce outcome *b*', research should concern the uncovering of causal mechanisms and provide knowledge on how the mechanisms work and interact (Danermark, 2002:63). An intensive research method such as life history interviews can help achieve this and produce data that is not only conducive to the understanding of the meaning and experience of the dwelling for physically disabled individuals and reveal the mechanism at play, but in this respect also 'valid'.

Moreover, echoing Bourdieu, what has to be recognised is that complete validity is also almost impossible to achieve (Jenkins, 1992:72). As a result validation comes to rest not on proving the truth of a particular life story- epistemic relativism is a given in critical realism (see Chapter 3)- but on the reflexive conduct of the life history interviews and on the way in which the data is used. Once again it is the notion of reflexivity that becomes crucial - especially given my status as a non-disabled researcher. Consequently reflexivity will become a key theme in the next section. It

is to exploring this, and to a detailed understanding of the conduct of the life history interviews to help facilitate a deeper understanding of the meaning of the home for disabled individuals, that the chapter shall now turn.

5.3 Conducting the research

The previous section sought to maintain that whilst critical realism does not demand a commitment to a particular research method, by making the link between research and ontology it becomes apparent that an intensive research method is necessary. It was argued that - whilst it has its weaknesses - the most appropriate method to help understand the underlying structures and mechanism in the meaning of the dwelling would be life history interviews. In this section attention turns to how the research was conducted including a questioning of the ability to conduct research on disability given my non-disabled status (3. 1); the sample selection process (3. 2); the three stage process of the life history interviews (3. 3); the process of analysis (3. 4); and finally a review of ethical considerations and a reflection on the research (3. 5).

5.3.1 A commitment to disability research: The need to justify disability research as a non-disabled researcher

In line with similar debates within feminism (see Oakley, 1981; Edwards, 1993; Finch, 1993) certain sections within disability studies are critical of non-disabled researchers who research and publish material relating to disability, fearing that it will lead to disabled individuals being exploited. Exploring this issue, Humphrey asserts that the objections to the non-disabled researcher centre around the belief that the non-disabled are not able to represent and understand the experiences of disabled people and indeed have no right to do so (2000).

The belief that non-disabled researchers are not able to represent disabled individuals is grounded in the notion that in order to research into disability issues the *experience* of disability is necessary. The sharing of experience comes to be seen as a requisite to being able to empathise with those being researched (Barnes, 1992b). However the notion of asserting epistemological privilege through shared experiences and that an individual can have a privileged insight into 'their own' group has met much criticism (see, for example, Hammersley, 1992; Fawcett, 2000; Humphrey, 2000; Ramazanoglu with Holland, 2002). Any attempt to 'demarcate sameness from otherness' is wholly

inadequate, nowhere more so than in disability (Humphrey, 2000:79). Creating a unitary category of disability is inappropriate and it would be wholly misleading to assume that a disabled researcher can be representative of every disability in every circumstance. Furthermore, as Barnes has noted, the cultural gulf between researchers and researched has as much to do with class, education and life experiences as it has to do with impairments (1992b:121). What has to be recognised is that essentialising a group to shared experiences of disability in order to assert epistemological privilege is not only deeply unhelpful but also dangerously inaccurate.

By arguing that only disabled individuals are allowed to conduct research on disability issues, not only does this raise ethical questions about the superiority of like researching like but would also lead to a 'path of separatism', bracketing off and further marginalising disabled individuals from society (Humphrey, 2000). By arguing from a standpoint that only disabled individuals can research those with a disability it reinforces the idea of a separate world between disabled and non-disabled, which could in turn act as a further boundary to trying to tackle the barriers that exist in society. Who conducts the research should thus be based not on ascribed characteristics but rather on who the researcher is in terms of their own integrity and their ability to research reflexively. In addition there should be an acknowledgment of how the research is being conducted and 'why' the research is being conducted (Connolly, 1996; cited by Humphrey, 2000:80). Experience -similar or not- should not be an issue. Rather the concern should be focussed upon the mediation and theorisation of this experience (Fawcett, 2000). The importance of non-disabled individuals contributing to disability research has now become widely acknowledged, and Clare Tregaskis, a disability studies academic who stresses the need for research to have a clear practical application and who herself is disabled, has argued the importance of non-disabled researchers being involved as a vital step towards understanding and inclusivity (2000, 2004; Tregaskis and Goodley, 2005). Perhaps more importantly, a study by Kitchen on disabled individuals' experience of research reveals that a great majority believe that research should not be conducted exclusively by disabled researchers (2000). Concurring with these arguments, it becomes entirely legitimate to conduct research into disability issues despite my 'non-disabled' status.

Whilst it may be justifiable to carry out research, nonetheless doing so still demands the continuation of reflexivity. Reflexivity has become a central concern within disability studies, and in 1992 a special issue of the journal *Disability, Handicap and Society* was published. A central concern was the way in which research on disability was alienating for respondents, often leaving them feeling betrayed. Indeed Oliver went as far as to argue that the way research was being conducted represented a 'rape model of research' (Oliver, 1992). Consequently the articles in the journal saw the authors work towards the formulation of an appropriate methodology for disability research, ushering in the concept of 'emancipatory disability research' (Barnes, 2003:5).

The notion of emancipatory disability research has been well rehearsed elsewhere and need not be discussed in detail here (see Morris, 1992; Oliver, 1992, 1997; Zarb, 1992, 1997; Stone and Priestley, 1996; Barnes and Mercer, 1997; Beazley, Moore and Benzie, 1997; Priestley, 1997; Vernon, 1997; Ward, 1997; Kitchen, 2000; Bennet, 2002; Barnes, 2003, 2004b). Whilst the concept has become an ambiguous one coming to take on a variety of different attributes, the central message is that disability research must be empowering with disabled individuals and organisations having as much control as possible over the framing of the research agenda and of gain to all those involved (for a detailed summary of the central tenets of emancipatory research see Stone and Priestley, 1996; Barnes, 2004b). Given such tenets a clear resemblance can be seen between emancipatory disability research and the epistemological ideas underlying the notion of 'action research'²³.

However emancipatory research design should not be adopted uncritically. It is not a panacea for the problems of disability research. Whilst there has been little by way of

²³ Like emancipatory disability research, whilst action research is not a unitary approach the different varieties do overlap and share common themes. At the core of all action research is the development of an empowering, participatory, non-hierarchical research relationship, one in which involves the collaboration of all those involved in the research inquiry. The primary purpose of this research is to develop practical knowledge that can help to bring about useful change to people in their everyday lives. For further writings on action research see Greenwood and Levin (2000), Kemmis and McTaggart (2000) and Winter and Munn-Giddings (2001).

investigation of the problems of the emancipatory research framework it is clear that such a position raises a number of issues. Firstly the researcher/researched relationship is far more complex than simply a question of power/lack of power (Cloke *et al*, 2000). As Cloke *et al* have previously noted, power is not always uni-dimensional. Rather, it can be the case that the 'powerful' researcher experiences fear during the research (2000:144). Moreover, as with action research, a central problem is the practical difficulties of doing emancipatory research²⁴. For example, how much involvement should there be from participants? Is there not a risk that the project becomes so designed that the conditions of research swamp the research? How are meaningful ongoing relations between researchers and organisations to be maintained? What constitutes commitment for researchers? Is it a life long commitment to only doing one type of research (in this case disability research)? If so how can you honestly commit to this? A further issue also lies in a commitment to the research being of gain to those involved. Even researchers who have tried to conduct research within the emancipatory paradigm have indicated that despite their best efforts the principal beneficiary of their research was themselves through gains in publications, presentations etc (Oliver, 1997; Vernon, 1997).

Given these practical issues, and added to the fact that the research for this thesis into physical disability is funded by the ESRC and not a disability organisation, the appropriateness of conducting emancipatory research seems questionable. However this is not to say that this research project is not influenced by the central principles of emancipatory disability research. Indeed, the purpose of the review of the literature on emancipatory disability research is not just to provide the reader with an awareness of these debates but rather it is about developing and outlining my position.

Emancipatory research debates have had a significant influence on the research position taken in this thesis. A commitment has been made throughout on ensuring that research is neither an alienating nor disempowering process and that all participants are actively involved throughout the research. Further, a critical position has been taken of 'detached' research with a vow placed on recognising that it is the researcher's responsibility when conducting research to ensure that the research has

²⁴ Further discussion of the problems surrounding emancipatory research design can be seen in Priestley (1997), Bennet (2002), Barnes (2003) and Danieli and Woodhams (2005).

potential to be of benefit to all those involved. What is necessary to understand is that whilst following an 'emancipatory research' or 'action research' design framework may have been impractical, the underlying principles still had an impact on research design.

Moreover, echoing the sentiments of Winter and Munn- Giddings, it can also be argued that recognising the principle of emancipatory social science research actually becomes essential in a research project based on critical realism (2001: 253-266). As with emancipatory research design and action research, Bhaskar asserts that social enquiry must be about a transformative process. Whilst a detailed discussion of emancipation is beyond the reaches of this thesis, in terms of critical realism, like Habermas, Bhaskar asserts the possibility of knowledge going beyond the technical and practical to be emancipatory (Bhaskar, 1986).²⁵ For Bhaskar the point of gaining knowledge and revealing underlying structures and mechanisms is to improve our understanding of how to change a situation and inform future practices. As with emancipatory disability research and action research the purpose of social enquiry becomes to produce research that may be of gain to those involved and produce knowledge that can help in the process of transforming/changing lives. Accordingly it follows that in adopting a critical realist position this research will inevitably have an emancipatory impulse and accordingly hold much in common with emancipatory disability research and action research.

5. 3. 2 *Negotiating access*

The difficulties and pitfalls of access negotiation have been well noted, in particular when sensitive subjects are under exploration (Burgess, 1984:45-47; Renzetti and Lee, 1993; Goode, 2000; Atkinson and Flint, 2001; Delamont, 2002; Feldman *et al*, 2003; Boucher, 2005). These difficulties are intensified when access to a population demands negotiating with powerful gatekeepers (Burgess, 1984:48-50 and 194-6; Hammersley and Atkinson, 1995; Delamont, 2002:96; Odendahl and Shaw, 2002). With no research framework to draw on, participants for this research could only be

²⁵ For further readings on critical realism and emancipation see Collier (1994:169- 204), Lacey (1998); Lawson (1999, 2003); for a critique of the critical realist position see Hammersley (2002).

recruited via negotiating with a range of powerful gatekeepers. As a result of this, considerable access difficulties were encountered in conducting this research.

Broadly, the negotiation of access for this research can be understood in two distinct stages. The first stage highlights the problems and pitfalls involved in gaining access. To identify individuals who might be willing to participate in the research it was initially decided to approach a hospital specialising in treating disabilities. However this proved to be an unviable proposition. After an extended period of communication via telephone calls and letters contact was made with an O.T. working in a hospital in South Wales who was keen to assist with the research. However despite an initial enthusiasm the O.T. eventually withdrew from the research as she was 'too busy for the foreseeable future'. Nevertheless with one foot in the door of the hospital after communicating with a range of ancillary staff at the hospital persistence won through and an interview was eventually arranged with the hospital manager to discuss the possibility of access to patients in the hospital. This enquiry was dealt with swiftly (the meeting lasted less than five minutes) and directly by the hospital manager:

Hospital manager: "No. No, no, no, no. I am afraid it is simply out of the question that you should be allowed onto the wards."

(Taken from field diary, 18/01/2004)

With admission to the hospital denied the second stage of access began. This access process can be seen in Figure 5.2:

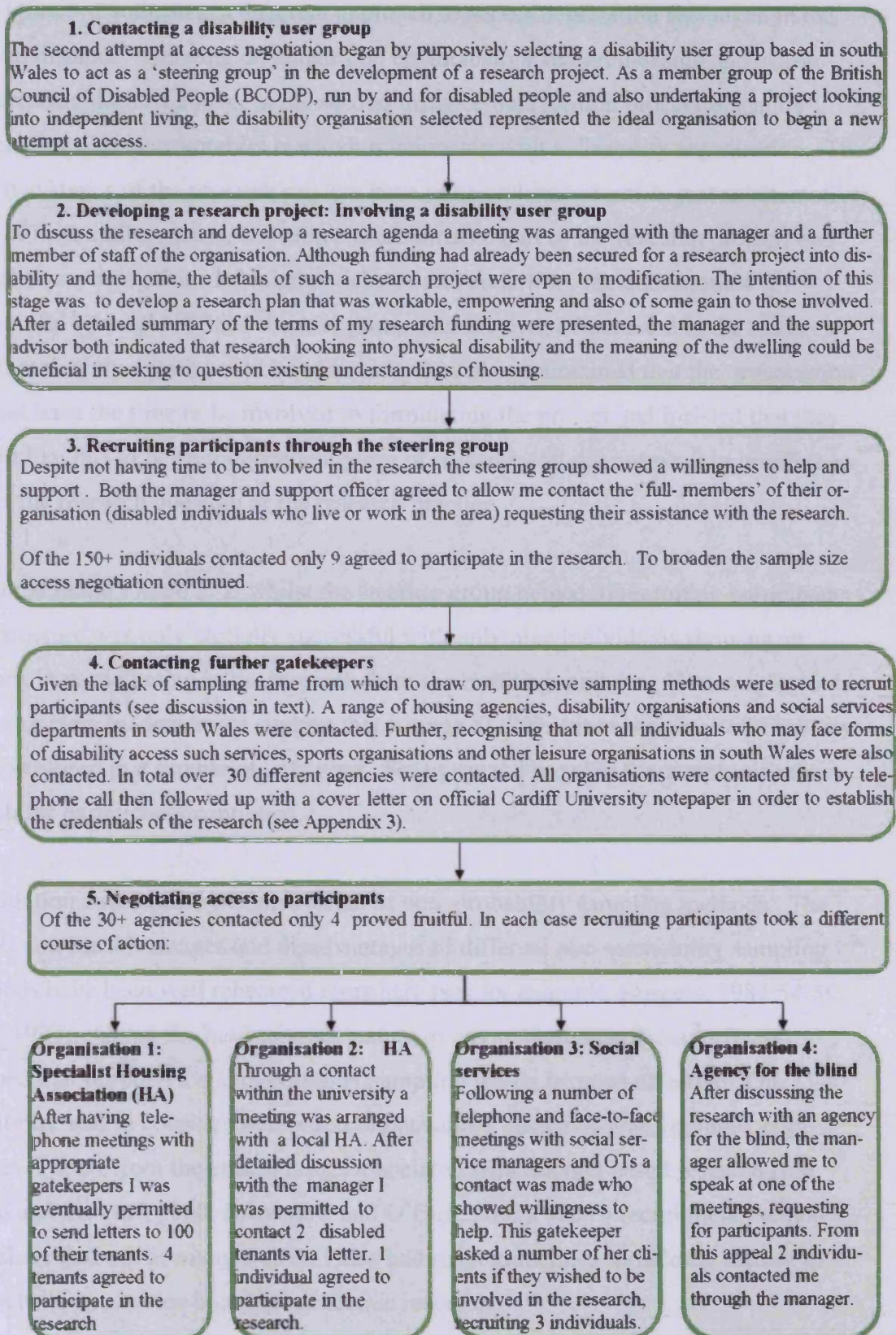


Figure 5. 2: Second period of access negotiation

As Figure 5. 2 indicates, a different approach to access negotiation was taken in the second instance. Drawing on debates on emancipatory research design and action research highlighted above, in the second instance the research process began by developing a (unaccountable) research relationship with a disability organisation. The first two stages of the research process have to be understood not as just an alternative way of negotiating access, but rather as an intrinsic part of the research project; one that shows a recognition of existing debates and underlines the commitment to purposeful research. Whilst the user group said they were interested in the research and that they thought it could be of benefit, they also maintained that the organisation did not have the time to be involved in formulating the project and insisted that they would like this to be an independent piece of research and did not want to interfere in either the research question or the research practice.

As noted in the Figure 5. 2, whilst the steering group helped in recruiting participants this measure was only partially successful with only nine individuals showing an interest in participating in the research from the resulting mail out. However it would be completely inadequate to suggest that a range of different experiences of disability were explored in a sample of only nine. So, to try and broaden the sample size the search for participants continued.

Negotiation continued by using a range of non-probability sampling methods. The debates on the advantages and disadvantages of different non-probability sampling methods have been well rehearsed elsewhere (see for example, Burgess, 1984:54-59; May, 1997). Given the hard-to-reach nature of any potential participants it was deemed that purposive and opportunity sampling would be most effective. One possibility was to consider web-based organisations such as www.yourable.com. However apart from the ethical issues associated with internet based research (see Mann and Stewart, 2000; Brownlow and O'Dell, 2002), such a recruitment method was also ruled out as many websites also had strict guidelines forbidding the use of the website as a notice board for academic research.

Rather, as outlined in Figure 5. 2, access continued by purposively selecting a range of services, agencies and organisations and requesting their assistance with the research. From this protracted stage of access negotiation four agencies showed a

willingness to engage with the research and act as gatekeepers, resulting in the recruitment of a further ten participants. To cater for different disabilities alongside sending out letters requesting participants a number of recruitment techniques were used. This included speaking at meetings for individuals with visual impairments. All those who self-identified themselves as 'disabled' and were willing to take part in the research were accepted. A self-assessment of disability was the only criterion used in selecting individuals and as discussed in Chapter 1 attributes such as gender, race, age, class and sexuality were not controlled for. Interviews with individuals keen to be involved with the research were then arranged either by phone or email, except in one instance where owing to the nature of the individual's disability an interview was arranged via post with the participant given a choice of dates and times to highlight (see Appendix 4).

The objective of the inclusion of a range of disabilities was achieved through this sample. Ten individuals used a wheelchair (two since birth, eight during the lifecourse; reasons for wheelchair use include muscular dystrophy, brain haemorrhage, spina bifida, multiple sclerosis, motor neurone disease and osteogenesis imperfecta), a further five had motor difficulties (one since birth, four during the life course; reasons for motor difficulties include cerebral palsy, arthritis, Parkinson's disease, stroke), two individuals were visually impaired (one since birth), one individual was deaf (hearing gradually worsening during lifecourse) and one individual had severe M. E. (since teenage years)²⁶. In addition a cross section of ages was represented from 21 to over 80. Eleven participants were female and eight were male, with one individual from a minority ethnic background (see Appendix 5 for further details and short biographies of participants). All participants lived in the South Wales area. This was not intentional. A number of agencies and individuals lying within a one hundred mile radius from Cardiff University were contacted requesting assistance with the research. The reason for this cut off was purely practical: the resources were not available to fund long-distance travel or cover overnight expenses. However it transpired that only agencies and individuals within thirty miles of Cardiff University showed any interest in helping with the research, and consequently all participants lived in South Wales.

²⁶ This brief identification of the impairment/disability issues stated in general. A more detailed presentation of impairment/disability can be seen in Appendix 5.

Whilst the research sought to gain the experiences of individuals with a wide range of different physical disabilities, with such a small qualitative sample it would be impossible to make any claims to have represented anywhere near the full spectrum of experiences. There is also a concern that many individuals with disabilities other than mobility difficulties may not have come forward as they may have felt that they had little to say.²⁷ Furthermore whilst the research does draw on the responses from individuals in a mixture of different types of dwellings, including individuals in residential care settings, the research did not seek to explore the experience's of those who lived in Smart Homes. The decision not to include those in Smart Homes was one of ethical responsibility. Whilst undoubtedly it would have proved a rich source of data, only a few schemes exist in the UK (none in south Wales) and because of the interest surrounding such designs and early teething troubles of the system, residents in Smart Homes projects have indicated that they feel they have been treated like 'guinea pigs' (Disability Now, 2003). As a researcher I have an ethical responsibility to ensure that such a situation is avoided.

The composition of the sample was inevitably biased in that it was self-selective. Consequently it is likely that the research only attracted those who had a certain level of confidence, or those who thought they had something to say. Of course with such a small self selected sample, any claims to representativeness would be fraught with difficulty. Therefore any findings cannot be statistically generalized to the population at large. As noted above though, this research project was not about achieving this. Rather it was concerned with seeking 'substantial connections' and looking to uncover underlying structures and mechanisms through the use of life history interviews with the nineteen individuals who did participate.

5. 3. 3 *The interview process*

After initial self-selection the research can best be understood as a three-stage process: the pre-interview, the interview and the post interview.

²⁷ Individuals who contacted me who did not rely on the use of a wheelchair seemed to be unsure as to whether they could be of assistance to the research or not. Indeed three individuals; Jimmy, Jodie and Harry; on phoning up told me the nature of their disability and then asked (words to the effect of) 'do you still want me?'

Stage 1. The pre-interview

All participants were contacted in advance of the interview to outline the objectives of the research in more detail and arrange where and when the interview would take place. This time was also used to discuss issues of confidentiality, privacy, research ethics and to assure all participants that unless they chose otherwise they would be anonymised in any discussion of the data. Whilst in the majority of instances (fourteen of the nineteen) this was conducted through email/ telephone conversations (depending on participants preference and disability), in three cases informal meetings took place in a public space (coffee shops, public buildings) and a further two participants invited me to accompany them around the National Museum of Wales as part of a programme they were involved in aimed at improving and widening access. In addition to discussing the nature of the research project, the pre interview also acted as an initial icebreaker, allowing rapport to develop and enabling the development of a 'sufficient relationship' prior to the interview (Beazley, Moore and Benzie, 1997:150).

Stage 2: The interview

All interviews were conducted between April 2004 and March 2005. Interviews lasted between 45mins and five and a half hours. The average (modal) length of interview was between two and a half and three and a half hours. Whilst the original intention was to conduct a series of successive interviews with all participants, developing rapport in the first instance and then returning for further clarification and to deepen understanding, the first interviews proved to be more in depth and insightful than originally anticipated. Rapport developed quickly, and many participants readily told their life story and answered any developing questions. For many participants the length of the interview was not an issue, and nine participants even asked whether they were taking up too much time of *my* time. Only one 'second interview' took place. The reason for this second interview was that the participant – 'Jodie' - wrote to me saying that since the interview she had thought of further issues and thoughts and invited me back. In a further case, that of 'Louise', whilst only a few of the themes to be covered had been explored the interview was stopped after three hours because it became apparent that the participant was becoming tired. However, whilst at the time she indicated she would be very keen to have me back and continue the

interview, despite efforts through mail no further contact was made and the interview never resumed.

All but three participants suggested performing the interview in their own dwelling²⁸. Of those who chose to carry out the interview outside their dwelling, two were conducted in an office at their work place (Melissa and Colette), and one was conducted in a private office in a university building which had been booked prior to the interview (Finn). The interview setting is of crucial importance and can, as Atkinson has noted, have an impact on the discussion of sensitive issues, restricting or encouraging the discussion of particular topics (1998). However the interviews conducted outside of the dwelling were conducted in private and proved to be as revealing and in depth as any other interview.

Interviews were recorded on a small un-obtrusive dictaphone (*Olympus Pearlcorde S713*). All participants were asked whether they had any objections to using a tape recorder. Only one individual indicated she would prefer if it were not used (Jodie), purely because she felt she might 'go all dry' and not be able to talk if the player was running. In this case extensive notes were made by hand, something that proved difficult in what became one of the most absorbing and emotional of all the interviews. Furthermore some participants asked for recording equipment to be paused and others waited until the recorder was off until they told of more painful experiences. In such cases this often produced some of the most insightful and interesting topic areas but unfortunately this will not be reported or explored, as it was clearly the participant's wishes never to make these experiences public²⁹. The only problem that emerged was that of the problem turning over/ changing the tape. However this often proved a source of conversation and data. For example one

²⁸ Interviewing individuals about whom I knew little, alone in their dwelling did leave me in a potentially vulnerable position. The associated risk and safety issues facing researchers has been discussed elsewhere, for example in Hammersley and Atkinson (1995). Recognising such issues, as a precaution I always let my partner know where the interview was taking place and took a mobile phone with me.

²⁹ This raises a very important issue: self-censorship. There were a number of instances where participants asked if certain topics could remain unreported – topics that were directly relevant to the research. However as noted previously I believe that researchers have an ethical responsibility to their participants and to the research. This responsibility includes ensuring that requests are respected, even if the material would be of benefit to the research.

participant revealed that he had previously been a journalist and used a similar tape player. For others the use of tapes was a conversation piece in itself, indicating that they “didn’t trust” new technology, a subject that could then be returned to when discussing adaptations and assistive technology.

In looking to challenge the possible power hierarchies between the researcher and participant certain measures were taken. These measures included encouraging an informal atmosphere, where possible sitting at an angle closer to 90 degrees rather than directly opposite the participant and wearing informal clothes (e.g. smart jeans, casual jumper; for writings on the way in which presentation can affect the research relationship see Moje, 2000). However developing a meaningful connection goes beyond these practical measures. The interviews were based on respect, trust and informality and the rapport – at least on the side of the researcher - was both empathetic and genuine. Whilst a certain level of rapport had been established in the pre interviews and before the main interview took place - with conversation from the weather to Terry Pratchett novels to why Cardiff should not have been in the running for the Capital of Culture 2008 - developing a connection between researcher and participant takes time and this, in part, explains the length of the research interviews. However, it must be recognised that my role in developing rapport was largely based on *listening* rather than any promise of friendship, a position advocated by Oakley (1981).

As discussed above, whilst the interviews were conducted on a semi-structured basis this term fails to convey the complexity of the research interview. Each unfolded in its own unique way, and some interviews were less structured than others. A more useful way of understanding the interview would be to understand it as a guided conversation or a ‘conversation with a purpose’ in that as a conversation it differed from normal day-to-day interaction as there was a specific intention to elicit specific information (Burgess, 1984:102; see also Spradley, 1979:58; Kvale, 1996; Rubin and Rubin, 2005). Every interview was approached with a list of topics to be covered (see Appendix 6), though in the large majority of cases the list became just that of an *aide memoir*, only being looked at very occasionally to ensure that all the topics had been covered (as explored by Burgess, 1984:108).

Centrally the emphasis was on listening and interacting; conducting what Holstein and Gubrium have referred to as the 'active interview' (1997). Given the nature of the research question the dwelling as a physical structure and items inside it became something that the participants would make use of. Where the research was conducted in the participant's dwelling, in all but two cases a 'tour' was given of the dwelling (or the part of the dwelling that was accessible to them). In the three cases where the interview was conducted outside the dwelling, participants were encouraged to give a 'virtual tour' of their dwelling. This gave the opportunity to enquire about specific areas/objects that had particular meanings/ emotions attached to them. In such cases a greater depth of understanding was obtained than could otherwise have been achieved through sole reliance on discourse. In a number of cases participants then drew on photographs and their material collection of assorted 'personal props' around the dwelling to help reveal their life history and demonstrate certain points (Plummer, 2001; for more on the need to move beyond a reliance on memory in life history research see Atkinson and Coffey, 2001).

However, in conducting life history interviews among individuals with a wide range of disabilities the research faced a particular practical difficulty: not all participants could communicate verbally. Overcoming this issue demanded taking a flexible approach to research and tailoring the interview to suit individual needs. For example, Alison could only speak with great difficulty and could not write. So, following the advice of Alison, using the interview schedule (see Appendix 6) 'factual' questions were asked to Alison's sister and her primary carer, with Alison in the room during this questioning. Questions were asked in a very much semi structured interview fashion, with both the carer and sister turning to Alison for nods of agreement when answering the questions asked. Through this questioning knowledge was gained about the dwelling, adaptations that have been made and the history of people who have lived there. Nonetheless, an individual's life history is inherently a very personal affair and from these background questions the interview 'proper' commenced, with the carer and sister leaving Alison to answer the questions

asked in private, with Alison using a computer programme called Tracker 2000 to communicate³⁰.

A further participant, Katy, could not speak, could only write with difficulty and was untrusting of computer technology. In this case questions were asked in a largely semi structured fashion, with time given for Katy to respond either through writing very short responses (often one word), through body language (hand gestures, head movements and 'acting out' situations) or by using props around the dwelling and encouraging me to try and communicate what she was trying to say, nodding or shaking her head to respond to my suggested responses. Given the unorthodox nature of the interview, allowing time to develop rapport was essential. Three other individuals also had speech difficulties, although could communicate verbally, and in these cases time was given to allow the participant to express their feelings. Of course for some deaf individuals the primary form of communication is British Sign Language (BSL). Whilst I attended basic BSL awareness training I did not have sufficient fluency to conduct an interview using BSL. Fortunately the participant who was deaf could lip read. However should I have been confronted with a situation where verbal communication would have been impossible, as was necessary with Alison, the suggestion would have been made to conduct the interview using a computer.

Broadly the interview topics themselves can be seen as falling into 3 categories: life history, dwelling, and assistance/ care received. These themes are clearly overlapping as indicated in Figure 5. 3 and were treated as such in the interview process.

³⁰ Tracker 2000 is a programme that enables individuals with restricted or no hand movement to use a computer. It works by enabling individuals to use a mouse by movement of the head. By wearing a small reflective sticker on a pair of glasses (or just on the forehead) any movement of the head is picked up by the Tracker positioned on the computer's monitor that becomes the movement of the mouse. A QWERTY keyboard is available on the screen and an individual types by placing the mouse over the character. Such a process can be physically exhausting as well as time consuming, which is why as many 'factual' questions as possible were asked prior to the interview.

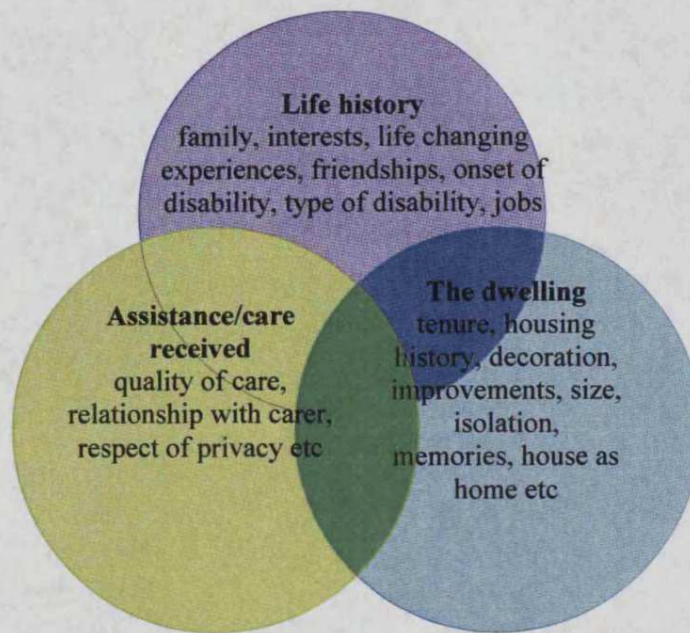


Figure 5. 3 Interconnection of interview topics

Each interview took its own direction with prompts being used. In taking an informal and collaborative approach to the interview, and in recognising feminist arguments on power, effort was taken to ensure that participants did not feel they were 'pumped' for information or pressed to answer questions that made them feel uncomfortable (Kvale, 1996; Stanley, 1997). Where prompting was used to deepen understanding a range of sympathetic forms of probing were used. The sorts of prompts used involved 'specifying questions' and 'follow up questions' as well as the use of silence and non committal verbal gestures such as 'mmm', 'uh-hu' and 'yeah' (Kvale, 1996:133-135).

Stage 3: The post-interview

At the end of the interview all participants were assured that they would receive an executive summary of the research when it was completed, with a full copy of the PhD available in the format of their choosing if they requested. All participants also received an update letter every six months over a period of two years, in which they were informed of the progress of the research. In line with debates on action research and emancipatory research design, at the end of the interview the intention to conduct a 'post interview' was also raised with all participants. Participants were informed

that the purpose of the post-interview was to discuss the findings and incorporate any comments into the analysis, ease any concerns they may have had concerning the use and interpretation of their life story, give them a further opportunity to withdraw anything they said, and ensure that no issues were 'haunting' them (for examples of research which conducted 'post interviews' see Priestley, 1997; Duneier, 1999). In short, the intention of the post interview was to break down the assumption that it is only the researcher who analyses and to minimise any harm that may have come to the participant (see discussion below). It was made clear at this stage that whilst the intention was to conduct a post interview with all participants, participants would not be forced into conducting such an interview: the intention was about empowerment rather than imposition. At the time of the main interview all participants indicated that they would be willing to be involved in this at a later date, even if this would be some time off.

For some of the participants' arrangements for the post interview came nearly 18 months after the initial pre interview. It was through trying to arrange the post interviews that it became apparent that two participants – Harry and Sam- had died. A further five participants also failed to return phone calls and/or letters. Of the remaining twelve participants, six thanked me for the offer and for keeping in touch through the update letters but said that they agreed with brief summary they had received and were happy for their transcript to be used without any further consultation. This meant that only six participants – Finn, Martin, Jodie, Katy, Sharon and Mick - expressed a desire to have a post interview. Of these six participants who expressed a desire to conduct a post interview, two participants – Katy and Finn- later withdrew.

As with the main interviews, the post interviews took an informal tone. Before any mention of the research there was an extended period of 'catching up', with participants filling me in on their life since the interview. Consequently the post-interviews lasted about the same time as the main interviews: between an hour and a half and three hours. The central concern of the post interviews was to discuss the analysis of the data, go through their transcripts to ensure that their words were being used in the right context and make sure that no issues were or had been haunting them. The latter concern seemed to perplex all participants, with Sharon's response

of “they are my memories so why should they worry me” typifying responses. In terms of the analysis all four participants were very happy with the way their memories and experiences had been expressed, and all were in strong agreement that it would be impossible to understand either their experiences or the wider collective understanding of the dwelling for disabled individuals without recognising the barriers they faced in society, understanding the physiological issues they faced and also acknowledging that their dwelling is a home, infused with their memories. When encouraged, no one said they that they had anything extra to add to the analysis. It is to the details of the analysis process that the chapter will now focus on.

5. 3. 4 Analysis of data

From the life history interviews a wealth of rich qualitative data had been gathered. With more than sixty hours of interview data, transcription became a considerable task. Indeed such was the size of this undertaking thought had been given to getting the tapes professionally transcribed. However given the sensitive data collected, to fulfil my ethical responsibility and protect all participants the decision was made to transcribe all the interviews myself. There were also further concerns as to whether a transcriber could faithfully produce the detailed accounts the participants were offering given that a number had difficulties communicating verbally. As the large majority of interviews were conducted in the dwelling a further challenge to transcription that emerged was external noise, notably from pets and appliances, making deciphering words a slow process (see Poland, 2002 for discussion of challenges to transcription quality). To ensure that my memory of the interview was vivid and fresh transcription began as soon as possible, often the day after and in a couple of occasions immediately after the interview.

As noted earlier in the chapter, Bhaskar has suggested that the analysis is a four stage process, comprising of (1) Description, (2) Retroduction, (3) Elaboration and elimination of alternative explanations and (4) Identification of structures and mechanisms. Whilst this process has been almost entirely overlooked in critical realist research, in looking to take an original approach this research adopted this DREI schema and accordingly analysis can be understood as a four stage process:

1. Description

This first stage was straightforwardly about describing and coding the surface events from the data generated by the life history interviews. Each interview was coded to identify events and experiences at the level of the actual and the empirical. The coding at this first stage in the analysis process however was not exhaustive or in depth, rather the aim was simply to provide a series of codes from each interview that could act as a starting point for deeper analysis to explore underlying structures and mechanisms at the level of the real.

Despite having an understanding of and access to Computer Assisted Qualitative Data Analysis Software (CAQDAS) packages the decision was made to manually code the transcripts³¹. The reason for this comes down to a belief that there is no substitute for really knowing the data. The acute closeness developed with the relatively small data set through transcribing the recordings and re-reading them furnished me with a familiarity and awareness of the data. Consequently, it was felt that a computer analysis programme would be superfluous. Furthermore the 'code and retrieve' nature of the software package would fragment the transcripts, taking narratives out of context and creating a series of seemingly theoretically relevant but disjointed and de-contextualised codes. An intimate awareness of the data achieved via manual coding can help to avoid this pitfall. Whilst basic, my method for coding – using highlighters and a sheet of paper per participant to note down codes - was the building block from which further stages of analysis began.

2. Retrodution

With all of the data coded it then became possible to focus on the process of retrodution. This required taking the coded data gathered from the life history interviews and seeking to understand the meaning and experience of the dwelling in terms of underlying structures and mechanisms; moving from the coded concrete data to abstract analysis.

³¹ A wealth of literature exists on the coding process and, of late, on the benefits of using CAQDAS such as ATLAS.ti, NVivo or MAXqda (see Fielding and Lee, 1998; St John and Johnson, 2000; Seale, 2002; Lee and Fielding, 2004). Kazi and Spurling have shown that such packages can be a powerful tool to assist in identifying mechanisms in a critical realist project (2000, cited by Kazi, 2003:43).

3. Elaboration and elimination of alternative explanations

What becomes important at this third stage of analysis is a process of counterfactual thinking. In this research this required questioning if it would be possible to imagine explaining the meaning of the dwelling with reference just to mechanisms and events emerging from the structure of society. In eliminating defective explanations, it was at this stage that it became apparent that it was necessary to recognise the existence of non-social factors and develop an alternative, multi-dimensional explanation of the meaning of the dwelling for physically disabled individuals.

4. Identification of structures and mechanisms

This final stage involves identifying the underlying structures and mechanisms, and in doing so moving from the abstract and back to the concrete. From the retroductive analysis of the nineteen life history interviews I assert that in seeking to understand the meaning of the dwelling for the disabled individuals who participated in this research it is necessary to acknowledge the existence of three structures – physiology, agency and society - and their resulting emergent generative mechanisms. Having identified these structures and mechanisms it then becomes necessary to return to the concrete and explore the way in which these mechanisms reinforce or conflict with one another, and seek to understand the impact this will have in determining the meaning of the dwelling. These identified structures and mechanisms are explored in detail in Chapter 7.

Whilst all four stages of the DREI process was made unaided, once analysis was completed through the post interviews participants were encouraged to comment on my proposals. As noted above, all the participants who conducted a post interview agreed with the analysis. However, there are of course problems with then simply accepting the analysis as being ‘right’. Recognising this highlights once again of the importance of reflexivity in the research process.

5. 3. 5 Ethical issues and a reflection on the research

5. 3. 5. 1 Ethical considerations

With the possibility of ‘power, abuse and exploitation’ ever present in life history interviewing, ethical issues become of central concern (Plummer, 2001: 400). Add to this the extra ethical and methodological issues concerning research on disability (see

Stalker, 1998; Duckett and Pratt, 2001; Goodley *et al* 2004; Andrews, 2005) and my commitment to questioning the hierarchical nature of research, the need to place ethical concerns at the very heart of the research project becomes clear.

Ethics has been a subject that has been well rehearsed in the literature (see Beauchamp *et al*, 1982; Burgess, 1984; Finch 1993; Lee, 1993; Coffey, 1999; Bulmer, 2001; Murphy and Dingwall, 2001; Ryen, 2004). Following guidelines outlined by the British Sociological Association (BSA) in its statement of ethical practice – in particular clauses 10 to 30 and 34 to 41 (2006) on the responsibility towards research participants and anonymity, privacy and confidentiality - this research **has striven to ensure the absence of harm to all participants.**

Informed consent was gained from all participants, with no attempt being made to deceive participants as to the nature of the research. Following the guidelines set out in the BSA this was achieved by explaining to participants what the research is about, what the data will be used for and their role in the research at the recruitment stage. Negotiating consent was however a continual process. Whilst an individual had invited me into their dwelling, as with the invitation to any guest this invitation did not extend to roaming around their dwelling *carte blanche*. Rather, it was only after further consent had been given that access to private areas of the dwelling such as the bedroom could be made. Furthermore at the start and end of the interview participants were assured that the interview was not the sociological equivalent of a Police caution that ‘anything you say or do may be taken down and used as data’, and were assured that if they changed their mind and wished to retract consent on anything they had said they could do so at anytime.

At the outset of the project all participants were also assured that they would be guaranteed anonymity and confidentiality. Given the importance of these factors and that all but one interview was recorded onto tape all participants were reassured at the start and end of the interview that no third parties would later hear the tape or have access to it. In the interview with Alison where it was conducted on computer only I had access to the file. Furthermore whilst her carer and sister offered background information on Alison they were not privy to any of the information revealed later by Alison. To maintain anonymity and confidentiality all participants were also assured

that a pseudonym would be used in the research and that any identifying information would be removed. However there is an issue here that after the sometimes difficult decision to reveal their life history the anonymising of the research can then be seen as disempowering to those involved (Grinyer, 2002). Therefore, all participants were given the choice of whether to present their life story anonymously or to present candidly their life story with their real name attached. The large majority of participants chose to remain anonymous.

Finally, of central concern was the need to protect participants from harm. Whilst the research will not have caused harm in the way that, for example, would be experienced in medical experiments, the potential for emotional and psychological harm was ever present. An immediate problem was that individuals were placing themselves in a vulnerable position by asking a relative stranger into their dwelling. This vulnerability is intensified given the disabling nature of some participants' impairments. Furthermore, as life history interviewing is riddled with ethical issues, the potential for harm in terms of anxiety, stress, guilt, undermining of self-esteem and feelings of exploitation are substantial. For example the individual may experience loss – in the form of both privacy and contact - when the study is over which could cause anxiety or distress (Stalker, 1998). Moreover, with participants 'abandoned' after the interview and left to 'piece together the memories that have been deconstructed' any positive feelings that may have arisen directly after the interview may be reversed (Roberts, 2002:104). Indeed, as Plummer warns, there may be a whole 'after-life' of a life history interview, one which haunts the participant for a long time after the interview (2001:403). This can be further complicated by concerns about how they will be represented and written about, in particular what material will be used and what will be left out, and this may be a cause of great angst and pain for the participants (Murphy and Dingwall, 2001).

To try and ensure that as little harm as possible came to participants a number of measures and precautions were taken. Centrally, echoing the arguments of Coffey (1999) and Murphy and Dingwall (2001), this centres on stressing the need for empathy, time and honesty. Participants were informed that agreeing to take part did not mean that they had to answer every thing they were asked, and in particular they did not have to answer questions that they found inappropriate or distressing.

Furthermore to ensure that participants did not feel abandoned, all participants were asked whether they would like me to contact them a week after the interview (no one chose to do this) and reminded that they could get in touch with me if they had any issues following the interview. The research also sought to minimise the harm that came to participants by seeking to sustain contact with participants throughout the research period through update letters and consulting them at the analysis stage through 'post interviews'.

Whilst such efforts ensured that any harmful effects were minimised – indeed a number of individuals thanked me for the way in which the research was being conducted- it has to be recognised that issues of harm can never be completely absolved (Hammersley and Atkinson, 1995:275). During the course of the research I had concerns that the research may have caused undue harm to two individuals – Valerie and Katy.

The first instance involved the possibility of issues haunting the individuals after the interview. Despite having severely restricted vision, Valerie was insistent on finding her photo album. Once found she asked me to look through it and say what the pictures were of so that she could tell the story behind each one. Whilst this revealed a great deal of information about her life history and additionally her relationship with her dwelling it was also a very emotional experience. with the participant having to imagine pictures that she could no longer see. I was concerned that such an action – and the renewed awareness that she may never see such pictures again - may have caused her upset after the interview. However following later contact it became apparent that such concerns were unfounded and that she had actually "enjoyed" going through the photos.

The second instance involved the possibility of harm through the misunderstanding of the 'research relationship'. As Katy could not communicate verbally and could only write with difficulty, mobile phone numbers were exchanged at the end of the interview so that Katy could contact me via sms text message. After sending out a six-monthly update letter, Katy sent me a text message asking "do you see me as a friend[?]" . It was my understanding that I had made it clear to all participants the nature of the research project and of the research relationship (following the advice of

Oakley, 1981). However I did not want to mislead Katy that the short-term research relationship was going to be anything more than that so responded accordingly via text message. To this she replied “sorry I class you as a friend of mine”, but then later text to say that she still wished to meet to discuss the research. Whilst Katy may have misunderstood the short-term nature of the research relationship – or indeed misinterpreted the giving out of my mobile phone number – her manner and the fact that she did not seek to contact me further or apportion blame suggested that no undue harm had been caused.

Both instances reveal the grey area between trying not to be detached from the research and trying not to be over concerned with participants. Furthermore, the instance with Katy also reveals the unexplored ethical problems of communicating via sms text message. Being limited in terms of how much you can type not only restricts what can be said but in doing so can create ambiguity. From the text ‘ sorry I class u a friend of mine’ I had inferred that I had potentially caused her psychological harm. This however may simply have been a misunderstanding as she later indicated that she still wished to meet to discuss the research. Whilst harm can never be completely absolved or fully understood, what has to be recognised is that efforts taken to prevent harm were placed at the very core of research design.

5. 3. 5. 2 A reflection on the research

“Reflexivity generally means attempting to make explicit the power relations and the exercise of power in the research process. ”

(Ramazanoglu with Holland, 2002:118)

The importance placed on reflexivity in qualitative research became most clearly revealed from the mid 1980s in the interpretive turn. A classic example of this reflexivity is seen in Nigel Barley’s work where he looks reflexively at his accounts of conducting research, coming across as an incompetent anthropologist who is literally carried through the research (1983). Indeed reflexivity has played a central role in a number of anthropological texts (see, for example, Clifford, 1986). Reflexivity now plays a crucial role in almost all social science research including feminist research and critical realist research – and hence it becomes an important consideration in this thesis (for the requirement of reflexivity in critical realism see Sayer, 2000:53; Danermark *et al*, 2002:42).

Reflecting on the data collected, it has to be acknowledged that any interview data will have inevitably been affected by what else was going on in the participant's life; for example how they felt on that particular day (Hammersley and Atkinson, 1995: 151). If participants were feeling physically ill, tired or depressed, their responses will almost without doubt have been different then if they were in good health, full of life and jovial. It is impossible to deny the effect this may have had on knowledge production and as a consequence it becomes necessary to be reflexive about the data collected and analyse it accordingly. Additionally, as noted previously in this chapter, memories of events and experiences are fallible and cannot be understood as definitive representations of reality.

However a reflexive inspection of the production of knowledge must also seek to recognise the role of the researcher in the creation of knowledge. The researcher is becoming increasingly visible in social science research and a wealth of literature now attests to the reality that the researcher's 'self' is inextricably part of the data. That is to say that any knowledge generated has to be understood as intermingled with the researcher's biography (Plummer, 1983: 102-104; Burgess, 1984:88-92; Coffey, 1999; Atkinson, Coffey and Delamont, 2003; Rubin and Rubin, 2005). As a white, male, middle class, able-bodied, university educated researcher I have to acknowledge that I came to the research setting with specific attributes, 'baggage' and power, which may have affected the narrative generated. My age may also have affected any data generated.³² I cannot deny that these things *may* have had an effect, and it is my responsibility to reflect on the potential impact it could have had on knowledge production.

More significantly the data does not speak for itself, it has to be interpreted. Except in rare circumstances it is the researcher who holds the power to interpret the data collected. Consequently it is the researcher in the conventional monograph who has the power to select which parts of an individual's life history they wish to reveal and the researcher who attributes meaning to the statements of others (Heyl, 2001:377).

³² Two participants; Jimmy and Sam, on greeting said me that I 'sounded much older on the phone'; whilst another, Alison, said that she thought it was me coming up the street as I 'looked like a student'.

By imposing an interpretation on the data it is possible that this might not reflect the way in which an individual understands their experiences or be the same interpretation that might be given by a different researcher. Whilst this research sought to overcome this issue by involving participants in the analysis process, and giving them a voice to comment on preliminary analysis in post interviews, the final interpretation was ultimately mine. Furthermore, as noted above only six of the nineteen participants chose to conduct a post interview. As a result it is important to be reflexive about my role as the researcher in creating the narrative that unfolds. As Kaul has reasoned: whose structural ontology and whose views is it that are actually being presented (2002)?

Answering this Hammersley and Atkinson (1995:13) argue that any interpretation of texts inevitably reflects the socio-cultural position of the researcher. Such a position has also been adopted within a feminist methodology, where there has been a comprehensive questioning of whether knowledge can be free from researcher's values, emphasising the need for a reflexive research agenda (Ramazanoglu with Holland, 2002). Whilst I have endeavoured to develop a reflexive research agenda, accepting that any data and knowledge produced will to a certain degree be affected by my biography, I do not believe it to be the case that the interpretations will be wholly shaped by my 'socio-cultural position'. Drawing on the work of Sayer it becomes possible to accept that despite having power and a given biography it is still possible to interpret texts in an objective fashion (2000). To achieve this Sayer identifies and distinguishes between three types of objectivity (Sayer, 2000: 58; see Chapter 3). Sayer argues that Objectivity₁ (notion of value neutrality) and Objectivity₂ (search for objective knowledge) are often combined, and it is assumed that to get true statements about the world (Objectivity₂) statements must be value free. By challenging this proposition by distinguishing Objectivity₁ and Objectivity₂ Sayer argues that we can all accept factual statements that we do not like. Applying this work, the case can be made that it becomes possible to recognise that whilst my biography will present a challenge to any claim to Objectivity₍₁₎, by refusing to conflate Objectivity₁ and Objectivity₂ it still remains possible to present an interpretation of the views and experiences of participants in an Objectivity₍₂₎ fashion. In doing so, I would assert that whilst I inevitably had power over analysis and

authorship and could make no claims to being value neutral, it is still the views and experiences of the participants that are being presented in this thesis.

5. 4 Conclusion

This chapter has sought to shed light on the research process and draw attention to the course of action involved in the conduct of empirical research based on critical realism.

In detailing the requirements of a critical realist research project, the need to understand underlying mechanisms through retroductive analysis was asserted. From here, it was suggested that an *intensive* approach to research would help to achieve this. More specifically, through the questioning of a range of research methods it was argued that life history interviews would be the most appropriate method. Whilst the problems associated with such a method were acknowledged, through reference to the need to develop ‘substantial connections’ rather than generalizable data, it was asserted that a life history approach could help to reveal the full range of events and explain the meaning of the dwelling for disabled individuals in a way that no other method could.

The second section described the research practice, exploring the practicalities of how this critical realist project was conducted. Here the challenges to accessing and recruiting individuals with a range of physical disabilities was presented alongside a detailed description of the data collection method as a three-stage process involving a pre-interview, a life history interview and a post interview. Furthermore, what also became apparent was the way in which the research process was intimately embedded in my commitment to questioning detached and hierarchical research practice.

In describing and evaluating how the research was conducted, this chapter paves the way for a detailed discussion of the data generated from the life history interviews. This analysis will take shape over the next two chapters. Chapter 6 will engage with the policy and academic debates developed in Chapter’s 2 and 4, building on the existing literature base and highlighting the range of events that emerged as impacting on the meaning of the dwelling from the nineteen life history interviews. From this description, through retroductive analysis Chapter 7 will consider the way in which

these events can be explained with reference to deep underlying structures and mechanisms and the three-dimensional framework developed in Chapter 3.

Chapter 6. A complex experience:

describing the data from the nineteen life

history interviews

Chapter 6

A complex experience: describing the data from the nineteen life history interviews

6.1 Introduction

This chapter is the first of two analysis chapters. Following the DREI schema outlined in Chapter 5 this chapter broadly corresponds to the *description* stage of analysis. Accordingly this chapter will present the data collected from the life-history interviews with nineteen participants and code the surface events that become apparent from the data generated.

The chapter begins by describing the data collected. To enable the reader to acquaint themselves with the nineteen participants the description provided in section 6. 2 offers a detailed account of the housing circumstances and care arrangements for all participants. This description then feeds into a discussion of this data in section 6.3 where links are forged between the primary data presented in 6. 2 and the policy and literature presented in Chapters 2 and 4. Specifically this section will highlight the complexity of the meaning of the dwelling, describing the way in which the data both supports the notion of the dwelling as a biographical accomplishment *and* throws into question the established conception of the dwelling as a site of privacy, security, independence and control. This discussion is then taken further in section 6. 4 through an appeal to the temporal dimension to the meaning of the dwelling. Drawing on the life history descriptions the section will engage with previous work on time to query the link between attachment to the dwelling and length of residency as well as exploring how meanings can change over time.

The final substantial section in this chapter, section 6. 5, goes beyond the description and discussion of this data and codes the descriptions into the seven events that appeared to have an impact on the meaning of the dwelling. These events will go on to become the basis of further retroductive analysis in Chapter 7. The chapter then closes by making general conclusions about the significance of this data and the identified events.

6. 2 “The thing about me is...”: describing the lives of the research participants

This section will focus on describing the life circumstances of all nineteen participants. To do this the section is broken into two parts. The first part explores the housing circumstances of each participant, highlighting how and why they are in the dwelling they are in, how they get about in the dwelling and who they live with. The second part will explore aspects of care in the dwelling, detailing the seven participants who receive regular care assistance in the dwelling and documenting emergent care issues.

6. 2. 1 Housing circumstances

Just as different impairments can lead to different barriers being faced, different disabilities can also affect people in different ways. For seven of the nineteen people interviewed for this research, the onset and/or progressive nature of disability and the resulting barriers faced in their dwelling forced them to move. For four individuals – Sam, Sissy, Stephen and Mick – the barriers presented forced a need to move into a supported accommodation setting. All four individuals lived in the same setting. The setting comprised of 30 self contained flats, with a communal living area and on site warden. Accordingly it can broadly be understood as ‘sheltered housing category 2’ (see Chapter 2). Whilst the setting was run by a HA, residents were free to decorate their flat as they chose. What is important to note is that all four participants saw the flat as their dwelling, not the supported accommodation setting itself.

Sam, 55, a retired accountant, school governor and amateur artist, had lived in a one bedroom flat in the setting for four years. Prior to the move he had lived for three years with his girlfriend in her dwelling. However the progressive effects of MS which he had been diagnosed with at 25, meant that this dwelling had become increasingly unsuitable:

Sam: ‘Well being in a wheel chair I faced all sorts of problems really. You know everything from getting in the house, moving from room to room that sort of thing. I couldn’t reach the work surfaces so I couldn’t do anything. I guess you could say my girlfriend had become my carer... Things were all going a bit pear shaped with me to be honest, and to get everything as good as it is here would have involved a lot of change and a lot of work, and well I guess I don’t think it [relationship with girlfriend] was quite there, so we came to a parting of ways. But being homeless I moved to the top of the queue and came in here. ’

This quote highlights the barriers posed by housing design, and the effects it can have. With the supported accommodation setting specifically designed for wheelchair users, design barriers were overcome, helping Sam to be “free to do what I want, when I want”. Indeed the new independence Sam had gained through good quality design had given Sam more confidence and had plans to meet up with his ex-girlfriend.

Steven a retired lorry driver in his 60s, had his “leg shattered in a huge pile up on the A1” nearly thirty years ago, leaving Steven unable to use his left leg and needing a walking stick to aid movement. With arthritis complicating problems, Steven faced a number of barriers in his dwelling, most notably stairs. Living alone and unable to adapt his property, Steven moved into a supported accommodation in London. After six years “of boredom” in this setting Steven moved into the supported accommodation setting in South Wales where he could be near his daughters, and has now been for six months. Steven indicated that his new flat was much bigger and the design and adaptations that had been made (grab rails being inserted throughout the flat) made moving around “dead easy”.

Whilst for Sam and Steven it was complications and the progressive nature of illness that led to a move into supported accommodation, for Sissy and Mick it was the onset of disability and the new barriers faced that forced such a move. Sissy, in her 60s, had lived in a farm house with her husband (who died twenty years ago) and four children. This dwelling contained a number of fond memories. However, after a routine operation went wrong Sissy was left paralysed from the waist down. With the farmhouse proving to be “unmanageable” and inaccessible now that Sissy was in a wheelchair, she was forced to move into the supported accommodation. Sissy had now lived in the two bed flat in the setting for twelve years. Whilst Sissy had lived alone for large periods, her time living alone had been punctuated by times (of up to a year) when one of her sons moved in when his marriage broke down. Adapted to suit Sissy’s needs, Sissy indicated that she “loved” her flat. What was more important than anything else though was her “photo wall”:

Sissy: “Rich people would have paintings all up their walls, well I am not rich so I have photos on mine! I would much rather have all these photos up, look there is the

one on my 60th birthday, and that's the old farm house. I think it's much nicer to have faces of people you know on the wall don't you?"

Placed by the front door the photo wall was a collection of tens of personal photos. Being able to have these photos up in her dwelling clearly meant a lot to Sissy.

Mick on the other hand was far less enthusiastic about moving into the supported accommodation setting. Prior to moving into the supported accommodation setting Mick, a journalist with a passion for folk music, lived in a 200 year old cottage with his wife and teenage children.

Mick: "I was oh so happy there and then I had a severe stroke, and I mean the mother of all strokes and suddenly the cottage presented real problems. I couldn't get down the garden, I couldn't get out of any of the rooms on my own, I couldn't use the stairs I was confined. The bathroom became a real battle too you know; with the wheelchair not fitting in properly I was left there having to keep the door open every time I used it, and that's not what you want when you have got teenage children.... I was there last night and it really is a no go area.... Well anyway because of all those problems a social worker – fucking woman, if she was to drop dead tomorrow I would dance on her grave and moreover piss on it to... anyway as I was saying because of everything she showed me this place and there was a vacant spot and here I am, I have squeezed myself in here. "

With a stroke leaving Mick with little control over the left side of his body, Mick faced a number of barriers in the cottage, forcing him to move into the supported accommodation setting. This setting, Mick acknowledged, was far easier to move around in and allowed him to live independently and without carers. However, whilst accessible and having lived there for three years Mick "just didn't feel any inspiration" in the setting and it was his "ambition, in fact all of my ambitions" to "recover" from the stroke and regain the use of the left side of his body and move back into the cottage with his wife and children.

The onset /progressive nature of disability also led to Martin, Deirdre and Finn having to move. A brain haemorrhage left Martin, now in his 40s, with speech difficulties and reliant on a wheelchair for movement. With no family in the UK after coming out of hospital Martin first moved in with friends and then into a one bed council flat where he has been for the last fourteen years. Martin's flat is on ground level, the doors have been widened to allow wheelchairs through and grab rails have been

installed in the bathroom. However, Martin faces a number of difficulties moving around the dwelling. Primarily this is an issue of space.

Martin: "I have applied to move into a special wheelchair place but the council give it to who they want to. I have been waiting here fourteen years. They said it would be OK for me but it's so small. I can't move around my bedroom or turn in the bathroom. I would love to have a side cabinet but there is just no room to put it, I wouldn't be able to turn my chair round if you put one here. "

As well as difficulties moving around the dwelling, the height of kitchen units also present a barrier to food preparation and with no shower unit Martin relied on carers for bathing. Whilst Martin enjoyed having the independence of his own flat, he indicated that he desperately wanted to move into somewhere that was more suited to the needs of a wheelchair user.³³

The problem of inadequate housing design led to former PE teacher Deirdre, 66, moving in with her daughter. Diagnosed with MS twelve years ago and now reliant on a wheelchair, Deirdre moved into her daughter's dwelling four years ago.

Interviewer: "Why did you leave your previous dwelling"

Deirdre: "Well my husband wouldn't do anything to make life easier for me. And there were so many problems with the place. I was forever asking him to do things for me because I just couldn't get around anymore. But that caused its own problems, and invariably he just wouldn't do them. I mean I had to climb the stairs every night to go to bed and it was getting impossible. So I said enough is enough! He paid for the extension here [in daughter's dwelling]. As you can see it's quite small but perfectly formed! Being on the ground level I don't have to worry about stairs and there is an en-suite bathroom with a wheel-in shower unit and adapted toilet... And as you can see we have just had this hoist installed which helps with getting up... So living here is a real joy. "

As the above quote shows, the problems of design coupled with marital difficulties resulted in Deirdre moving to live with her daughter (her husband remains in the previous dwelling). Her room has been decorated with photos of her grandchildren, photos of Deirdre in her youth and a signed photo of Des O'Connor, a personal 'idol'. "I met him once such a fantastic man". Deirdre never returns to her previous dwelling and describes her daughter's dwelling as her "home", and "loves" living with her

³³ Martin has now moved into a specially adapted wheelchair property. It was too late re-interview Martin and include a detailed analysis of his experience of the new dwelling. However, Martin did indicate that he is "much, much happier" in his new flat.

daughter, son-in-law and two grandchildren. However, this is not to say that Deirdre can move freely around the dwelling. Stairs mean that Deirdre only has access to the ground floor and even here steps to the kitchen and out to the garden mean that she can not access these areas independently and remains confined to two rooms – her bedroom and the shared lounge. Nevertheless, for Deirdre this remains superior to her previous dwelling.

Unlike the previous participants noted so far, Finn, 21, was born with Muscular Dystrophy and has been a wheelchair user all his life. Finn and his family (parents and one brother) were forced to move from their previous property after it became apparent that the dwelling was completely inadequate for Finn. The doors and the hallway were too narrow to allow Finn adequate space to get his wheel chair through, leaving Finn literally trapped in a room until someone came to help him out. Poor construction of walls and ceilings also meant that it was not possible to install hoists or lifts. Finn and his family have now lived for the last eleven years in a new HA property, which has been specifically designed (e. g. through wide doorways and rooms big enough to turn around in his wheelchair) to enable wheelchair users to move between rooms independently, though Finn can still only access the ground floor of the property. A full time university student, Finn is now keen to move out of this setting and into a flat of his own. This is not because he does not like it there, quite the contrary he feels “at home” in the dwelling. For Finn the reason for moving - like most twenty one year olds - is about seeking to obtain independence.

For the majority of participants the onset and/or progressive nature of impairment did not lead to having to move dwelling. Principally, this was due to individuals adapting their dwelling. Five participants - Carrie, Alison, Louise, Harry and Melissa had significant structural alterations made to their dwelling.

Carrie has had Spina Bifida since birth and has used a wheelchair her whole life. Now in her late 60s, a retired clerical officer and dressmaker, Carrie enjoys amateur dramatics and has received an MBE for services for the community. Carrie has lived in her current 2 bed owner occupied dwelling for the last forty two years. A number of photos adorn the walls and gardening paraphernalia is scattered throughout the dwelling. Since her mother’s death, Carrie has lived alone and has decorated the

dwelling entirely to her choosing. Initially Carrie resisted adapting the property, preferring instead to “crawl” up and down the stairs. However when her mother died it became necessary to adapt the property in a number of ways:

Carrie: “When my mother died I had a to make a few changes and now half the kitchen is at my height and half at normal height if anyone wants to help. I had already adapted the bathroom [installing grab rails and a wheel in shower unit] and I had ramps put in all over the place and walls taken out to help me move between rooms. Then when I had my leg amputated in ’89 I couldn’t get upstairs so I’ve had that put in [points to through-floor lift].

The adaptations Carrie had made to the property helped her move around it with greater ease and could now access all areas of her dwelling.

Alison has lived in her owner-occupied house for twenty-one years. A recently retired engineer, Alison, 64, used to share the dwelling with her husband and watched her daughter grow up in it. However since her husband died five years ago Alison has lived on her own in the dwelling. Since being diagnosed with Motor Neurone Disease (MND) three years ago MND has left Alison with difficulty communicating verbally, has little control over her hands and has restricted use of her legs, becoming reliant on a wheelchair for movement. Consequently Alison has had to have “extensive alterations” to her bungalow. Over the last three years walls have been taken out to allow Alison to get in and out of rooms, hoists fitted in the bedroom, the bathroom adapted with a wheel-in shower unit and electronic aids fitted to help Alison open/close windows and turn lights on/off. These adaptations have enabled Alison to move around the property and “stay at home”. The adaptations were largely carried out by drawing on savings; thus limiting engagement with social services. The only area Alison cannot access is the garden, though she has now had a conservatory built so she can look out onto it. The only area that has remained completely unchanged is the dining area.

Louise, a retired social worker in her 60s, has lived in her current owner occupied dwelling with her husband, four birds, two snakes and two dogs for the past thirteen years. Louise and her husband moved into the dwelling after being victim to a series of burglaries in their previous dwelling, making it “very difficult to stay there”. Whilst Louise had been diagnosed with MS ten years before moving into their current

dwelling, Louise admits she was “unprepared for what was to come”. Louise is now paraplegic and uses an electric wheelchair with limited use of her hands. Despite having a series of adaptations to the dwelling – adaptations that she hated - including 2 lifts, ramps, hoists around the dwelling and a ramp up to the front door, Louise still faces a number of barriers in the dwelling. These barriers include steps out to the garden, heavy doors and small room sizes which prevent Louise moving independently. Louise is desperate to move out of the place where she feels trapped and “desperately unhappy”, but has found it “impossible” to sell the dwelling because of the adaptations that have been made.

Melissa, 38, works full time and has osteogenesis imperfecta which has left her reliant on an oxygen tank for breathing and a wheel-chair for mobility. Whilst Melissa used to live on her own in a flat, she found living on her own “very lonely”. To overcome this Melissa decided to move back to the home where she grew up, a dwelling that had been occupied by her sister and sister’s young children since their parents died “some years back”. Melissa has lived in this dwelling for the past ten years. As Melissa’s physical condition has “deteriorated” it has been necessary to carry out a number of structural changes to the dwelling:

Melissa: “Well after I moved in we had what you could call a bedsit made up at the back of the house. It’s all been set up for me with an en suite bathroom and as things have got worse, you know, with me, we had to have things added and things taken away but yeah I guess you could say it is all accessible.”

Changes to the layout of the kitchen and the lounge have meant that Melissa can also access these areas. However, with no room for a through-floor lift Melissa is only able to access the rooms on the ground floor. Further as Melissa’s physical condition has deteriorated over the last few years she no longer has the ability to use the bathroom independently. Nevertheless, Melissa still “loves” the dwelling which contains “so many memories” and has no plans to move.

Harry too has had a number of adaptations. Harry was a retired engineer who had worked and lived in Wales, Canada, Nigeria and Libya over his career. However fifteen years ago Harry was diagnosed with having Parkinson’s disease, which left Harry with little control over his limbs. Harry and his wife have lived in their three-

bed house for the last six years, making the move from their previous dwelling to be closer to their sons and grandchildren. However, as the effects of Parkinson's have got worse, it has been necessary to conduct a number of structural changes to this dwelling. These include installing a downstairs bathroom, an en-suite toilet, turning the upstairs bathroom into a shower room and installing a hoist in the bedroom. To avoid having to install a stair-lift Harry and his wife converted the downstairs study into a bedroom for times when Harry could not manage the stairs. For Harry this was a sacrifice he was prepared to make to "keep the home from being totally adapted".

Rather than extensive structural change a number of participants just had smaller adaptations and cosmetic changes. Six participants fall into this category – Katy, Jimmy, Jodie, Sharon, Valerie and Colette.

Katy, now in her 40s, is a law student who enjoys shopping and going to the pub. After developing Cerebral Palsy as a child Katy was placed into care by her father who "couldn't cope". Cerebral Palsy has left Katy unable to communicate verbally and with restricted use of her hands. After moving from her previous property because she felt unsafe in the area, Katy "loves" her current dwelling and has lived alone in the HA first floor flat for the last sixteen years. However, whilst Katy has had her kitchen redesigned so that cupboards and cooker are at the right height and shower cubicle fitted, Katy still feels more needs to be done to give her more independence. Of particular concern to Katy was the fact that all her light fittings were too high meaning that she couldn't change a light bulb when it went. After "fighting for fourteen and a half years" to get a shower installed though Katy was not convinced that she would ever "win the battle" to get her lights lowered.

Council worker Jimmy, 43, also faced a battle to get the minor adaptations he needed done. Jimmy has lived on his own in his current owner occupied two bed house for the last twenty years and has lived in the area for forty two years. A brain haemorrhage fourteen years ago left Jimmy paralysed from the shoulders down. However, Jimmy has now regained the use of his limbs, walking with stagger and having difficulty controlling his hands. Returning to the dwelling after a period of nine months in hospital, Jimmy was faced with a number of barriers:

Jimmy: "When I came out I realised then that was it - my life was going to change. The bath had to be lowered so that I could get in and out unaided, the stairs had to have a double rail put up and my kitchen units lowered by three inches. Well the OT said 'yeah, yeah, yeah no problems'. So I got it all done expecting to get all my money back and the OT phoned and said 'er [name of participant] you earn too much'. ...I earn two pound seventy too much a year. "

Jimmy has now been "fighting" to reclaim the money he feels he is rightly entitled to, though as yet he has not received what he is after. To assist movement around the dwelling Jimmy ensures that there is "not much furniture" and "little on the walls" to help him be "as independent as possible" and avoid tripping up on things. Whilst completely accessible, like Katy, Jimmy would also like to have his lights lowered so that he could change a light bulb "without having to get someone in. "

Jodie, a university graduate, has been "suffering" with ME since she was a teenager. ME has left Jodie very weak with very little energy or strength, unable to cook or some days even get out of bed and "hyper-sensitive" to sights, sounds and smells. Jodie has lived in her 3 bed privately rented dwelling with her friend for the last four years. Whilst very happy in her previous house, she was forced to move on after the landlord decided to sell it. Jodie's current landlord had been very understanding, however aside from painting the walls a softer colour and having the kitchen adapted so that cupboards were at her level (thus avoiding the need to bend down), Jodie had not made any other adaptations. This was very much a conscious effort as she did not want to turn her dwelling "into a hospital". This decision had a significant impact on Jodie's ability to negotiate the dwelling. On days when Jodie was feeling particularly weak she would not have the energy to climb the stairs. Whilst the landlord had permitted the instillation of a stair lift Jodie refused to have one as she felt it would look horrible. With Jodie's bedroom on a different floor to the lounge the consequence of this decision not to have a stair lift installed was that Jodie would be confined to her bedroom. Whilst ill suited to her needs, Jodie had no plans of moving out of her dwelling.

Sharon, Valerie and Colette could all move around their dwelling with relative ease and did not need adaptations to aid movement in the property. However due to the nature of their disability all three participants had their dwelling adapted in someway. Sharon, in her 30s, had a cataract operation when she was eight years old. It later

became apparent though that it was not a cataract, but rather that Sharon had a rare condition – hypoparathyroidism - which affected both her eye sight and calcium levels, leaving her partially sighted and weak. Sharon has lived in her current two bed owner-occupied dwelling with her husband, cat and dog for the last four and a half years. Previously Sharon had lived at home for a brief period after breaking up with her previous husband after he committed adultery. Sharon’s weakness as a result of her illness means that she is unable to hold down a full time job and only on “good days” can she do household chores like cleaning. Whilst Sharon does not have the strength to lift pans or lift things out of the oven she can cook using the microwave, which has coloured stickers on to help Sharon push the right buttons. This technique was also used on other electronic equipment such as remote controls, the T. V. , stereo and DVD player.

Valerie, 84, moved into her two bed ground floor owner occupied flat in 1973 with her husband. After Valerie’s husband died nearly twenty years ago, Valerie has rarely spent long periods living alone, with various children and grandchildren living with her for extended periods. Valerie currently now shares her property with her son who moved in after a break-down of his marriage. A former seamstress, Valerie’s vision has been gradually deteriorating over the last four years, to the point where she can now only make out vague shapes. Whilst Valerie has little difficulty moving around the property she has had a few adaptations to help her live independently. These include raised buttons and stickers on electrical items and “talking” appliances.

Valerie: “Well since it [eyesight] has got worse I have had to put stickers on the washing machine and count them round to make sure I get the right setting ... and I’ve got all sorts of talking things – I’ve actually got a microwave that talks to me!... I might have to change the worksurfaces because the colour makes it very difficult to see what’s on it, you see the plates just blend in. It is also hard because I don’t know if it is dirty or grubby. ”

This concern of not knowing whether the dwelling was clean was one that Valerie returned to a number of times. Valerie made it clear that she could live with this and had no intention of moving, noting that she is very happy living so close to all her family and that they had all enjoyed “some happy times here”.

Colette, 52, has a degree in Classics and Mathematics, is a part-time yoga teacher and has been a manager in her current post for the last six and a half years. Colette explained that she has had Asbergers Syndrome since birth which has affected her hearing. As noted in Chapter 1 this research is only exploring the impacts of physical disability. However, Colette's circumstances show the way in which mental disability and physical disability can overlap. Nevertheless, in this research it is just the impact of hearing impairment on the meaning of the dwelling that will be explored. Colette lives with her husband of nine years and has two children from a previous marriage who used to live in the dwelling but have now "flown the nest". Colette has lived in her current "semi detached rabbit hutch" for nine years. For Colette the dwelling may be small but it represents her "breaking free of my first husband and gaining independence". To help negotiate the dwelling Colette has a visual door bell system fitted around the dwelling, a hearing loop fitted and has a number of text phones.

Whilst a number of participants sought to avoid adapting their property and make only minor changes, one participant indicated that he did not want to adapt his dwelling at all. John, 67, was a retired University lecturer who had been diagnosed with primary progressive MS four years prior to the interview and had been using a wheelchair to move around for the past two years. John moved into his current five bed dwelling with his wife when they got married sixteen years ago, and his now grown up children from a previous relationship often came to visit. However with the onset of MS and the need to use a wheelchair a number of barriers became apparent:

John: "Well as you may have noticed we have got a great step at the front door which means that I can't get in or out without [wife's] help... there is a step up to our shower unit so I cannot use that.... the kitchen units are now just too high for me to get at ... and I used to go upstairs but about two years ago the doctor said you mustn't keep going up there and, well, I can't even if I wanted to anymore now that I am in this [points to wheelchair]."

However, despite these barriers John did not want to adapt his dwelling. For John the dwelling was a home not a "machine to live in" and was "not happy with the idea" of damaging the appearance and character of the property in order to install adaptations that would aid his movement. Consequently John was restricted to just one floor of the three floor dwelling, limited to using the kitchen, bathroom, lounge and "guest bedroom" which he had adopted as his own. Whilst John's movement around the

dwelling was wholly restricted, he preferred it this way then to “wreck the house” with adaptations, and had no desire to move. This decision will be discussed in greater detail later in the chapter and again in Chapter 7.

6. 2. 2 Care in the dwelling

Different disabilities give rise to different care issues. Of the nineteen participants only eight – Finn, Martin, Jodie, Carrie, Louise, Alison, Melissa and Deirdre - received formal care through community care services. For John and Harry their wife became their primary carer; inside the specially designed supported accommodation setting Sam, Sissy, Steven and Mick did not need any care support; Jimmy, Katy, Sharon and Valerie did not need any form of care and whilst Colette had been offered care services she had turned them down in order to maintain her privacy.

Of those who received assistance from carers, seven employed their own carers through the direct payments scheme with only one participant, Deirdre, having carers provided by the social services. Deirdre’s carers came twice a day – once in the morning and once in the evening to “get me up and put me to bed”. Whilst Deirdre almost always had the same carers in the morning in the evening it was a different story:

Deirdre: “It is a shame really because in the evening it just seems to be anyone who is available will come. I would like to have the same ones, they get to know what you want, what you like and what you don’t like...it is very annoying to have to tell people every time, things like ‘I would like to have my teeth cleaned please’ - you would think doing that would be obvious! ”

Despite this Deirdre was “happy enough” with the care that she received from social services. Deirdre’s positive overall opinion of care provided by social services however was the exception rather than the rule. All seven participants who used the direct payments scheme had previously received care from social services. Indeed it was their unhappy experience of receiving care from social services that led to all of them choosing to go on the direct payments scheme.

Since his brain haemorrhage, Martin has required care services to help him cook and assist him getting up in the morning and to wash himself. Martin indicated that under care from social services he had little control over his life:

Martin: "Err well they just didn't use to bother with you much. And if they would it would be at 7 o'clock in the morning, get you up and showered."

A further problem was the lack of respect carers showed to Martin in his dwelling. Due to the carers coming in and using his telephone for private calls Martin felt the need to put a sign up in his own dwelling asking others not to use the phone for private calls, especially to mobile phones. Since moving to the direct payments scheme though Martin claimed that he has had more "control" and had "got my independence back". Martin employs just one carer through the money he receives via direct payments, a carer he feels he can trust. Indeed Martin even described his current carer as "a friend".

Owing to the effects of her disability, Alison is "unable to get into or out of bed, wash dress or prepare food", requiring assistance from "a small army of carers". The problem Alison found with receiving care from social services was that "you always got strangers in the home, new people all the time". This was a problem to Alison as she "hated" different people coming into her dwelling everyday, and in particular different people washing her. Since moving onto direct payments Alison has been "much happier" with the care she received, indicating that the carers give her "a little dignity" in the bathroom. Further, like Martin, Alison also indicated that by having the same carers everyday she had developed "a bond" with them.

Carrie also requires assistance cooking, washing, getting up and going to bed, and receives 21 hours a week of care assistance to do these tasks. Carrie had been on the direct payments scheme for five years at the time of interview, prior to this receiving care from social services. The reason for the change was that:

Carrie: "I was always on edge before they came... half of them were lazy and couldn't wait to get out. And woe betide if you ever had to cancel – that was it you lost your day."

In comparison, Carrie thinks that the direct payments scheme is "brilliant". By employing one carer for weekdays and one for weekends Carrie has been able to develop a bond with the carers, one that transcends the previous carer/cared for relationship to a rapport based on respect.

Finn also moved from receiving social service care to direct payments after years of struggling to maintain control over his life:

Finn: "The reason for changing to direct payments was very simple really. I wanted more flexibility and I wanted to be more of an independent young person... basically the independence bit swayed me. "

Whilst requiring assistance to go to the toilet and get dressed, Finn asserts that without being on direct payments he would not be able to go to university or live as independently as he does. With independence and a commitment to the values of direct payments so crucial, Finn explained that he looks to employ assistants through the direct payment scheme that share his ideology. As a consequence Finn gets on well with his carers and believes that they help give him more control and "more scope for life" than he ever had before.

Owing to the effects of osteogenesis imperfecta Melissa needs support to help her get up and go to bed, go to the toilet, wash and assist her in getting places. Melissa's biggest concern with social services was the vulnerability of having unknown carers enter the dwelling:

Melissa: "I don't like having different people every day.... I'll never forget it ... I wakes up one morning and this woman is standing by my bed, can you imagine? I was screaming! GET OUT OF MY HOUSE! ... I find that you can be vulnerable sometimes you know and I understand how people less mouthier than me and less confident get frightened. "

These experiences contributed to Melissa reluctantly moving to a direct payment scheme which meant working with "paperwork and all that crap". However Melissa does not regret moving on to the direct payments scheme for a second, welcoming having the same carer every day. Moreover Melissa also asserted that without the direct payment scheme she would not be able to hold down a full time job.

For Jodie the effects of ME have at times left her so weak that she requires assistance eating, cooking, getting dressed and getting up. Indeed Jodie noted that at one point she became so weak that she could not speak. Whilst social service carers were always "very unhelpful" moving to direct payments has helped Jodie to "regain

control over my life and my home... it has become something personal". Through the money received through direct payments Jodie is able to employ a carer for 30 hours a week, giving Jodie the opportunity to develop a "good relationship in a difficult situation" with her carer.

Finally, Louise has experienced what can best be described as a 'turbulent' relationship with carers. Louise receives substantial care support with carers assisting Louise to cook get up, go to bed, wash, move around and help Louise with her injections. After receiving care from social services for eight years Louise got "fed up with all the different intruders (care workers)" coming into her dwelling. The biggest problem for Louise was the lack of respect from the carers who came into her dwelling. To try and overcome these problems Louise moved to the direct payments scheme where she would be in control over who entered the dwelling. However this led to further problems:

Louise: "I have had nightmares with carers, really dreadful. [current carer] was here when the police had to come and arrest one of my carers, she had stolen so much from me, taken my money, taken all sorts and the police arrested her here, and it was a very hurtful and horrible time it really was awful ... I had one who was a drug addict, another whose husband was a murderer, her son a rapist and I found out later that she had done a lot of things herself. So you have got to rely on them being honest and her telling me things, and they are not going to do that. And I had another one who unbeknown to me she was a [pause] lesbian. And her partner thought that I was in love with her. Now I go 'urrrrgh, no way please not that'. That was a very dreadful time again."

The implications of these problems will be discussed below. Despite this experience Louise has stuck with the direct payments scheme, seeing it as "the best option". This decision has proved favourable with Louise now having a "good working relationship" with her current two carers.

6. 3 Discussing the descriptions: linking the description to literature and policy

This section links the descriptions presented above to the literature and policy presented in Chapters 2 and 4. To do this the section will be split into three themes: the data that supported the notion of the dwelling as a biographical accomplishment/psychic warehouse; data that questions the dwelling as a source of ontological security; and finally descriptions which appear to challenge the prevailing academic acceptance of the dwelling as necessarily the site for biographical accomplishment.

6. 3. 1 *The dwelling as a biographical accomplishment* “...the only way to get me out of here would be in a box!”

A dominant theme throughout many of the interviews was that the dwelling was spoken of in affectionate terms. The sentiments of Katy: “I love my home”; Deirdre: “My home is super”; and Sissy: “I love my little flat”; typify this attachment. Indeed such was the extent of this fondness that for some a motivating force to get out of hospital was simply just to be back in the dwelling (Mick, Jimmy and Carrie).

One explanation for this lies in comprehending the dwelling as a ‘psychic warehouse’ where experiences are continually formed and deposited (Gurney, 1996:69). The way in which the dwelling embodies past memories, experiences and emotions was a premise that became clearly relevant to explaining the experiences of a number of participants in this research. Of particular importance to many participants was that the dwelling contained the memories of family life. The dwelling was the place where the children grew up (Alison); the place where family would come to in times of celebration (John, Alison, Sissy, Harry, Valerie) the place where offspring would return to in times of difficulty (Sissy, Valerie), the place to be surrounded by family (Finn, John, Deirdre, Sharon, Harry, Colette, Melissa) and the place that was once shared with now deceased loved ones (Carrie, Alison, Melissa and Valerie). What became undeniably apparent was that the dwelling stored a whole wealth of memories, and had become a biographical accomplishment. Such was the importance of the dwelling as a psychic warehouse, it prevented Carrie, John, Alison, Melissa and Valerie from even considering a move. Melissa’s reaction exemplifies the responses here:

Interviewer: “Are you thinking about moving then?”

Melissa: “Oh no, I don’t think we would ever sell the house”

Interviewer: “Oh really, why’s that?”

Melissa: “Well there are just so many memories in this place ... I mean, well, we have all lived here at one point, including mum and dad.”

In becoming a place for close relationships and a centre of activities, it became obvious that positive attachments to the dwelling had come into being. Moving and consequently leaving behind memories was just not an option. For Carrie and Alison moving would have been a far easier option than the comprehensive series of

adaptations that became necessary. Despite the problems associated with adaptations and the adaptation process (as noted in Chapter 2), this for Carrie and Alison was all worth it to stay in the dwelling that was so infused with memories. It was not a question of aesthetics or the material structure, but rather about the dwelling being a container for their biography. Indeed Carrie indicated that she would rather have the whole place completely adapted than ever have to leave it, and more evocatively noted that “I think the only way to get me out of here would be in a box!”.

In becoming a biographical accomplishment, the memories contained within the dwelling appeared to help it become a source of ontological security. This became clear in Colette’s account:

Colette: “For me my home is all about breaking free of my first husband and to independence. I was so desperate to get out of there [previous dwelling with first husband], so the thing about the house is that it is new so it is free from other people’s vibes if you like. I wanted to be somewhere which wasn’t influenced at all by my first husband and just wanted to make a fresh start of it all. Um and although it is a rabbit hutch and is cluttered never the less it is my rubbish, it’s my hutch... I really do feel happy and at home here.”

For Colette the dwelling clearly became more than bricks and mortar. It became a place that through emotional attachment became one to offer security, a place from which to start a new life, a place to escape past memories and a place from which it was possible to create – and store - new experiences and (positive) memories. It wasn’t about size or whether it was appropriately designed but rather about being ‘home’ - being a space to feel secure, in control, confident, part of a family unit and loved.

Colette’s account also raises a further line of enquiry: the dwelling as an expression of self. If she wanted it to be cluttered, she could. Echoing the work of Cooper Marcus (1995), the way in which the dwelling became a reflection of ideas and values, an expression of the way in which individuals felt, was evident in a number of cases. The highly personalised meaning of the decoration (Jimmy, Carrie, John, Alison, Sissy, Sharon and Colette), photos (Katy, Sissy, Harry and Valerie), trinkets and bric-a-brac (Katy, Jodie, Mick, Sissy, Deirdre, Sharon, Harry and Valerie) and the garden

(Jodie, Louise, Alison, Deirdre and John) all became an integral part of an individual's feelings about the dwelling.

As discussed in Chapter 4 items of furniture can also take on specific meaning and importance. Carrie, John, Melissa, Sissy, Sharon, Harry and Valerie all identified particular items of furniture in the dwelling as containing special memories, ones that reflected their ideals. The table was one item that held particularly evocative memories. From crowding around it for Christmas festivities (Alison and Valerie), to the simple act of eating at it everyday (Melissa) the table became a focal point of the dwelling, a place that individuals had made an attachment to. In being a space that contained valuable memories and had become a reflection of one's own ideas and values, the dwelling, for many participants, appeared to hold positive meanings, offering psychological benefits in spite of other problems.

Such was the sense of attachment to the dwelling, and in particular, of it as a reflection of ideas and values, that for four participants - Jodie, John, Deirdre and Harry – adapting it was simply beyond the question. As John explains:

John: "Oh, the home is very important to me, it's the only thing I have got really. I mean, yes we are very pleased with our house, it very much is a home. What I was saying earlier, there are things I will put up with rather than wreck the house, it is more important to me to have a home than to have a house that is a machine to live in."

This quote from John highlights the importance of the dwelling as a home space – a space that contains memories and is a place for the whole family. For John it was more important to him that the dwelling should maintain its character and remain "homely" for all the family than it was to adapt it so that it would become more accessible to him. John did not want the dwelling just to become a 'functional space'. Indeed such was the extent of this feeling of attachment that despite being confined to a wheelchair John refused to have a stair lift or elevator installed in the dwelling, preferring to be confined to one floor of the dwelling. This response to the problem of design was not atypical. Jodie, an ME sufferer indicated that some days she would be so weak she could not manage to climb the stairs. Rather than adapting the property or moving elsewhere, she would be content just to stay on one floor of the

dwelling. Deirdre also indicated that whilst “upstairs is out of bounds” - leaving her confined to the ground floor - she hated the thought of the dwelling being adapted as it was not just a space for her, but rather for the whole family unit. Despite being confined to two rooms, Deirdre indicated she “just love living here so much” that she would never want to have any adaptations done to the property, or even consider moving.

John’s fear of turning the dwelling into a hospital was also echoed by Jodie and Harry. Despite not being able to access and use certain areas of the dwelling, Harry had not had it adapted in any way. He liked it “just the way it was” and suggested they did not want to turn it into a hospital; that was not what a home was about. Jodie hated the thought of having to adapt her dwelling indicating that she was terrified of it turning into a hospital ward. Whilst at certain times she needed aids to move around the dwelling, Jodie opted for a more unconventional approach:

Jodie: “At the top of the stairs is an ironing board, I use it as something to grab on to and balance on ... I think that it still looks homely and doesn’t look like my home has been adapted. ”

By using the ironing board as a grab rail Jodie had avoided having to adapt her home, and was able to maintain its “homely feel”. These examples reveal a great deal about the way in which the dwelling comes to be a reflection of ideas and values. By avoiding adapting the property, participants had managed to maintain a sense of ‘home’ in the dwelling; they had kept the dwelling how they wanted it to be seen and preserved the memories contained inside. The importance of the dwelling as a reflection of ideas and values is revealed in the refusal to adapt or change the property in any respect.

In the range of experiences presented above, we see the dwelling as embodying and reflecting an individual’s biography. It was a space that participants indicated they could control, a space they could modify and adapt or a space to hold unchanged as they chose. The dwelling became more than a shell; it became a biographical accomplishment with emotional significance. In this way, the dwelling held a positive value. However whilst many participants were keen to express their affection towards the way in which their dwelling was a reflection of their ideas and a container

of their most cherished memories, such a position did not command universal agreement.

6. 3. 2 Questioning the dwelling as a source of ontological security

Not all participants spoke so joyfully about their dwelling in the way that Carrie, Alison and John did. As well as holding positive emotional attachments, it was clear from the interviews that negative emotions also had a significant impact on the meaning of the dwelling. To discuss the descriptions from participants on this issue, section 6. 3. 2 will be divided into four parts exploring: concerns arising from inaccessible housing design; challenges to biographical accomplishment from the installation of adaptations; issues arising from community care policies; and descriptions of the dwelling as a space of confinement and isolation.

6. 3. 2. 1 The implications of inadequate housing design

The inadequacies of housing design for disabled individuals were discussed at length in Chapter 2. Here it was noted that this inadequate design enforces dependency. Building on this argument, as noted in Chapter 4, the case has also been made that inadequate housing design is also at odds with conceptions of the dwelling as a place of privacy, security and control (Imrie, 2004a:746, 2006a).

The findings from this research support the wealth of literature on inadequate housing design for disabled individuals. Indeed Mick's description that after his stroke much of his dwelling literally became a "no go area" succinctly encapsulates the problems of design. Moreover, concurring with the work of Imrie, the testimonies of the nineteen participants reveal the way in which inadequate housing design comes to challenge the meanings attributed to the dwelling by authors such as Despres (1991).

A recurrent theme in the interviews was the *dependency* that inadequate design caused. One way in which this dependency manifested itself, one also highlighted by Heywood, was the difficulties design posed to cleaning and maintenance of the dwelling and the need to rely on other people (Heywood, 2004a; see Chapter 2). The height of light sockets made it impossible to change bulbs, the height and location of plug sockets made it almost impossible to plug in appliances such as vacuum cleaners and irons, steps to doors made it impossible to enter certain rooms and the colours of

work surfaces made it difficult to see if they were dirty. As Heywood notes such design problems ‘rob’ disabled individuals of their sense of control and self-respect (2004a:718). It can also be argued that such design inadequacies present a barrier to an individual’s independence and prevent the dwelling becoming a reflection of one’s own ideas and values. For example, a number of participants noted that the height of light bulbs meant they had to ask someone else to change the bulb when it blew, thus limiting their ability to live independently.

The loss of independence and control through inadequate design became compellingly revealed in a number of instances in the difficulty of getting into the garden (Louise, Jodie, Alison, and Deirdre). Work on the meaning of the home has by and large neglected the role of the garden in creating meaning. However as Bhatti and Church have previously noted the garden carries a great deal of significance, importance and meaning (2004). The reason for the neglect largely lies in the definition of home that focuses on emotions within the property and consequently excludes the curtilage. By seeking to explore the meaning of the *dwelling* – which as noted in Chapter 1 comprises of the home and the house (including curtilage)- rather than just the *home*, the need to understand attachments to all areas of the property including the garden becomes implicit.

Steps, heavy doors, lack of turning space and even fear of being seen outside prevented individuals from (independently) using and controlling a much loved area of the dwelling. As Deirdre noted:

Deirdre: “I go out but I find it hard to get in again and, um, I suffer if it is too hot, so I am a nuisance, I am always asking to be let out like a dog! [laughs]”

Deirdre’s comparison to that of an animal powerfully reveals the problems created by inadequate design and clearly challenges meanings such as control that have previously been ascribed to the dwelling.

Like the garden, the bathroom can also become a space where independence, control and privacy can be lost because of inadequate design (as previously noted by Twigg, 2000; Imrie, 2004a; see Chapter 4). This problem was demonstrated by a number of

participants (Louise, Alison, Melissa, Mick), none more forcefully than Mick. As noted above, after a stroke left Mick in a wheelchair, using the bathroom became a difficult and embarrassing “battle”. For example, because the door to the bathroom would not close with a wheelchair in it, Mick recalled instances when his teenage children would come in. In addition to raising questions about the home as a site of privacy and control such a situation also highlights the difficulty of trying to maintain dignity – something that is usually taken for granted in the dwelling. Given the range of issues noted here, it becomes clear that inadequate design can present a significant challenge to the dwelling becoming a source of ontological security and subsequently has a negative impact on the overall meaning of the dwelling.

6. 3. 2. 2 *“it’s all very . . . convenient”: challenges to biographical accomplishment*

The way in which inadequate design forces many individuals to reassess their dwelling after the onset of disability was a theme explored by Imrie (2004a) and highlighted in Chapter 4. Imrie observed that individuals create ‘useable spaces’ by installing adaptations, ‘clearing up the clutter’ or literally chucking everything out (2004a:756, 759). However, what is not explored here or elsewhere is the impact that clearing the clutter can have.

For Jimmy, the loss of balance following a brain haemorrhage forced him to “get rid of” smaller items of furniture that could cause him harm should he fall into them. Furthermore it was also necessary for him take down all the pictures and photographs that were either hanging on the wall or resting on items of furniture to ensure that they were not knocked off. Removing such items clearly had a significant impact. During the ‘tour’ of the dwelling Jimmy showed me all of the photos that once adorned his walls. They were just lying in a heap, still in their frames, in a big pile in a corner of bedroom. Clearly these items were more than just ‘clutter’. They were infused with personal meaning and attachment. Indeed by keeping them it is possible that not only was Jimmy not prepared to ‘let go’ of such ‘clutter’ but also that there may be some hope that these photos will once again be able to decorate his walls. It can be argued that the furniture, photos and pictures were all props in Jimmy’s creation of the dwelling as a biographical accomplishment. In losing such ‘props’, Jimmy lost an integral element of his personal expression, something that consequently had a negative effect on the meaning he attached to the dwelling.

Alongside losing items in the dwelling, forced changes to the dwelling also became a source of much unhappiness. For Jodie the progressive effects of ME meant that over time it was necessary to change a number of things in her dwelling. This included the décor as certain colours would over-stimulate her. Accordingly, the room was painted a deep burgundy colour. Patterns also had to be removed throughout the house as they became too much of a stimulant. Thus rather than controlling her decoration, it was imposed upon her by her physiology. The progressive nature of her ME meant that Jodie was losing control over her body and as a result her dwelling. Rather than reflecting her ideas and values, to a certain extent the dwelling just came to reflect her needs.

Forced changes in the form of adaptations to the dwelling also became a clear source of resentment and negative emotions; none more so than for Louise. For Louise no longer was the dwelling a reflection of her ideas and values, but rather the adaptations had become a challenge to biographical accomplishment.

Louise: “There is a lift over there; see by the window, and if you look up you see a hole in the ceiling and that is where the lift goes up into my bedroom. And there are hoists up there and as you can see all along here in the lounge to move me around. I guess you could say that it’s all very . . . (pause) convenient. (long pause)”

Presented textually, the quote above fails to demonstrate the extent of Louise’s dissatisfaction. Louise sought more than just convenience from her dwelling. Echoing the work of Heywood (2004a, 2004b, 2005) and Taam (1999) discussed in Chapter 4, it becomes apparent from Louise’s account that there is a need to recognise the psychological effect of adaptations and changes to the interior design of the home. Drawing on the work of Cooper Marcus it becomes important to appreciate the way in which for Louise the dwelling no longer reflected her ideas and values but rather came to reflect what she can and cannot do. The clear resentment of having the ‘convenient’ adaptations inserted throughout her dwelling raises issues about the way in which adaptations can have a negative impact on the biographical accomplishment of the setting. Indeed Louise said that with hoists in many rooms, a specially adapted bathroom and a hospital bed her dwelling was “more like a hospital”. This sentiment supports the work of Madigan and Milner (1999), Taam, (1999) and Heywood (2005)

presented in Chapter 4, who asserted the need to recognise the way the way in which adaptations can appear institutional rather than 'homely'. In Louise's experience this institutional appearance and with it, the loss of reflection of the dwelling as a reflection of ideas and values, had a significant influence on the meaning she attributed to her dwelling.

Whilst adaptations are clearly visible, elsewhere Gurney has noted the way in which corporeal dirt is 'organised' and kept out of sight in the embodied home (2000a). Building on the arguments made here by Gurney, what needs to be recognised is the impact of having to accept that 'corporeal dirt' and associated functional items will be 'on display' in the dwelling.

This issue became immediately apparent when interviewing Louise. Louise made clear that she "hated" the additional objects placed around the dwelling that were demanded by her bodily needs:

Louise: "I am in pain twenty-four hours a day and hidden away in there [points to cupboard under the stairs] I think I have got enough drugs to keep everyone in [area in South Wales] going! But that's all ok because it's all in there out of harms way, but it's the other things, they are ... well they are embarrassing aren't they?"

Whilst some items could be "hidden" away in a cupboard, bodily requirements meant that it was necessary to have additional objects such as machines to assist with breathing and bladder "on show" around the dwelling. It was the 'untidiness' of her body and the consequent need to have these additional items around the dwelling that became the cause of significant concern for Louise, with the dwelling consequently coming to reflect not her personal identity but her limitations.

Something that also became apparent from the interviews was that for a number of participants particular spaces within the dwelling evoked particular negative memories. From falls in the lounge (Sissy) and bathroom (Steven) to concerns over the capacity to ensure the cleanliness of the kitchen (Sharon, Valerie and Carrie), and from spaces in bedrooms that were once shared with now departed loved ones (Carrie, Alison, Melissa and Valerie) to spaces that evoked feelings of loneliness (Sam, Jodie), the way in which particular spaces - and the memories they embodied - added to or

potentially conflicted with the overall meaning about the dwelling was evident. However, it was the testimony of Jimmy that highlighted the way in which specific spaces within the dwelling could embody markedly distressing memories.

Two spaces in the dwelling constantly reminded Jimmy of events he would rather forget. The first space was his bedroom. It was in his bedroom where Jimmy had a brain haemorrhage. In Jimmy's own words, there was so much blood that "the bedroom looked like a battlefield". Despite extensive professional cleaning to tidy the room, such was the emotions tied to the space that after a while Jimmy felt that the only way he could "move on" was to actually burn the carpet, bed linen and even the bed. Jimmy indicated that despite watching this and the fact that the room had now completely altered with all items of furniture in a different position, whenever he enters the bedroom he always remembers "that night" (see Miller, 2001 for further work on 'haunting' memories). The second space was the lounge. Or more specifically one end of the lounge. For it was in this space that following a stream of abusive phone calls from his manager at work that Jimmy contemplated suicide:

Jimmy: "What went on has just been the worst ever. I was sitting where you are now and I was ready to top myself. I wanted to, believe me. If I could've I would've"

As the area evokes memories of this low point in Jimmy's life, to avoid confronting these memories Jimmy now no longer goes in that end of the lounge. Indeed, by re-positioning the television, he now no longer has to even look in that direction. It would be unambiguous to suggest that the memories of events that occurred in the dwelling such as these highlighted by Jimmy would have a negative impact on the meaning of the dwelling. Jimmy's evidence highlights the way in which for many individuals the memories that particular spaces evoke run counter to the notion that the dwelling is a site that offers psychological benefits. Indeed quite the reverse is the case. Such unique and individualised memories of spaces within the dwelling must be recognised as at the very least questioning the way in which the dwelling is assumed to be a site of ontological security and a mirror of an individual's ideas and values.

6. 3. 2. 3 The impact of community care policies

As noted in Chapter 2, inadequate design of housing can present a challenge to successful performance of certain activities and consequently has led to many disabled individuals being forced to rely on 'care' in order to live 'independently'.

All eight participants who received care via social services indicated that the uncertainty over who would come through the front door to 'administer care' from day-to-day that was a significant concern. Not knowing who would come into the dwelling came to be seen as an intrusion of an individual's privacy and demonstrates the way in which community care has come to be seen as 'institutionalisation within the community' (Morris, 1993:179; see Chapter 2). In one case the care workers were actually called "intruders" (Louise). With social service departments deciding on care workers, individuals lose control over who enters their dwelling. Consequently, the dwelling no longer becomes a place of control, no longer a place to avoid intrusions and no longer a place of privacy. This lack of control over who enters the dwelling - and its associated loss of privacy - challenges previous understandings of the meaning of the dwelling.

Alongside a loss of privacy, with unknown carers entering the dwelling security was inevitably compromised. In the work of Dovey (1985), Saunders and Williams (1988), Saunders (1990) and Despres (1991) noted in Chapter 4, the dwelling's function as a site of security was stressed. However as a number of feminist writers have noted (see Chapter 4) the dwelling can be a site of insecurity and even abuse. Whilst no participant made any claim that they had been abused by their carer, a number of participants noted how the thought of an unknown social services carer coming into the dwelling left them "on edge" and that they would begin to "dread them coming" (Carrie). These feelings of insecurity highlight the way in which individuals can feel unsafe in the dwelling.

It was not just the loss of control and security over who enters the dwelling but also the lack of respect from those who did enter that caused upset. Louise spoke of the negative experiences with social services' carers who treated her with very little thought for her dignity and treated her dwelling as if it were their own. For example Louise noted that there was a number of instances when the carer would invite her

friends round to Louise's dwelling whilst she was there working for Louise. Further, Martin pointed to signs that he was forced to put up on his wall asking carers not to use his phone for private calls after previous carers had run up a large phone bill.

Whilst previous research into disability and the dwelling has focussed on design issues affecting the meaning of the dwelling it becomes apparent that the relationships with carers that occur in the dwelling can also have a substantial impact. In losing control over when carers entered the dwelling and crucially who entered, participants also lost some of their privacy. In addition to having a significant impact on the meaning of the dwelling it can also be argued that in losing privacy and control over the dwelling it no longer became a source of ontological security.

As discussed in Chapter 2 the introduction of Community Care (Direct Payments) Act 1996 gave LAs the discretionary power to offer a *direct* payment to disabled adults assessed as needing community care services, giving individuals the opportunity to hire and fire their own staff. As numerous studies have noted (see Chapter 2), the action of hiring carers gives individuals a greater level of control. In the case of this research what became immediately apparent from those seven participants who received direct payments was that this meant they had control over who entered the house, and consequently could ensure that it would be the same people every time not a stranger in the dwelling every day. What also became important was the possibility to control *when* carers come into the dwelling:

Finn: "If you imagine you are in bed with your girlfriend, if your carer comes round and says "right you got to get up now" you would have to, that's how it used to be. Where as now I will say, well I've got people over so come round at this time, rather than the time they actually set for me. "

As this quote from Finn illustrates, the power and control obtained through employing carers can also foster an increased sense of privacy within the dwelling.

Of the seven participants on direct payments, five (Finn, Martin, Jodie, Louise and Alison) indicated that they had developed a 'close friendship' with their carer:

Martin: "Yeah, it was nice the other day, [carer] and her friend were bored at home and had nothing to do, so they came round here for an hour or two to play cards. You bond with your carers; you make friends out of it. "

Indeed, for Louise these friendships in the dwelling brought about a more respectful relationship than that experienced through social services:

Louise: "But it's the little things as well, lets say for example if I am struggling to do something, they will say do you need a hand, and I'll say 'no I am ok' and then ten minutes later I'll say 'oh [carers name] can you give us a hand'. I am grateful for the fact she gives me the dignity that she at least lets me try for myself. "

The enjoyable relationship that Louise had been able to develop with her carer facilitated an environment where she could feel not only in control but also confident. Jodie echoed these sentiments about the benefits of direct payments, arguing that the mutual understanding that developed from the close friendship with the carer allowed her to take more control over her home life. The power given by direct payment appeared to transform relationships in the dwelling, giving individuals an increased sense of control, privacy, respect, and self-esteem; all of which have come to be seen in the literature on the meaning of home as central to the dwelling becoming a source of ontological security.

This is not to say of course that direct payments are unproblematic and positive meanings are always created. As identified in Chapter 2, a number of problems still exist with the direct payments scheme, notably that of recruitment. Whilst at the time of the interview Louise expressed her deep satisfaction with the trusting relationship she had developed with her current carers, as noted above this had not always been the case. The extract from Louise on page 161 serves as a poignant reminder of the problems that still exist with the direct payments scheme. Currently, ensuring that a carer has been police checked through the criminal records bureau is the responsibility of the employer (the disabled individual receiving direct payments). However, obtaining police checks can be a lengthy and costly process and as a result many participants noted that they are choosing not to get them before they employ carers. This is putting individuals at risk. At risk in their own dwelling. Louise's description of previous carers says a lot about the way in which relationships in the home can make an individual feel unsafe, humiliated and abused. Indeed Louise said

that she used to dread certain carers coming round. The anxiety and fear of someone coming into the dwelling will once again have an impact on the meaning of the dwelling and inevitably challenge the home as haven hypothesis.

The issue of ‘outsiders’ entering the dwellings of disabled individuals did not stop at carers. Additional social service workers also appeared to be a cause for concern. Of primary concern were care workers - and in particular occupational therapists – whose role it was to assess the disabled individuals. Much has been written on the way in which the assessment process can be a stressful and disempowering process, leaving individuals at the mercy of care professionals (see Chapter 2). Concurring with such literature on the disempowering nature of this assessment process, Louise noted her experience of this process:

Louise: “Oh you wouldn’t believe, when [name of occupational therapist] was finally going to come round I was literally shaking, and I mean more than usual! I mean what if she thought that I didn’t need it [adapted bathroom]?”

In addition to a clear loss of control as well as privacy in the dwelling, what also becomes crucial to note is the anxiety brought about in anticipation of such workers coming to the dwelling. What has been missing from previous explanations on the assessment process is that this assessment happens in an individual’s dwelling. The disempowering assessment from professionals and the resulting anxiety occurs in and is about the dwelling. The loss of control, privacy and power all occur in the dwelling and inevitably impact upon the meaning of the dwelling for the individual. What this also marks is the importance of recognising that interactions, including working relationships, which occur in the dwelling can also have a significant bearing on the *meaning* attached to the dwelling.

Moreover, it also became clear that it was not just individuals who actually entered the dwelling that became a cause for concern. A number of participants voiced their unease about strangers who knocked at the door of the dwelling (Jimmy, Katy, Deirdre, Sharon, Valerie, Colette). The issue here was a fear over safety. For example, Sharon who was visually impaired noted that in being partially sighted she felt unsafe answering the door. Indeed she would not answer it unless a previous appointment had been made and she was expecting someone. This position was also

held by Valerie who too was visually impaired and by Colette who defined herself as being deaf. In fact, Colette noted that when she was in the dwelling alone she ensures that all doors and windows are locked as she was concerned that should someone enter she would not hear them. Further, Colette also held that if people she did not know knocked on the door she would “duck and hide” as answering “ could compromise your security”.

Once again, this feeling of insecurity in the dwelling runs counter to the work noted in Chapter 4 which stressed the way in which the dwelling provided security from the outside world. As noted above with reference to carers entering the dwelling, losing such security and feeling unsafe in the dwelling clearly represents a challenge to the dwelling as a source of ontological security. What is different here however is that it is the fear not that someone is coming but simply the fear that someone *might* come to the dwelling and prey on their vulnerable status. Consequently, the dwelling comes to offer very little protection from the outside world as has previously suggested by various authors (see Chapter 4).

This particular issue appeared to be heightened amongst the four participants living in supported housing. As noted above Sissy, Steven, Sam and Mick all unequivocally stated that the attention to detail in creating an accessible design was of great benefit to them in comparison to their previous dwelling. In becoming a space where they could move around and complete tasks independently a more positive meaning of the dwelling could be established. However there were still issues that threatened to undermine the positive impact of the inclusive design measures on the meaning of the dwelling. All four participants independently indicated that they thought there was a security problem, with people gaining access to the setting who should not have been. As Steven noted:

Steven: “You don’t actually have any control over who comes in; yeah into your room but not the building... they have had a few people here who they shouldn’t have. One who pretended he was a policeman. The police have been here once or twice and said don’t let people in unless you know who they are but people just buzz people in without checking first. ”

In addition to raising an interesting issue about what counts as a front door in the setting, Steven highlights the inability to control who enters the building. This lack of control led Sissy, Steven, Sam and Mick to independently voice their concerns about security, indicating that in not having control over who entered the building they did not always feel safe. What becomes important to recognise here is that the threshold has an important symbolic role to play. Without having direct control over this threshold, security was deemed to be compromised. As noted in Chapter 4 security and control were reasoned as being central attributes in the creation of the dwelling as a source of ontological security. However for Sissy, Steven, Sam and Mick this loss of control and security clearly lead to a questioning of the dwelling as a source of ontological security and in doing so had a very negative impact on the meaning of the dwelling.

Whilst the four participants living in the supported housing property may have felt a loss of control over who entered the building, all four individuals noted that the appropriate design of the setting helped to foster independence and avoid/limit the need to have carers in the dwelling. However whilst care was no longer required, for Sam, Mick and Steven the “institutional nature” of the setting meant that workers in the supported housing setting still intruded on their private space to ‘care’ for them (Mick).

Whilst interviewing Sam, one of the workers in the supported housing setting entered Sam’s flat - without knocking first - to empty Sam’s bin. Sam just shrugged his shoulders and said, “Well, that’s just normal ‘round here’”. For Mick however such intrusions were part of the “mental attitude” of the setting that he described as “stifflingly oppressive”. During the interview with Mick a worker entered (once again without knocking first) to change a light bulb. The worker then quizzed Mick whether he was taking showers before 7 am (something not permitted within the setting), clearly warning him that such actions were in breach of regulations and had been the subject of complaint by another resident. Mick returned to this incident later in the interview:

Mick: “Sorry, I am still rattling over [worker’s] careless remarks when he came in here. [name of housing association] think it is a school here with all the rules and regulations, I mean you are a guest and for [worker] to question me about goings on

in front of you, well I would never... (long pause). He is a nice guy and a marvellous carpenter, but he just doesn't think. ”

In Chapter 2, principally through the work of Goffman (1961), it was noted that within institutions constant surveillance and control effectively created a strict divide between staff and patients; with privacy, dignity and independence becoming difficult to establish and maintain. Whilst the supported housing setting was no where near as overtly oppressive as those depicted by Goffman, the testimonies of Mick, Sam and Steven revealed that power inequalities still existed within the setting, and consequently privacy and control was lost. Rather than being a space for relationships and activities in private, the dwelling was a space where you were monitored. Consequently the dwellings in the supported housing property can be seen as challenging the claim that the dwelling is a source of ontological security and questioning meanings such as privacy and control that have often been attributed to the dwelling. Moreover, as an indicator of personal status, for Mick in particular, the dwelling simply came to epitomise all that had been lost.

6. 3. 2. 4 Trapped and isolated: the dwelling as a prison

Compounding problems of care and housing design, the interviews revealed that many individuals felt trapped in their dwelling.

As noted in Chapter 1, inadequate design has led to disabled individuals facing a number of barriers in the built environment. The difficulties faced were a subject of wide spread agreement in this research. Uneven pavements, lack of lowered kerbs, inadequate road crossings, steps into and within buildings, narrow doorways and street furniture all became barriers to moving around the built environment for a number of participants (John, Martin, Jodie, Melissa, Finn, Sissy, Louise, Deirdre, Jimmy and Valerie). Furthermore a number of participants also noted that the lack of accessible (and affordable) hotel accommodation and poor public transport also prevented them from travelling, taking day trips or going on holidays (Martin, Carrie, John, Sissy, Louise). Such issues have been noted elsewhere, and consequently come as little surprise (Bury, 1982; Imrie, 2004b). Nevertheless, recognising these issues has important ramifications in terms of the meaning of the dwelling. Principally these issues lead to concerns over feeling trapped within the dwelling.

Despite wanting to leave the dwelling to visit friends, go shopping, go on holiday etc the deficient design of the environment left some individuals quite literally trapped in the dwelling. Rather than being a refuge to return to, as Sissy – a wheelchair user - made clear, the inaccessible external environment rendered the dwelling a space of confinement:

Sissy: “Well you have to understand that getting out and about is just not that easy. The pavements... in (area in South Wales) are so bad and bumpy that I just cannot get around. And don’t get me started on the public transport – I tried to get a bus and when I finally got on it I was rolling about all over the place! And the trains you would not believe. Getting in to Cardiff is OK but it’s getting back that the problem. You see they only have [wheelchair] access on one of the platforms, so I am alright going into Cardiff but I am stuck on the platform when I get back! ... So I just stay in mostly. ”

As Sissy herself notes, the consequence of the various barriers she faced meant that she would “stay in” the dwelling. The impact on such confinement was not lost on Mick, who said that because of the difficulties he faced negotiating the environment his dwelling “just proved to be a prison”. Trapped in the dwelling by disabling barriers in society a number of individuals indicated they felt they had become more isolated since the onset of disability (Martin, Jimmy, Jodie, Louise, John and Steven). Such sentiments clearly challenge any notion of the ‘home as haven’ presented in Chapter 4, and the feeling of being trapped in the dwelling because of design barriers in the wider environment appeared to have a significantly negative impact on the meaning of the dwelling.

In addition to feeling trapped in the dwelling something that was also noted was the way in which design barriers *within* the dwelling left individuals feeling trapped in particular rooms/spaces within the dwelling. The way in which design left individuals trapped inside or out in the garden was noted above. However inadequate door widths, steps/stairs, uneven floors and floor space also all meant that a number of individuals were confined to set areas in the dwelling (Finn, John, Alison, Louise, Melissa, Deirdre and Harry). Whilst some participants did not see these restrictions as an issue, for Finn this was tantamount to “a loss of freedom”. Losing the freedom to move freely around the dwelling runs counter to claims of the dwelling as a place of

independence and space to act autonomously. Indeed in having movement restricted once again the dwelling comes to have much in common with a prison.

As noted in Chapter 1, in addition to design barriers, many disabled individuals also face attitudinal barriers in the wider environment. For one participant, Jimmy, these attitudinal barriers led to him feeling “trapped” in the dwelling. Jimmy described how whenever he went out people “gawped and stared” at him, how he was not let into the pubs he used to go to because the brain haemorrhage had left him “with a stagger and looking like drunk”. Further, when he applied for promotion in work his application had “No time wasters please!” hand written at the top with tasks that the employers knew he could not do highlighted. However, what affected Jimmy most was the bullying he got from colleagues and managers at work:

Jimmy: “I was suicidal, I was petrified to open the door, I just wanted to be left alone, the fear was unbelievable. ... I wasn’t sleeping, I wasn’t eating, I was frightened to go out, it was like I had agoraphobia.”

As the quote above shows, the bullying and discrimination he faced because of his disability left him so frightened that he dare not leave the dwelling. Jimmy went on to note how following the constant abuse and discrimination he faced he became more and more reluctant to leave the dwelling, leaving him isolated from the rest of the world. As a result, like Mick, Jimmy also came to describe how his dwelling had effectively become his “prison”. Indeed such was the feeling of being trapped in the dwelling for Jimmy that he resorted to “regularly sleeping in the car” just to try and escape. This feeling of being trapped and needing to escape appeared to have a significant impact on the meaning of the dwelling, conflicting with the notion of the ‘home as haven’.

The need to recognise the disabling impact of impairments alongside design and attitudinal barriers was discussed in detail in Chapter 4. Acknowledging the impact of such effects had important implications for this research. One aspect of this concerned appreciating the way in which impairment effects could leave individuals feeling trapped in their dwelling.

For John the “ton of stuff” that was needed to support his physiological demands prevented him from going on breaks away. The consequent planning involved just “took away all the fun of being somewhere” and therefore he and his wife now rarely had breaks away from the dwelling. Whilst John felt that at times his physiology constrained his ability to leave the dwelling, Jodie asserted that because of her physiological restrictions she quite literally felt trapped inside the dwelling. Experiencing the effects of severe ME, Jodie indicated that over stimulation from the sun forced her to stay inside:

Jodie: “I love to go outside, but I am being imprisoned. I am an outdoor person but the trouble is sometimes even when I do have sunglasses on the sun is just too much stimulant.”

The use of the word ‘imprisoned’ to describe how she feels in her dwelling because of her physiology serves as a reminder of the way in which physiology can influence the meaning of the dwelling. The dwelling no longer becomes a refuge but instead a prison. Indeed Jodie noted that in being ‘imprisoned’ in the dwelling she felt as if she was becoming isolated, having less and less to talk to her friends about. What is important to recognise is that the reason for feeling trapped and isolated in this case is not because of an inaccessible built environment but rather a physiological issue that dictates the ability to engage with the natural environment.

Whilst Jodie noted that in the summer time she often felt ‘trapped’ inside, she indicated that it was actually during the spring and summer periods when she felt at her best, with winter periods being the most detrimental to her health. During the interviews Jodie described how during her ‘low’ periods she often did not have the energy to even get out of bed, leaving her confined not just to the dwelling but one room within the dwelling; the bedroom. These episodic periods of feeling trapped in one room was a theme touched upon by a number of other participants. Alison noted there were days when she would be feeling so ill that even with the help of her carers she just did not have the energy to get out of bed, Steven explained the way in which he felt trapped inside during the winter months because he was in “agony” with his arthritis and Louise emotionally expressed that the pain she was in some days was so “brutal” that she “just could not get out of bed” and that most days the pain was such that she could only be out of bed for a few hours. As well as adding support to this

literature that argues for the need to recognise the reality of pain and other episodic concerns (see Chapter 4), from the statements of these participants what also becomes important to recognise is the real affect these episodic issues have and acknowledge the resulting impact they can have on the meaning of the dwelling.

For Jodie, Steven, Alison and Louise the temporal effects of physiological issues had a significantly negative impact on the meaning of the dwelling. All four participants independently used the word ‘trapped’ to describe how they felt in the particular spaces within the dwelling at such times. Whilst for Alison it was only the room in which she was confined to – the bedroom – that developed negative meanings (adding support to the work of Cooper-Marcus, 1995 and Gurney, 1996, 2000a highlighted in Chapter 4 that certain rooms/spaces can have particular meanings), for the other three participants it became apparent that this feeling of being trapped in one room contributed to a very negative association with the dwelling as a whole. This became clearly evident in the interview with Louise:

Louise: “Well you see when it kicks in (the pain) it really is like I am a prisoner in this place. I mean, there I am just lying in bed waiting for the next day. (pause). It is, it is like a prison sentence, but only one where you have it in your own home.”

In being confined or ‘trapped in’ the bedroom the effect of these occasions evidently had an impact on the wider meaning of the dwelling for Louise. The negative feelings connected with the bedroom simply came to embody those associated with the dwelling as a whole. Whether the affect of being trapped in a particular room/space embodies wider feelings about the dwelling or not, what has to be recognised is that the feeling of being trapped because of an episodic physiological matter can have a considerable impact on the meaning of the dwelling. Indeed it has to be understood as once again challenging characteristics previously associated with the meaning of the dwelling, ones that were developed with an able-bodied bias.

6. 3. 3 Being ‘an outside person’: questioning the biographical accomplishment hypothesis

The data presented in 6.3.2 clearly represent a challenge to the dwelling as a site of biographical accomplishment. However what also became apparent was that whether

such challenges were presented or not, some individuals simply did not seek for their dwelling to become a reflection of their ideas and values.

Three participants – Jodie, Sam and Katy - independently described themselves straightforwardly as being ‘an outside person’. For these three participants it was not a case of having negative associations with their dwelling or not, just that they saw their dwellings as nothing more than a physical building. Or as Sam described, “a crash pad”. As such, they simply did not seek to attach any major significance or hope for a reflection of ideas from their dwelling.

Being able to live independently in her own flat by herself was of crucial importance to Katy. She indicated that the very thought of not having it made her upset.

However, whilst Katy loved her home, of over-riding importance was that living independently meant that she could meet up with her friends; be it to go to pubs, shops, clubs or college. That is that whilst she had a flat and loved it, her dwelling was just a comfortable place to rest. Despite living in the dwelling for sixteen years, for Katy all her emotional attachments were tied to places outside the dwelling.

Similarly for Sam the dwelling was not a place that he sought in any way to become a reflection of his identity. There were no pictures on the walls (aside from a poster of a page 3 model that his friends had insisted that he put up to make it “more homely”) and in the three and a half years he had lived there Sam had made no changes to the decoration. When questioned on this Sam said that he had “never understood” why people treasured inanimate objects or kept items for memories sake. He had also recently been given the opportunity to change the decoration but was said he was “happy with it as it is”. Rather than being in the dwelling, Sam enjoyed being with his friends, either at the rugby ground, at the pub or at Church. Even the supermarket store ‘Tesco’ came to hold more treasured memories, with Sam recalling a number of accounts of “friends” he had made whilst shopping there. Sam was a very sociable person and liked to be “out and about”. The dwelling was fully accessible and this was all that Sam wanted from it.

Finally, Jodie indicated that she had a ‘special connection with the sea’ and the coastal areas in general, over and above any connections she could ever make with

her dwelling. Given the range of negative events that Jodie faced in the dwelling (see preceding findings) it could easily be suggested that such events have *forced* her to look outside the dwelling for spaces to seek attachments. However this would be inaccurate. Jodie's fascination and attachment with the sea began as a young child – before the onset of ME. For Jodie it was the coast that she was attached to, with the beach embodying her memories and biography. As such living by the sea was of utmost importance, rather than attempting to create the dwelling as a site of 'biographical accomplishment'.

Of critical importance here is recognising that not all individuals want their dwelling to become a biographical accomplishment. There has been an assumption that all individuals *want* and even *need* to do this. Such a position, it can be argued, is at best a simplification, casting individuals simply as dopes and neglecting to recognise the differences that exist between people. The findings presented here indicate that the unquestioning acceptance of the biographical accomplishment hypothesis needs to be challenged.

6. 4 Embodied life histories: understanding the temporal dimension to the meaning of the dwelling

A crucial dimension has been missing from all the material presented so far in this chapter: time. As noted in Chapter 5, this research sought to understand the life histories of the nineteen participants. Consequently, it is necessary to recognise that the meaning of the dwelling carries a temporal dimension and can change over time. This section will explore such changes. To do so the section will be broken in to two parts. The first will explore whether the meaning of the dwelling is affected by length of residency. The second part will explore how meanings can change over time seeking to contextualise events such as the onset of disability.

6. 4. 1 "Developing" an attachment: the influence of time on the meaning of the dwelling

Previous literature has highlighted the way in which the length of residency affects attachment to the dwelling, with attachments increasing with time spent living in the dwelling (Gurney and Means, 1993; Heywood, Oldman and Means, 2002). Broadly, this temporal hypothesis was borne out in this research, with those having lived in

their dwelling for a significant period displaying a strong emotional attachment to their dwelling (Carrie, John, Katy, Alison, Harry, Valerie and Colette), whilst those who had lived in their dwelling for a shorter period of time (five years or less) were less likely to see their dwelling as a biographical accomplishment and viewed it in a less favourable or indifferent fashion (Finn, Sam, Martin, Jodie, Steven and Mick).

Of principal importance here was exploring an individual's life history and understanding the way in which the dwelling had become a biographical accomplishment over *time*. As noted above, for a number of participants the dwelling had come to embody certain emotions and memories, becoming a 'psychic warehouse' of events. In contrast a number of participants who had recently moved into their dwelling indicated they had little by the way of memories in the dwelling to draw on. For example when Steven was asked whether he felt any attachment to his dwelling he responded that as he had only lived there a couple of months and had not had the time to "develop" any lasting memories or attachments. Accordingly the dwelling was yet to become a biographical accomplishment, something that had a significant impact on the meaning of the dwelling for Stephen.

However whilst this account can help to explain differences in meaning and why some participants had strong attachments and others did not, to assume that length of residency determines feelings about the dwelling is simply inadequate. As noted above, Jimmy and Louise had both lived in their dwelling for a significant period yet they both had a very negative meanings associated with their dwelling. Conversely, Deirdre had only lived in her dwelling for a couple of years but had developed a very strong emotional attachment. Whilst significant, what has to be recognised is that there is no deterministic cause and effect relationship between length of residency and any emotional attachment to the dwelling.

6. 4. 2 Ever changing meanings: the importance of a temporal dimension

One reason why length of residency does not deterministically dictate attachment to the dwelling is that rather than simply time spent in a dwelling what is important is the events that occur during this time.

In a now widely rehearsed argument, Bury contended that the onset of disability can bring about 'biographical disruption' (1982). Whilst Bury's work has come under fierce criticism (see in particular Williams, 2003a) his arguments have much to offer understanding the way in which the meaning of the dwelling can change.

The dwelling embodies how the onset of disability can become a biographically disruptive event. As noted from the testimonies of the nineteen participants above, the onset of disability can lead to a loss of control, independence and privacy in the dwelling; force the need for adaptations/ modifications to the dwelling; initiate a need to allow care services into the dwelling and even compel an individual to move out of a dwelling all together. All of which, it can be argued, reinforce the biographical disruption caused by the onset of disability.

Given that the dwelling is a site of biographical accomplishment, this biographical disruption will have a significant impact on the meaning of the dwelling. As shown in the case of Jimmy having to take pictures and photos down, this biographical disruption can even challenge the dwelling as a site of biographical accomplishment. Rather than being a site of security refuge and privacy it changes, becoming one that highlights what can no longer be achieved, reinforcing bodily changes. In some cases rather than being the much loved haven to return to it becoming a much despised prison. In recognising this it becomes possible to explain the way in which an occurrence such as the onset of disability can have a significant affect on the meaning of the dwelling.

In addition to biographically disruptive events it also became apparent that episodic issues arising from impairment effects also affected the meaning of the dwelling. Indeed for Jodie and Steven the change in the meaning of the dwelling was quite literally seasonal. For Stephen his arthritis was so "bad" in the winter that he was could not leave the dwelling, leaving him trapped inside, and similarly for Jodie the effects of ME in the winter were such that she could often not get out of bed, once again leaving her confined to one space in the dwelling. Sharon also indicated that the pain she experienced during winter months often prevented her from cleaning the house (thus questioning the dwelling as a site of control and a reflection of values). What becomes important is to recognise that these physiological effects are temporal

rather than enduring, and in doing so recognise that any resulting shift in the meaning associated with the dwelling is only temporal. The 'temporal dimension' of the meaning of the dwelling will be explored in greater detail in Chapter 7.

6. 5 Coding the data

As noted in Chapter 5, the first stage of the DREI analysis scheme involves both describing the research findings and coding the surface events.

The findings described over the course of this chapter can broadly be coded as 7 events which impacted on the meaning of the dwelling. These are:

- impairment effects
- the inaccessible environment,
- inadequate housing design (and the resulting need for adaptations),
- discrimination,
- 'care' dynamics ,
- emotional attachment to the dwelling,
- relationship with co-habitants.

These seven events were coded and discovered inductively through amassing instances of their existence from the sixty hours of interview data gathered from the nineteen participants. Whilst a number of these events have previously been documented in the literature as having an impact on the lives of disabled individuals, it was only after conducting the interviews, analysing the data and coding it into themes that it became apparent that from the experiences presented by the participants that these events really did have an impact on the meaning of the dwelling for those interviewed. What is crucial to note here is that these seven **events were not imposed *a priori*** but rather derived directly from the evidence and experiences of the nineteen participants.

Proposing that seven events impact on the meaning of the dwelling adds to the existing literature that highlights the impact of inadequate design on the meaning of the dwelling. Acknowledging that there may be more than one event at play highlights the complexity involved in the meaning of the dwelling.

These seven coded events need explaining. As explored in Chapter 4 the term 'impairment effects' refers to the 'restrictions of activity which are associated with being impaired but which are not disabilities in the social relational sense' (Thomas, 1999:43). In other words impairment effects describe events such as episodic issues, bodily demands and constraints that are the result of a particular impairment. As was made clear above the event of 'impairment effects' can have a serious negative impact on the meaning of the dwelling. Alongside presenting a challenge to the creation of the dwelling as a biographical accomplishment (Louise, Jodie, Jimmy), impairment effects also turned the dwelling into a site of insecurity (Valerie, Sharon and Colette) and even a prison (Louise, Jodie, Steven, Alison).

The inaccessible environment refers to a range of design barriers in the built environment. As noted above, the inaccessible environment left a number of participants feeling trapped or isolated in their dwelling (Sissy, Martin, Jimmy, Jodie, Louise, John and Steve). Accordingly, this event had a negative impact on the meaning of the dwelling.

Inadequate housing refers to the difficulties posed by design. Drawing on the testimonies from all participants it appears that inadequate housing design is at odds with conceptions of the home as a place of privacy, security and control and also had a negative impact on the meaning of the dwelling.

As noted in Chapter 1, as well as design barriers many disabled individuals also face attitudinal barriers. Jimmy's experience of such barriers was presented in detail above. The term to 'discrimination' is used to describe these attitudinal barriers. Drawing on the data from the interview with Jimmy it became evident that the event of 'discrimination' seemed to have a negative impact on the meaning of the dwelling, leaving individuals feeling 'trapped' inside it.

The event of 'care' dynamics is a slightly more complex affair. It refers to the policies and systems in place - including the assessment process - to 'care' for disabled individuals and the power relationships that accompany it. Individuals living

in supported housing noted how they were constantly being 'cared for'. For Mick and Sam being cared for amounted to an invasion of their privacy and a loss of control over their dwelling. Additionally, the testimonies of participants who had received community care services revealed that care dynamics had considerable impact on the meaning of the dwelling. Being 'cared for' left participants feeling they had lost both privacy and control over their dwelling. Furthermore carers often treated the individual's dwelling with plain disregard. However, what became immediately apparent from all seven participants who had changed from receiving community care packages to taking control of their care through the direct payments scheme was that the dynamics of care changed and had a positive impact on the meaning of the dwelling.

The event of 'emotional attachment to the dwelling' refers to any emotions and memories tied to the dwelling. Such feelings seemed to have a significant impact on the meaning of the dwelling. As documented above, for the majority of participants a strong degree of attachment to the dwelling had developed. Individuals formed emotional attachments to the dwelling, ascribing significance not only to particular items within the dwelling but also to the dwelling itself as a container of past memories and experiences of family life. Indeed such was the level of attachment to the dwelling that it stopped some individuals from moving out and prevented four participants even considering adapting their dwelling. However what has to be noted is that it would be a mistake to think that everyone will develop a strong attachment to his or her dwelling. For some participants there appeared to be very negative emotional attachments to the dwelling. By ascribing significance to the bad memories within the dwelling; from adaptations to accidents and from feeling segregated to contemplating suicide, individuals came to hate either areas of the dwelling or the dwelling as a whole. Furthermore, what was also noted was that three individuals – Jodie, Sam and Katy - simply chose not to attach any significance to the dwelling. Emotional attachments were made to areas outside the dwelling; for example to the sea or to local pubs. By choosing to make emotional connections to such areas over the dwelling it comes as little surprise for such individuals the dwelling did not become a site of biographical accomplishment and they only had a weak attachment to their dwelling.

The final event identified is relationship with co-habitants. This event refers to the bond individuals have with those they share their dwelling with – be they family or friends. A good relationship with those that share the dwelling space, such as that described by Finn, Jodie, Melissa, Sharon, Harry, Valerie, Colette and Deirdre appeared to have a very positive impact on the meaning of the dwelling. The simple fact that they enjoyed the company of those they shared the dwelling with came to be of great consequence. For Deirdre and Colette the positive relationship with their current co-habitants lay in stark contrast to the past. Both Deirdre and Colette had both moved out of a dwelling they shared with a partner whom they no longer got on with. The conflict of personalities led to tension and anxiety in the dwelling. This negative relationship had a damaging impact on the meaning of the dwelling and ultimately led to both individuals moving out of the dwelling, referring to it using disapproving nouns such as ‘cage’ etc.

From the data collected from the nineteen participants it appeared that it was these seven events that came to make up a *complex* meaning of the dwelling. However, this is only half of the story. Critical realist analysis looks to go beyond description and coding of surface level data and understand the underlying structures and mechanisms through retroductive analysis. This task will be the subject of Chapter 7.

6. 6 Conclusion

The data described and discussed in this chapter raises a number of challenges to widely accepted beliefs on the meaning of the dwelling. From the outset the chapter documented testimonies that contest the ‘home as haven’ hypothesis. Through recognising the impact of inadequate housing design, adaptations, design/additional barriers, impairment effects and community care policies, the dwelling was presented as a space where individuals felt trapped, isolated, powerless, dependent and unsafe without either privacy or control.

Echoing the previous claim by Imrie (2004a, 2006a), the testimonies of the nineteen participants in this chapter revealed that the onset of disability throws into question many previously held assumptions of the meaning of the dwelling. Where this chapter goes further however, is in filling the gaps that Imrie’s exploratory investigation left open. In addition to recognising the impact of inadequate design the

case has been made in this chapter for the need to acknowledge that challenges to the home as a source of ontological security can emerge from a variety of different sources for disabled individuals.

Nevertheless, what also became apparent was that the dwelling has to be understood as being a biographical accomplishment. Whilst the onset of disability - and with it the possible need for additional items/ adaptations - became a challenge to this achievement, for some participants despite a number of emerging issues the dwelling maintained its status as a 'psychic warehouse', embodying past memories and events. The dwelling was still 'home'. Grasping this lies in understanding an individual's biography. Descriptions from the life history interviews presented in this Chapter revealed the importance of recognising the temporal dimension of the meaning of the home and the way in which the experience 'developed' over time. What also became apparent was the way in which any meaning of the dwelling could change over time, shifting constantly between meanings.

In short what becomes evident is that the meaning of the dwelling is a *complex* experience. From the descriptions documented in this chapter it was suggested that in addition to inadequate housing design there are a further six events which impact on the meaning of the dwelling. These are: impairment effects, the inaccessible environment, 'care' dynamics, discrimination, emotional attachment to the dwelling and relationship with co-habitants.

The focus and purpose of this chapter was on describing the data collected. Consequently whilst this chapter identified how events can impact on the meaning of the dwelling it did not explore the implication of these contrasting events. The next chapter will explore the compromises, conflicts and ambiguities involved in the meaning of the dwelling and investigate how such conflicts are negotiated. Of central importance will be exploring how the different events interact and also the differences that exist between the nineteen participants. In doing so it will become possible to assert that the meaning of the dwelling is in fact a unique experience. To grasp this unique experience and comprehend the meaning of the dwelling in a new way in Chapter 7 the three-dimensional framework developed in Chapters 3 and 4 will be operationalised.

Chapter 7. A unique experience:

understanding the meaning of the dwelling
through the three-dimensional framework

Chapter 7

A unique experience: understanding the meaning of the dwelling through the three-dimensional framework

7. 1 Introduction

This chapter seeks to explain the research findings presented in Chapter 6 through the three dimensional framework developed in Chapter 3. In doing so the chapter is able to address the remaining research objectives and understand the meaning of the dwelling in an innovative manner.

The chapter begins by describing the research findings through the DREI schema (see Chapter 5). Through retroductive analysis the underlying structures and mechanisms behind the events that had an impact on the meaning of the dwelling will be revealed. Having done this, the chapter will then proceed to operationalise the three-dimensional framework, explaining how the identified events and generative mechanisms can be explained through this analytical framework. In doing so the case will be made that the meaning of the dwelling is unique to the individual; dependent on the events that are present. Indeed the case will also be made that it may not be just be the meaning singular, but rather meanings plural. To help demonstrate the arguments made, section 7. 4 will explain the meaning(s) of the dwelling for three participants – Louise, John and Jodie – through the operationalised three-dimensional framework. Here the events that impacted on the meaning of the dwelling for each participant will be described, along with a comprehensive explanation of how the different (and often conflicting) events interacted to produce a temporally located meaning; one that was unique to the individual.

The purpose of this detailed analysis is simple: to help facilitate a greater understanding of the meaning of the dwelling for physically disabled individuals. What becomes apparent is that as well as being a complex experience, the meaning of the dwelling is also a unique one. The meaning is not always clear-cut and involves a number of compromises and conflicts. Moreover it is also subject to constant change and re-appraisal. The chapter will contend that it is only through using the three-

dimensional framework as an analytical tool that the ambiguous and unique nature of the meaning of the dwelling can be truly understood.

7. 2 Understanding the research findings through the DREI schema

Drawing on the findings presented in Chapter 6, seven events were noted as impacting on the meaning of the dwelling. These are:

- impairment effects,
- the inaccessible environment,
- inadequate housing design (and the resulting need for adaptations),
- discrimination,
- ‘care’ dynamics ,
- emotional attachment to the dwelling,
- relationship with co-habitants.

However as noted in previous chapters, in addition to recognising that a number of events will impact on an experience, a critical realist project also seeks to understand the underlying structures and mechanisms that can explain these events.

Identification of the events should be understood as the description phase of the DREI schema (see Chapter 5). Following this description, what is also needed is to conduct retroductive analysis, eliminate alternative explanations and identify underlying structures and mechanisms. Doing so will help to develop a greater understanding of the experience of the meaning of the dwelling. It is to retroductive analysis of the events to bring to light their underlying structures and mechanisms that the chapter shall now turn.

7. 2. 1 Impairment effects

To explain the event ‘impairment effects’, it becomes necessary to understand the underlying structures and mechanisms from which impairment effects emerge. This process of emergence is presented diagrammatically in Figure 7. 1:

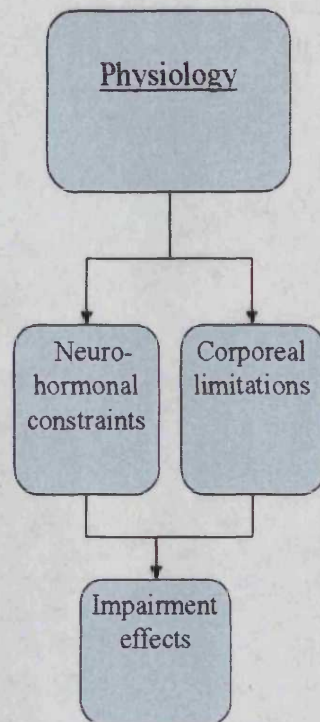


Figure 7. 1 –Structure and mechanism underlying the event of impairment effects

Any appeal to impairment effects first of all lies in recognising the reality of physiology as a distinct structure. A detailed discussion was presented in Chapter 3 on the need to recognise the reality of physiology as an ontologically distinct structure, one that is irreducible to the structures of society or agency. The case was then made in Chapter 4 – and supported by the testimonies of participants in Chapter 6 - that whilst social constructionist approaches have made it difficult to talk about a body in a corporeal sense, the failure to recognise physiology as a distinct structure is inadequate.

Emerging from the structure of physiology are two mechanisms. The first is ‘Corporeal limitations’. The term corporeal is used to refer to the material, physical characteristics of the human body ³⁴. ‘Corporeal limitations’ then is used to represent

³⁴ Whilst this thesis recognises the body as a complex interaction of physiology, agency and society - see Chapter 4 – and acknowledges the existence of debates surrounding the use of the terms corporeal (Newton, 2003) and neurohormonal (Grosz, 1994:62 -86; Freund, 2006) and the way in which they can be influenced by agency and society, this section will

changes/limitations in bodily functioning that are the direct result of corporeal damage/failure.

The second mechanism is 'Neurohormonal constraints'. Neurohormonal refers to the hormones produced by specialized neurons either in the brain or in the nervous system that can be seen as 'informational networks' acting on various parts of the body including the nervous system itself (Freund, 2006:90). Like 'Corporeal limitations', the mechanism 'Neurohormonal constraints' is used to represent constraints in bodily functioning that are the direct result of neurohormonal disruption/damage/failure. Multiple sclerosis (MS), a neurological condition affecting Louise, John, Sam and Deirdre, serves as a good example here. MS is believed to be the result of 'damage to myelin - a protective sheath surrounding nerve fibres of the central nervous system' (Multiple Sclerosis Society, 2006). The result of this damage is that messages between the brain and other parts of the body get distorted with the immune system 'mistaking the body's own tissue for a foreign body' and consequently attacking it (Multiple Sclerosis Society, 2006).

Given the nature of the human physiology the prospect of corporeal limitations or neurohormonal constraints is an ever present possibility. However it is only when the physiological disruptions/damage/failures occur that one of the mechanisms is 'triggered'. When triggered, it is contended these mechanisms can then independently give rise to the event described as 'impairment effects'.

7. 2. 2 The inaccessible environment and inadequate housing

Through retroductive analysis, and echoing the arguments of the social model theorists (see Chapter 1) - albeit arriving at the same conclusions in a different way- both the inaccessible environment and inadequate housing have to be understood as a being a product of a disablist society. A detailed discussion of what is meant by the term society was presented in Chapter 3. What is crucial to understand here is that the

focus simply on the *physiological* aspects of these terms. This does not amount to a discounting of the sociological/psychological significance in any way but that for clarity of explanation here the terms corporeal and neurohormonal will just refer to extra-discursive properties.

structure of society as it currently exists is disablist, constructing the 'norm' as a narrowly defined notion of the able body.

Emerging from the disablist arrangements inherent in the structure of society is the mechanism 'Design based on notions of the able-body'. Inspired by the wealth of existing literature within the social model tradition highlighted in Chapter 1 this mechanism refers to the way in which because of a disablist society design is premised on a vague notion of the 'able bodied' user. This mechanism of 'design based on notions of the able-body' will exist whether it is triggered or not. However it will only operate and generate events when it is triggered. That is, given the power arrangements from the structure of society the mechanism 'design based on notions of able-body' will always be present. However this mechanism is only 'triggered' when an individual falls outside the narrowly defined notion of the 'able-body'.

When the mechanism is triggered two events become apparent: the inaccessible nature of the built environment and the inadequate design of housing. This process of emergence and the underlying mechanism and structure behind the inaccessible built environment and the inadequate design of housing is presented diagrammatically in Figure 7. 2

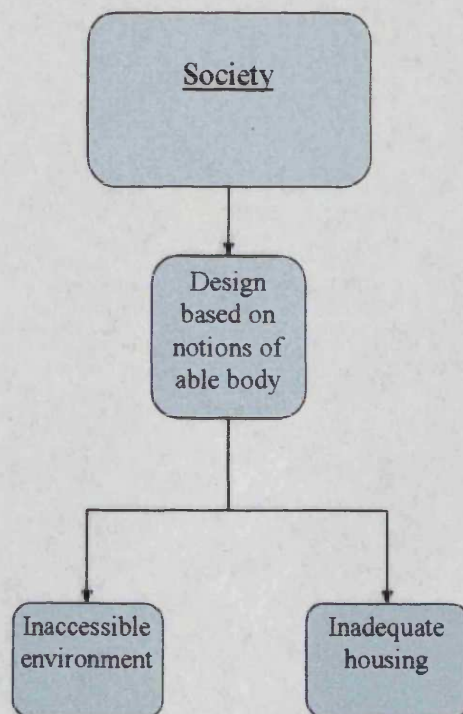


Figure 7. 2 –Structure and mechanism underlying the events of the inaccessible environment and inadequate housing

7. 2. 3 Discrimination and 'care' dynamics

From careful retroductive analysis and elimination of inadequate explanations, it becomes possible to assert that both 'discrimination' and 'care dynamics' have to be understood as being a product of a disablist society. A society that holds disabled individuals as being somehow less significant, less able to do things and as a group who need to be cared for. Crucially, as previously noted by social model theorists, the disablist structure of society sets out a clear hierarchy between those who have power and those who do not, with disabled individuals becoming the 'have not'.

From society emerges the mechanism 'Social attitudes'. This term refers to the attitudes of individuals towards others. The nature of society will dictate any such attitudes. Given that the mechanism emerges from a structure of society which is inherently disablist, the mechanism 'Social attitudes' contributes to the creation of negative, stigmatising attitudes towards disabled individuals. For this reason this mechanism 'Social attitudes' once again draws on writings within the social model of disability.

When 'triggered' – i.e. when an individual 'becomes' disabled – the disabled individual will encounter a particular set of social attitudes from wider society. As noted above, these attitudes can be understood as manifested in two events: discrimination and 'care' dynamics. Given the negative and stigmatising set of social attitudes that emerge from the disablist society, discrimination comes as little surprise. Similarly given the stigmatising attitude that disabled individuals are literally less 'able' than their able bodied counterparts the attitude is that they need to be cared for. The resulting event is a care system where disabled individuals have very little power or control over their circumstances (see discussion on community care presented in Chapter 2).

However, what is important to note here is that changes can occur over time, and that these changes (such as those brought about through the direct payments scheme) emerge from a change in the mechanism of social attitudes, which in turn arise from a change in society. As noted in Chapter 3, whilst the structure of society pre-exists

active human agents it is only relatively enduring and is subject to change by agency. As each mechanism only exists by virtue of the structure, changes in the structure of society consequently change the resulting mechanisms, which in turn will change events. In the case of this research what became apparent was that recent changes in society regarding disability through the social model led to changing social attitudes in terms of ‘caring’ for disabled individuals which in turn led to a change in care packages, and consequently a change in care dynamics. This change, as shown in Chapter 6, appeared to have a positive impact on the meaning of the dwelling.

This process of emergence and the underlying mechanism and structure behind discrimination and care dynamics is presented diagrammatically in Figure 7. 3:

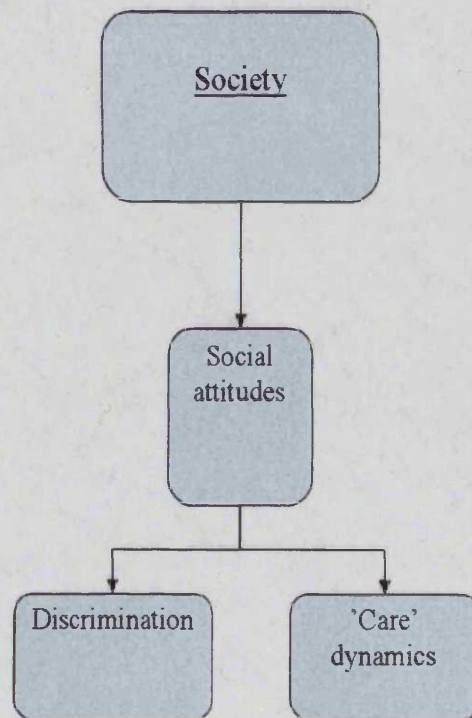


Figure 7. 3 –Structure and mechanism underlying the events of discrimination and care dynamics.

7. 2. 4 Emotional attachment to the dwelling

To understand the impact of emotional attachment on the meaning of the dwelling it becomes necessary to understand its underlying structures and mechanisms. This process of emergence can be seen in Figure 7. 4:

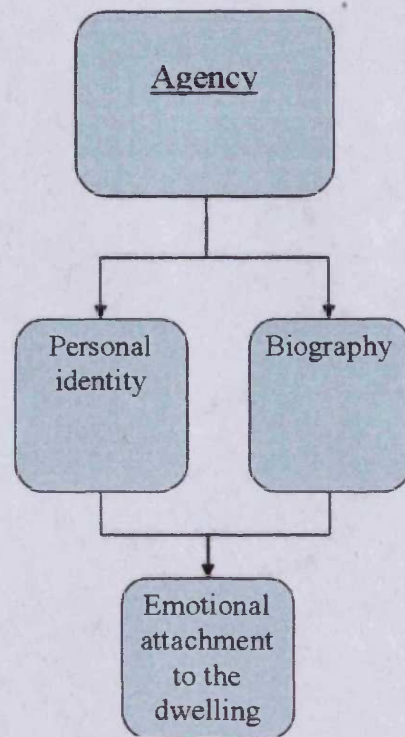


Figure 7. 4 –Structure and mechanisms underlying the event of emotional attachment to the dwelling

Recognising that an individual can create emotional attachments to the dwelling in spite of issues arising from the structures of society and physiology lies in appealing to a notion of agency. As noted in Chapter 3, agency has to be understood as ‘causally and taxonomically irreducible’ to the biological matter out of which agents were formed (Bhaskar, 1993: 51). Similarly, whilst society mediates agency, as we finish the shaping of our own biography, agency has to be understood as irreducible to society. Asserting the reality of agency is about eliminating explanations that reduce everything to society and entails a recognition that humans are neither physiological nor societal dopes.

The effect of the structure of agency then becomes manifested in the resulting generative mechanism. The two mechanisms identified as emerging from the structure of agency to explain the event of emotional attachment are ‘Personal Identity’ and ‘Biography’. ‘Personal Identity’ refers to the individual as a unique

human agent, one with their own distinct personality. Our personal identity defines what we care about in the world. As noted in discussions on the work of Archer (2000) in Chapter 3, personal identity must be understood as distinct from 'social identity' which is a direct product of society (for further discussion on the notion of personal identity see Archer; 2000, 2002). As personal identity shapes what we care about, when triggered this mechanisms will influence what an individual chooses to develop emotional connections with.

More straightforwardly, 'Biography' refers to the series of happenings that make up an individual's life. An individual's biographical activities contribute towards the creation of the dwelling as a 'biographical accomplishment' or 'psychic warehouse' and are unique to the individual. A number of positive biographical activities can help towards the development of a positive emotional attachment towards the dwelling. Conversely, negative memories and events can challenge the development of a positive emotional attachment towards the dwelling.

Both biography and personal identity are unique to the individual. This produces a range of different outcomes to the event of emotional attachment to the dwelling. Given this variety of responses it is imperative that the event of emotional attachment to the dwelling is understood through reference to the structure of agency. Moreover, what also has to be recognised is that through the notion of agency it becomes possible to appreciate the ambivalence of the emotional attachment. In some ways the attachment can be strong, in other ways weak. The two are not mutually exclusive. For example, for Carrie the dwelling was very much a biographical accomplishment, a psychic warehouse containing many happy memories of past activities. Therefore it became apparent the dwelling was a place she was emotionally attached to. However now that her husband had died and many spaces in the dwelling had been adapted the spaces in the dwelling also brought her great sadness, giving rise to a number of negative emotions. As such the influence of this event of this event on the experience of the meaning of the dwelling is not just considerable but also complex.

7. 2. 5 Relationship with co-habitants

Whilst the rules and norms of habitation are shaped by society's values, in living arrangements that currently prevail in Britain agency plays a pivotal role in influencing the event of relationship with co-habitants. As noted above, from the structure of agency emerges the generative mechanism biography. To recap, biography refers to the happenings that make up an individual's life. Who we live with arises from our biography as does our relationship with them. Past, present and future happenings affect how we relate to those we share the dwelling with. Positive relationships with those we live with will have a positive impact on the meaning of the dwelling, whilst harmful relationships appeared to have a significantly negative impact. Of course any relationship is located at a particular moment in time and any changes in this relationship may in turn have an impact on the overall meaning of the dwelling.

The process of emergence underlying the event of relationship with co-habitants can be seen diagrammatically below:

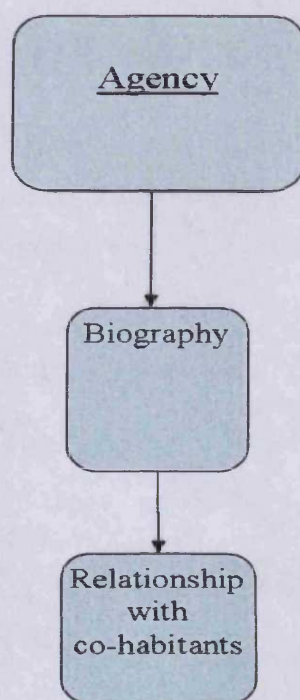


Figure 7. 5 –Structure and mechanisms underlying the event of relationship with co-habitants

Whilst this event may play a significant role, as noted in Chapters 3 and 4, there is no deterministic cause and effect relationship between any mechanism or event and the meaning of the dwelling. So, whilst it is crucial to recognise the influence of agency on the meaning of the dwelling, it is of central importance to recognise the impact and interaction of the structures of physiology and society and their resulting generative mechanisms on the meaning of the dwelling. It is to the recognition and discussion of the interaction of the various structures, mechanisms and events identified within this chapter that the chapter shall now turn, and in doing so highlight the unique experience of the meaning of the dwelling.

7.3 A unique experience: understanding the data through the three-dimensional framework

Through careful analysis of these findings, it is proposed that these seven events can be understood as emerging from one of three structures: physiology, society or agency. Acknowledging these three structures represents a marked departure from the existing literature. Whilst previous explanations have concentrated on the structure of society, retroductive analysis reveals that is necessary to reassess these 'ontological and epistemological commitments to the social' (Allen 2000:50). Events arising from the structures of physiology and agency have to be recognised as playing an important role in the meaning of the dwelling.

However, so far this chapter has only discussed these structures and their emergent generative mechanisms and events in isolation. What is now necessary is to explore the way in which the different structures and events interact to produce a meaning of the dwelling unique to the individual. From the analysis of the nineteen life history interviews presented above and building on the three-dimensional framework developed in Chapter 3, Figure 7. 6 diagrammatically represents the full schema of structures, generative mechanisms and events that appeared to have an impact on the meaning of the dwelling:

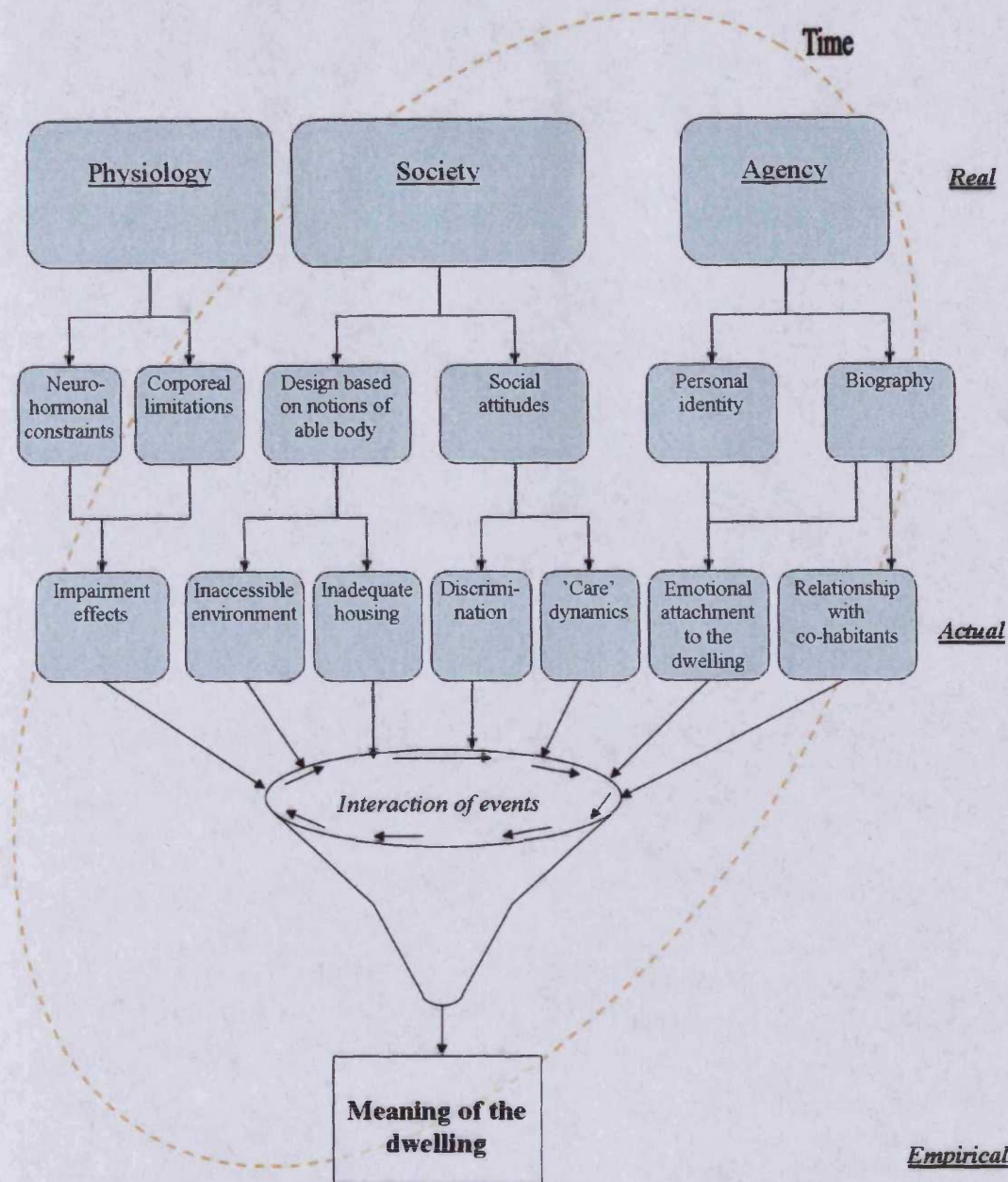


Figure 7. 6 – Full schema of structures, mechanisms and events identified in the determination of the meaning of the dwelling.

This figure needs explanation. Working top down from the abstract to the concrete, at the level of the real in the framework we can see the three structures – physiology, society and agency -, and the resulting six generative mechanisms (identified above) - corporeal limitations, neurohormonal constraints, design based on notions of the able-body, social attitudes, personal identity and biography. At the level of the actual we can see the seven emergent events (identified in Chapter 6) - impairment effects, the

inaccessible environment, inadequate housing design, discrimination, 'care' dynamics, emotional attachment to the dwelling and relationship with cohabitants. As discussed in detail in Chapter 3, the funnel represents the interaction of these different events. At the base of the figure is the level of the empirical, in this case the meaning of the dwelling. This is the result of the interaction of the different events at play that arise from the different structures and their emergent generative mechanisms (for further description of the framework see Chapters 3 and 4).

What became apparent throughout all nineteen interviews was that the meaning of the dwelling was not a product of any one event, but rather was co-determined by a number of events. However what has to be recognised is that all individuals were different. Consequently *not all individuals experienced all events*. Rather the number of events at play was determined by the number of mechanisms that had been triggered in each individual case. In fact only in one case were all seven events present (Jodie). In the majority of cases only a couple of the events impacted on the meaning of the dwelling. In each individual case the events present interacted to produce a specific and *unique* meaning of the dwelling at the level of the empirical.

This process of interaction occurring at the level of the actual is central to determining the unique meaning of the dwelling. Where events reinforced one another they further entrenched a particular meaning of the dwelling. For example, the feeling of being trapped in the dwelling because of inadequate housing design could have been reinforced by the events of impairment effects and discrimination.

However, not all events would have coincided with one another. Some events may actually have conflicted with another. For example whilst events such as inadequate housing design would have produced a very negative meaning of the dwelling, events such as emotional attachments to the dwelling would have produced a more positive meaning of the dwelling. If both events were present there would have been a conflict between the dwelling as a prison/haven. The result of this conflict – largely determined by the potency of a particular event over another and whether it receives support from additional events- will then shape the meaning of the dwelling. Recognising conflicting events and understanding how they interact and were negotiated becomes central to comprehending the way in which the meaning of the

dwelling becomes unique to each individual. In section 7. 4 the interaction of events and the process of conflict resolution will be explored in depth through the use of three case studies.

The result of the interacting events is the experience, here being the meaning of the dwelling. However, what is important to note is that there may not be just one meaning but rather a set of meanings. From the nineteen interviews it became apparent that as well as negative meanings of the dwelling as a prison/cage, a site of insecurity, isolation and neglect, a place that reflected their loss of privacy and control and dependency being attributed, there were also more positive meanings such as the dwelling as a centre of activities, a reflection of their biography, ideas and values, a site of control, and a space within which to have a relationship with family and friends. Moreover, what also became apparent was that from the interaction of events, the resultant meaning may have comprised of a number of these seemingly contradictory experiences. In such instances the overall meaning then became subject to rapid change and in a constant state of flux, dependent upon which ever event exerted the greatest force at any particular point in time. It is in this way that the meaning of the dwelling has to be understood as being complex, changeable and unique.

Given that the meaning was a fluctuating one, time becomes a fundamental characteristic. Any meaning has to be understood as being temporally located, and subject to change. The change in meaning can come from changes to any of the events arising from changes to any one of the three structures:

1. *Physiology*: Contra reductionist portrayals of the homogenous experience of disability that rule out impairment effects, it is these impairment effects that become important to understand here. Physiology can change over time causing corporeal/neurohormonal changes which can change the impact of impairment effect. This change can occur over years, seasons, days or even seconds. The change in the event of the impairment effect will have a direct impact on the meaning of the dwelling. If the impairment effect gets worse its effect on the meaning will be stronger and could lead to an individual feeling trapped in the dwelling. Similarly should the impact of the event of

impairment effect ease off either momentarily or over a long period this could lead to the individual feeling less trapped and more in control, and hence hold a more positive meaning of the dwelling. Either way, in recognising that physiology and its emergent mechanisms and events are subject to change, it becomes a fundamental necessity to acknowledge the influence time can have on the meaning of the dwelling.

2. *Society*: As discussed in Chapter 3, society is also subject to change over time. Like physiology the change in society will cause a change to its mechanisms and events. As noted above, changing values have led to a change in care policies and dynamics, which has subsequently changed the impact this event had on the meaning of the dwelling. Similarly, recent changes to building design have seen the dismantling of certain design barriers. Over time this could have a substantial impact on the meaning of the dwelling with individuals no longer feeling trapped in the dwelling because of inadequate design of the built environment. Whilst these changes occur over a long period of time, on a more immediate level the events will have a more significant effect when they have recently been encountered. For example if an individual has very recently encountered discrimination, faced barriers in the built environment or been confronted with the inadequate design of their dwelling, these events will carry a stronger impact on the meaning of the dwelling. Consequently at that point in time the meaning of the dwelling is more likely to be as one of a space that embodies their dependency and confinement.
3. *Agency*: Changes over the life course can change the level of emotional attachment to the dwelling. Of key importance here is the mechanism of biography. Biographical changes and activities within the dwelling will have a direct bearing on the strength of emotional attachment to the dwelling (see Gurney and Means, 1993; Gurney, 1996; Heywood, Oldman and Means, 2002). Over time more activities occur in the dwelling, activities that may strengthen or weaken the emotional attachment to the dwelling. If over time a number of positive activities have taken place it becomes more likely that the emotional attachment to the dwelling will be strong. The strength of this event

then plays an increasingly important role in casting the meaning of the dwelling as a space of control and a reflection of their biography.

Given that all structures and their emergent generative mechanisms and events are subject to change over time, the meaning of the dwelling must be accepted as being only relatively enduring. Any meaning is not static, rather it is constantly shifting in line with the changes to events. Indeed over time new events could emerge, events that may substantially change any meaning currently ascribed to the dwelling.

By using the three dimensional framework as an analytical tool the meaning of the dwelling can be understood in a new light. Through recognising the influence of multiple structures, mechanisms and events and acknowledging the significant role of time on the meaning of the dwelling it becomes possible to avoid charges of reductionism, essentialism and determinism. Crucially what becomes important is understanding that there are *differences* between individuals. Each individual will have their own particular set of meanings of the dwelling, depending on the mechanisms and emergent events triggered. As a result, the meaning of the dwelling is not just complex but also unique, temporally located and created by the joint determination of a number of structures, mechanisms and events distinctive to each individual.

To demonstrate the arguments made in this section and illustrate how the meaning of the dwelling is a unique experience, by using the three-dimensional framework as an analytical tool the chapter will now explore the meaning of the dwelling from the perspective of three different participants.

7. 4 Explaining the meaning of the dwelling: Case studies

To demonstrate the arguments made above, this section will explain the meaning(s) of the dwelling for three participants – Louise, John and Jodie. These three cases were chosen for a variety of reasons. Firstly, the three cases have been selected because they demonstrate the variety of meanings associated with the dwelling. Secondly, these three were chosen because they highlight the differing ways in which events can interact. For Louise the different events largely reinforced one another, for John the events conflicted with one another and for Jodie a large number of events were at play

some which reinforced one another, others which conflicted with one another. Finally in seeking to provide an explanation of the meaning of the dwelling for individuals with a range of disabilities it was deemed important to select a case where the participant did not rely on the use of a wheelchair.

Given that retroductive analysis of the events was presented in depth earlier in the chapter there will be no discussion here of how events emerged from underlying structures and mechanisms. Rather the focus of this section will be on identifying the events that impacted on the meaning of the dwelling for each participant, understanding how they interacted and in doing so exploring how conflicts, ambiguities and compromises were negotiated.

7. 4. 1 Case study one - Louise

The first individual to focus on in detail is Louise. Louise has lived with her husband in her current owner occupied dwelling for the last thirteen years. Louise moved into current dwelling after her previous dwelling had been broken into. In her 60's at the time of interview, Louise had been diagnosed with MS for twenty three years. MS has had a significant impact on Louise's motor skills, leaving her reliant on a wheelchair for movement with restricted movement in her hands. Furthermore, the pain experienced as a result of MS has lead to Louise having to take a "cocktail" of drugs, leaving her drowsy and with little energy. Louise has been on the direct payments scheme for four years, using the payments to employ her own carers.

The case of Louise is useful to focus on in that it highlights the way in which different events interact to *reinforce* a particular meaning. For Louise the meaning of the dwelling came to be a very negative one. In stark contrast to Despres' categories of meaning (1991:97-99, see Chapter 4) for Louise the dwelling was not a source of security or control, it no longer reflected her ideas and rather than being a refuge from the outside world the dwelling became a prison that she could not leave.

Detailed analysis from the interview with Louise reveals that six events had a significant impact on the meaning of the dwelling. The six events were: (i) impairment effects; (ii) the inaccessible environment; (iii) inadequate housing design; (iv) 'care' dynamics; (v) emotional attachment to the dwelling and (vi) relationship

with co-habitant.

(i) Impairment effects

As noted above, impairment effects refer to bodily demands and constraints that are the result of a particular impairment. One such demand Louise faced was that of pain. Whilst to a certain degree pain is a social construction, as discussed in Chapter 4 it also has to be recognised as having a real physiological base (Morris, 1991; Williams and Bendalov, 1996, 1998). In view of this, pain can be referred to as an impairment effect – one emerging from the mechanism ‘neurohormonal constraints’ which in turn arises from the structure of physiology.

For Louise the impairment effect of pain had a significant impact on the meaning of the dwelling. Most days the pain was such that she could only manage a few hours out of bed. Rarely could Louise handle the pain long enough to leave the house. When she did it was only because she had taken a “cocktail” of prescribed drugs, leaving her in a semi-conscious state from which she would not be able to remember leaving the dwelling anyway. Consequently, the dwelling became a place in which she felt “trapped” and isolated. No longer was the dwelling a haven to return to, but rather a result of the MS, become a place she was confined to. In her words, the onset of MS and the pain accompanying it had turned the dwelling into a “prison”.

Furthermore, impairment effects as a result of MS led to the necessity of having equipment “on show” around the dwelling. For Louise in being forced to have such items around the dwelling to assist with daily living and allow her out of bed was the cause of much resentment. The need to have additional items can be understood as diminishing the control Louise had over her dwelling. Moreover, the need for such items can also be understood as presenting a challenge to the dwelling as a biographical accomplishment.

(ii) The inaccessible environment

Louise’s testimony revealed that the outside environment can have a significant impact on the meaning of the dwelling (see also Allen, Milner and Price, 2002). As a wheelchair user the thought of tackling uneven pavements, steps and narrow

doorways proved to be a significant barrier to leaving the dwelling. As Louise explained:

Louise: “Well it is very difficult to get out, you know with the pain there is everything else. The way the pavements are I always fall over to one side, and every little bump (groans in pain)... Anywhere with steps is just a complete no-go. So I just don’t want to go out often.”

Inadequate design meant that going out would actually exacerbate the pain Louise was in. As a result, the inaccessible environment effectively left Louise trapped in the dwelling.

(iii) Inadequate housing design

Inadequate housing design also had a substantial impact on the meaning of the dwelling for Louise. The inadequate design of Louise’s dwelling meant that rather than being a site of independence and control the dwelling became a place of dependency and defeat.

Firstly, heavy doors, small room sizes (preventing circulation in a wheelchair) and narrow doorways meant that once in some rooms Louise was often trapped inside them until her husband or carer came to help her out. Consequently, Louise was stripped of the ability to move independently around the dwelling. In short, design enforced dependency.

For Louise it was not so much being trapped in certain rooms that caused distress, but rather that the design prevented accessing certain spaces altogether – namely the garden. With a small flight of stairs leading from the house to the garden Louise could no longer access this once much loved area independently (Louise had tried to get a ramp installed but the garden was too small to get the necessary gradient). More than any other design barrier these four steps embodied Louise’s dependency on others. They also came to represent exactly what had been lost, highlighting the problems caused by inadequate design. For Louise, the event of inadequate design had a significantly negative effect on the meaning of the dwelling.

(iv) 'Care' dynamics

The meaning of the dwelling for Louise was also influenced by 'care' dynamics that occurred within the setting. As noted in Chapter 6, the assessment process left Louise feeling anxious and disempowered in her dwelling. Further, Louise hated the "random" "intruders" who would enter her dwelling every day to care for her. She recalled how she would have nightmares and lived in fear, anxious over the prospect of once again being ignored, humiliated and/or disrespected by the care workers in her own dwelling. To save repeating the observations presented in Chapter 6, in summary, with unknown care workers entering the dwelling Louise not only lost control over the dwelling but was also treated with a lack of respect by those who entered. All this in a setting that is supposedly a 'haven' from the outside world. Given this, the event of care dynamics must be recognised as having a negative impact on the meaning of the dwelling for Louise.

However, these experiences were in the past. At the time of interview Louise noted that she had now employed carers (through the direct payments scheme) whom she felt she could trust. Having a carer she could trust changed the care dynamics:

Louise: "It is so much better now, I really have a good friendship with [names of carers]...and also they are there for me, it is really about them caring for me. And I care for them too you know, I really feel that it's quite cemented. I just trust them all explicitly."

A more respectful relationship had been developed, one that facilitated an environment where Louise not only felt secure and in control but also more confident in the dwelling. The change in care dynamics highlights the way in which events can change over time, and the impact this change can have on the meaning of the dwelling. A further discussion on the importance of this change, and the impact it had on the meaning of the dwelling for Louise will be provided later.

(v) Emotional attachment to the dwelling

A further event which had a significant impact on the meaning of the dwelling for Louise was emotional attachment to the dwelling. It soon became apparent in the interview with Louise that there was little by way of positive attachment to the dwelling.

Given the inadequate design of her dwelling and following EC regulations on manual lifting (see Chapter 4), Louise was forced to install a series of adaptations in her dwelling. Furthermore, bodily requirements meant that it was necessary to have additional objects such as ventilation machines to assist with breathing around the dwelling. As noted in Chapter 6, these items and adaptations became the source of great resentment. They came to create an institutional appearance to the home, making the dwelling feel “more like a hospital”. Accordingly, the items and adaptations appeared to compromise the sense of homeliness in the dwelling, threatening the dwelling as a site of biographical accomplishment by forcing the removal of once cherished items to make way for adaptations. The effect of these changes had a significant influence on the meaning Louise attributed to her dwelling. To Louise her dwelling came to be an embodiment of her losses and limitations rather than her ideas, values and biography.

Whilst the loss of items in the dwelling to make room for adaptations presented a challenge to the biographical accomplishment of the dwelling it was the garden that reflected the greatest loss. As Louise explains:

Louise: “The back garden is a place that I love. When we first came here I dug it all up, got rid of the rats, the rubbish and the weeds and I planted all new flowers. It looked really lovely. But now I just cannot get out there... I used to take all my energy to do the little bits I could do, but now ... (shrugs shoulders). I went down yesterday and I was really upset because [husband] has just let it go. He just doesn’t understand what it means to me. You know it doesn’t take long to do things, all the beautiful trees and freesias which I loved to grow had all died because no one had looked after them. (pause) I would dearly love to go out there again, but, um I think that’s just a dream.”

The garden was something that Louise looked on as an accomplishment, something she had worked on for years. As she explains, even with the onset of disability she did her utmost to keep it the way she wanted. But now she lacked the energy to do this, and consequently it had been left to ruin. In doing so it no longer reflected a biographical accomplishment, but once again came to reflect what had been lost.

In presenting a challenge to her biography it comes as little surprise that Louise holds little attachment to the dwelling. Indeed despite living in it for thirteen years she hates her dwelling:

Louise: "...there were various reasons why we moved, the burglaries being the main one. But I wish we had never moved in here, it's brought a lot of sadness. A lot of sadness."

Louise explained how she was "very happy" in her previous dwelling, but after being burgled felt unsafe and thought it would be best to move. However, the dwelling Louise has now lived in for thirteen years just embodies bad memories and feelings. She desperately wants to leave but with all the adaptations it is now "unsellable". The event of this negative emotional attachment appeared to have a very damaging impact on the meaning of the dwelling.

(vi) Relationship with co-habitant

Louise lives with her husband of over thirty years. However, Louise fears that the onset of MS has put added strain on the relationship:

Louise: "Err well yes err it's like the garden again. I have to rely on him to do it and, well, if he doesn't want to do it he shouldn't have to should he? And it's all the little things like that really, having to say 'oh [husband's name] can you do this or that for me' it isn't good [for the relationship]."

As well as being concerned that she relied on her husband to 'care' for her Louise also revealed concerns that she felt her disability had a negative affect on their relationship, limiting the amount of "quality time" they could spend together as well as restricting their ability to go out together. In Louise's eyes the relationship was not like it used to be. With relationships strained the dwelling may become an uncomfortable environment to live in, something that in turn could have a negative impact on the meaning of the dwelling. This event, alongside the other five identified in the interview with Louise can be seen diagrammatically in Figure 7. 7:

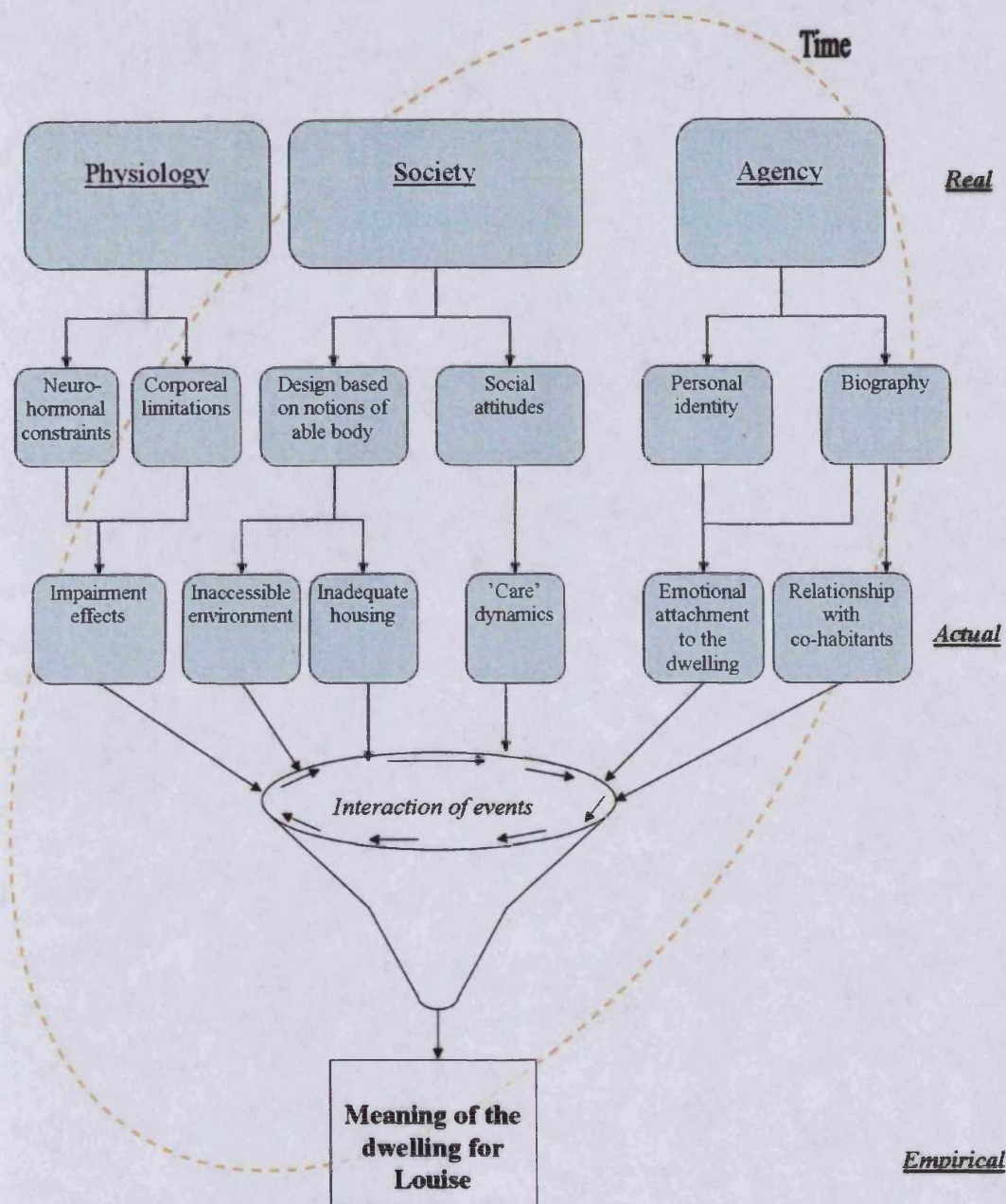


Figure 7. 7—Structures, mechanisms and events identified in the determination of the meaning of the dwelling for Louise

Figure 7. 7 outlines the events and the underlying structures and mechanisms that impacted on the meaning of the dwelling for Louise. There is no need to repeat the explanation of these underlying structures and mechanisms again here. What is important to understand is that the events should not be taken in isolation – they are relational. They interact to produce a unique meaning of the dwelling. The meaning

of the dwelling for Louise was a negative one. The events of impairment effects and the inaccessible environment left Louise feeling trapped and isolated. This was then compounded by the dwelling coming to embody notions of dependency, defeat and a loss of privacy through inadequate housing design and a further loss of control through care dynamics which also left Louise feeling unsafe in the dwelling. Finally with the relationship with her husband not “as it once was” and with Louise hating her dwelling - seeing it as bringing sadness to her life - the event of emotional attachment to the dwelling (or in this case the lack of it) contributed towards a very negative meaning of the dwelling. The importance of these relational connections must not be overlooked.

Taken together these events make up the present meaning of the dwelling for Louise. In this case the events interact and support one another, confirming a meaning that clearly runs counter to any notion of the home as haven. By recognising the involvement and interaction of a number of events it becomes possible to avoid essentialist assumptions in explaining the meaning of the dwelling for Louise.

However whilst all these events seem to conspire to make a very negative meaning of the dwelling the event of care dynamics shows that certain ambiguities can still emerge. With the uptake of the direct payments scheme this event of care dynamics changed from having a negative effect on the dwelling to a more positive one – with Louise looking forward to having her carers in the dwelling and enjoying their company. As well as giving her an increased feeling of security, the new carers also made her feel more in control in her dwelling. In spite of this conflicting event, when this altered event interacted with the other five events this ambiguity came to have little overall effect on the meaning of the dwelling for Louise. In short this event of care dynamics did not hold enough significance and consequently came to be suppressed under the wave of more negative events.

In addition to highlighting the potential for conflict between events, what this also shows is the importance of recognising the temporal dimension to the meaning of the dwelling. Over time, structures and their emergent generative mechanisms and events can change. This change can have a significant effect on the meaning of the dwelling.

Accordingly, the meaning of the dwelling for Louise is not fixed, rather just temporally located and subject to future change.

7. 4. 2 Case study two - John

The second participant to be focussed on is John. As noted in Chapter 6 John, 67, has lived in his current owner occupied dwelling with his wife for sixteen years. The first signs of Multiple Sclerosis came five years ago and John is now a wheelchair user. Despite the progressive nature of John's illness he does not receive any care assistance.

Like the majority of participants the testimony of John reveals the way in which the meaning of the dwelling was created through competing events. However in contrast to Louise, for John the meaning of the dwelling was overall a very positive one. Detailed analysis from the interview with John revealed that five events had a significant impact on the meaning of the dwelling. The five events were:

(i) Impairment effects

As a result of MS, John's bladder had started to malfunction. To use John's words he had "a number of plumbing problems". The resulting impairment effect was that he needed specialist equipment to assist "going to the toilet". Consequently, when leaving the dwelling a "ton of stuff" was needed to support his physiological demands. For John the need for advanced preparation and the planning involved in bringing this equipment "took away all the fun of being somewhere". As a result, as noted in Chapter 6 John and his wife now rarely had breaks away from the dwelling.

This enforced entrapment was something that John "found hard to come to terms with". Having just retired John had been look forward to travelling with his wife and was finding it very difficult not being able to do this. As with Louise, this forced confinement to the dwelling presented a challenge to the notion of the dwelling as a haven.

(ii) The inaccessible environment

The inappropriate design of the built environment also left John confined to his dwelling. As well as facing problems with uneven pavements ("we basically don't go

out because of the pavements”) steps became an insurmountable challenge. On this subject John recounted an occasion where he met up with his friends and the difficulty he had getting into a public building:

John: “[name of building] has the most colossal step on the door and they just can’t seem to work it out. The first time they did it they actually tipped me out the chair and now I am terrified... it spoils the evening then because I am worried about that and it’s that sort of thing.”

To avoid the problems associated with an inaccessible environment John noted that he had now stopped meeting up with his friends. Similarly to avoid the “almost lethal” steps into shops and banks he had stopped going shopping with his wife. The inaccessible environment effectively left John with little choice but to remain confined to the dwelling; being simultaneously trapped and isolated in one space. This enforced confinement could lead to resentment and the event of the inaccessible environment has to be recognised as having a significantly negative impact on the meaning of the dwelling.

(iii) Inadequate design

As well as being trapped in the dwelling, inadequate housing design meant that John was also confined to certain areas of the dwelling. As with Louise the inadequate design meant that rather than being a site of independence and control the dwelling became a place of dependency.

A step up to the front door meant that John was confronted with a barrier from the very threshold of his dwelling. It meant that he could neither get into or out of the dwelling independently. The threshold became a barrier to the outside world. Additionally, the narrow space of the hallway leading from the front door also meant that John was unable to even open the front door, denying him any control over who should come into the dwelling. However, it was the steps inside the dwelling that proved to be the most significant barrier. Stairs leading from the ground floor to the first floor meant that he could no longer access the first floor. Rather John lived on the ground floor. Indeed he had “no idea” what the first floor looked like since his wife had re-decorated it. What becomes important to note here is the limits design put on John. Not only was he confined to the dwelling but also trapped in specific areas

inside his dwelling. Inconsiderate design meant that in needing to use a wheelchair John lost access to over half of his dwelling.

Furthermore, even on the ground level the inappropriate design of the bathroom meant that John could not wash himself; rather he had to rely on his wife to get him in to and out of the shower cubicle. Again as noted in the case study of Louise, as well as raising the issue of losing control in the dwelling it also highlights the way in which design can compromise privacy. The bathroom was no longer a space in which John could enjoy privately but instead embodied his dependency (for further work on the psychological importance of bathing see Twigg, 2000). In short the dwelling was simply inadequately designed for the needs of a wheelchair user.

(iv) Emotional attachment to the dwelling

For John this event of emotional attachment appeared to have the most significant influence on the meaning of the dwelling.

Unlike Louise, despite the above events John spoke of the dwelling in very affectionate terms. From the highly personalised decoration and treasured items of furniture to the books and articles he had written that surrounded his office, the dwelling was very much part of John's biographical accomplishment. John explained how the dwelling was filled with memories. It was the dwelling he and his wife had bought together when they got married sixteen years ago. It was the place that his children would come to during festive periods. It was the space that reflected his achievements. Indeed despite the inadequate design such was the importance of the dwelling as a psychic warehouse it prevented John from even considering a move. Moreover, as noted in Chapter 6 adapting it was simply beyond the question.

Adapting the dwelling would have threatened the dwelling's status as a family home. As John explained:

John: "This is such a lovely house, I don't want to wreck it, its my great feeling that I don't want to have to do adaptations to such a stage that you make a mess of your home. Putting a lift in would mean knocking through so much, and I am just not happy with that... I don't want to turn my home into a hospital."

Keeping the dwelling as it was became more important to John than making it accessible to him. Even though not adapting meant being confined to a small area on the ground floor, John was adamant that he did not want to install adaptations as they could turn his much loved dwelling into a hospital. The dwelling for John was more than just bricks and mortar. It was a space infused with memories and a place for all the family to feel comfortable in. As an embodiment of John's biography a strong emotional attachment had been formed with the dwelling. It reflected his ideas and values, was the centre of his activities and an indicator of his personal status. As such this event of emotional attachment came to have a considerable impact on the meaning of the dwelling for John.

(v) Relationship with co-habitant

John moved into the dwelling with his wife as newly weds sixteen years ago, and clearly still enjoyed spending time in her company:

John: "Erm well it's always nice at the end of the day we have got a television in my room; it is one of those built in TV and video ones, and invariably there will be something on that we both want to watch. That time is real quality time together... Of course we would like to spend the whole night together but we tried that before and it just didn't work."

Interviewer: "Oh and why was that?"

John: "Well you see I just don't sleep at all well at night, in my natural state I would be up 4 or 5 times on a good night which would mean [wife] would get no sleep at all and that's not what we want. I don't want her to start cursing me, we have got a good relationship and it is important to us that it stays that way. We spend a lot of time together, I mean yes [wife] does see her grandchildren from time to time but when we go out it will always be together."

Being together with his wife was very important to John. They enjoyed the same things, held the same principles and ultimately felt concerned over the welfare of each other. For John the event of relationship with co-habitants was entirely a positive one and the source of much happiness. As a consequence this event came to have a favourable impact on the meaning of the dwelling.

Using the three-dimensional framework all five events that impacted on the meaning of the dwelling for John are presented diagrammatically in Figure 7. 8:

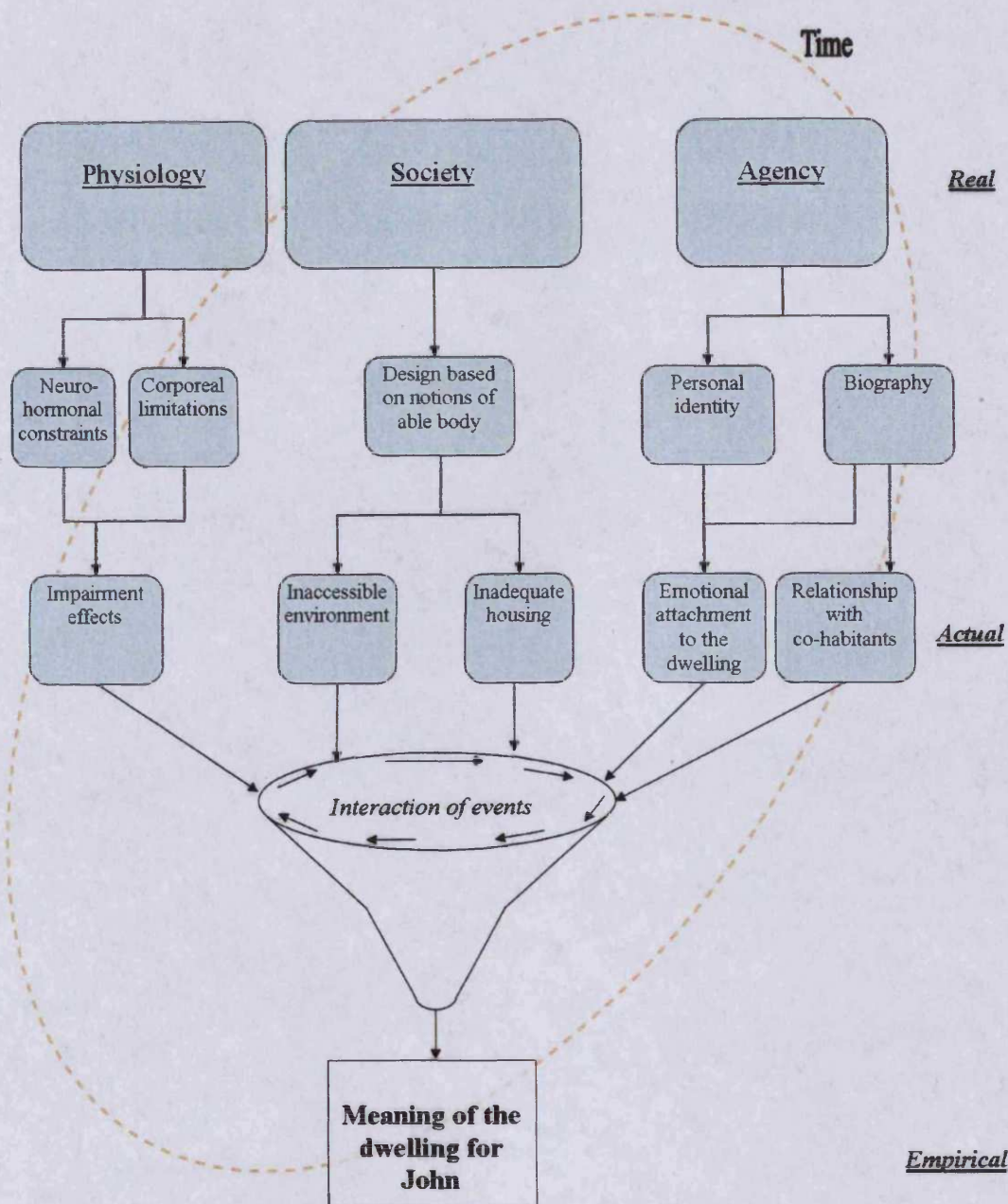


Figure 7.8 –Structures, mechanisms and events identified in the determination of the meaning of the dwelling for John

Figure 7.8 outlines the events and the underlying structures and mechanisms that impacted on the meaning of the dwelling for John. The relational aspects of these events must not be ignored and these five events interact to produce a unique meaning of the dwelling. Overall the meaning of the dwelling for John appeared to be a very positive one. Given that the events of impairment effects and the inaccessible environment left John feeling trapped and isolated and the event of inadequate housing design left John dependent with a loss of control over the dwelling this

meaning appears somewhat out of place. However the answer lies in understanding the events emergent from the structure of agency.

As noted above, with his biography tied to the dwelling John had developed a very strong emotional attachment to it. Further John had a very good relationship with his wife with whom he shared the dwelling with. These events clearly conflicted with the other events that would have conspired to produce a very negative meaning of the dwelling. Indeed such was the strength of these events, in particular that of emotional attachment, that this conflict came to be resolved fairly discreetly with the event of emotional attachment ultimately prevailing over the difficulties created by the other three negative events. Consequently the meaning of the dwelling to John appeared to be very similar to the list of meanings presented in the literature on the meaning of home (see Chapter 4) despite design barriers.

Recognising this meaning of the dwelling for John lies in acknowledging the way in which the different events arising from the three structures interact, and appreciating the substantial impact of emotional attachment. In doing so an explanation can be presented that is neither essentialist or determinist and one that highlights the stories of happiness in the dwelling in the face of design issues.

Of course, John's experience must be understood as being temporally located. Changes over time may mean that John is forced to install adaptations. Faced with adapting the property this could then have a damaging impact on the emotional attachment to the dwelling. Accepting this, the meaning of the dwelling must be understood as being situated at a particular point in time and subject to future change according to any relational changes in/between events.

7. 4. 3 Case study three – Jodie

The final individual to be focussed on in detail is Jodie. Jodie has lived in her current privately rented dwelling with her friend for four years. She has suffered with the effects of ME since she was a teenager and employs her own personal assistant through the direct payments scheme.

For Jodie the meaning of the dwelling came to be a very negative one. However, this short summary is overly simplistic. Rather, as will become apparent a number of events seemed to conflict against one another to create not *the* meaning of the dwelling but rather a number of fluctuating meanings. The seven events which impacted on the meaning of the dwelling for Jodie were:

(i) Impairment effects

As with Louise and John impairment effects had an impact on the meaning of the dwelling for Jodie. Once again, impairment effects left Jodie feeling trapped inside the dwelling. As noted in Chapter 6, in experiencing the effects of severe ME Jodie noted that because the sun over stimulated her she was forced to stay inside the dwelling. This made her feel “imprisoned” in the dwelling. This feeling of imprisonment was not limited to the summer period though. During winter periods Jodie explained that her energy levels would be so low that it left her unable to even get out of bed. This left Jodie feeling trapped not just to the dwelling but one room within the dwelling. In this way the impairment effects from ME caused the dwelling to take on attributes and meanings normally associated with a prison rather than a place of refuge.

Further, the effects of ME also had an impact on Jodie’s ability to use the dwelling as a site of self expression. With certain colours over-stimulating Jodie, she was forced to change the décor of the dwelling. Bold colours, stripes and complex patterns had to go. Rather than reflecting her ideas and values, the dwelling just came to reflect her needs.

The possibility of “over-stimulation” also meant that most days Jodie could not watch TV, listen to music or read books. Even though Jodie enjoyed these things – indeed they helped Jodie “escape from this place” (referring to the dwelling) - she was aware that engaging in such activities would aggravate her physiological state.

Consequently Jodie just felt isolated and frustrated in the dwelling. Rather than being a centre of activities, Jodie became bored. Bored quite literally to tears. Because of this boredom for Jodie the dwelling came to take on a very negative meaning, being the place she longed to escape. The dwelling was not her sanctuary but her “cage”.

Recognising these accounts shows the way in which the event of impairment effects had a significant impact on the meaning of the dwelling for Jodie.

(ii) The inaccessible environment

Barriers in the built environment also left Jodie feeling confined to her dwelling. The principal problem was steps into buildings:

Jodie: "Steps become such a challenge to me. Like I really wanted to learn how to use the internet. But access to the computer room at the library was up some stairs which meant I couldn't get up. So I just gave up."

The inadequate design of the built environment through barriers such as steps compounded Jodie's feeling of "always stuck in here [the dwelling] with no change of scene", further entrenching feelings of being imprisoned and isolated in the dwelling. As such inadequate design also appeared to have a negative impact on the meaning of the dwelling.

(iii) Inadequate housing design

Jodie faced a whole range of design problems in her dwelling. Again, the main problem for Jodie was steps. However such was the problem of the design of the dwelling that Jodie spoke at great length of her 'dream house'. In this space everything in the kitchen was at an appropriate height and weight, the bathroom had a shower unit with bench in so that she could spend time relaxing in there and the bedroom opened out onto the garden so that on days when she was too weak to get out of bed she still had something nice to look out on to.

Jodie noted that she spent hours designing and re-designing her dream house in her mind. The dream house came to be her escape, her fantasy away from the reality of a dwelling that was inadequately designed. Jodie has designed this dream house to meticulous detail. As well as functional design issues to assist the accessibility of the dwelling – such as a shower with a seat in, a kitchen where all units were at the appropriate height for her and a bedroom on the ground floor with the bed having wheels on so that she could be wheeled out on to the beach on days when confined to the bed – Jodie had also invested her identity into the "dream house". For example as a keen environmentalist Jodie had 'built in' a number of "recycling bins under the

work surfaces”. Furthermore what also became important was that the dwelling was a communal house, a space where she lives with all her friends. Crucially however the dream house was all about location. Jodie knew exactly where she wanted this dream house to built – a spot a few miles away on the seafront. The location became crucial to Jodie’s dreams. Dreams that came to take on considerable significance:

Jodie: “Those dreams are important to me. When things get a bit out of perspective I need to hold onto them to keep in touch with reality.”

Accordingly it appears that it was this dream house – and importantly dreaming about being by the sea – that came to offer ontological security, a space she could escape to and space in which to feel secure given the problems of design within her own dwelling.

With the dwelling leaving Jodie dependent and powerless – to the extent that Jodie sought refuge in a “dream house”- the event of inadequate housing design must be understood as having a negative impact on the meaning of the dwelling. Indeed, as discussed by Chapman and Hockey in their edited book ‘*Ideal Homes*’ the very fact of having an ideal dwelling that is markedly different to the present dwelling in itself can have a very negative impact on any meanings attributed to the dwelling (Chapman and Hockey, 1999).

(iv) Discrimination

Because Jodie had no ‘visible’ sign of being disabled she indicated that she was constantly facing derogatory remarks when she went out. When in public, Jodie said that people often accused her of faking her illness. To use just one of Jodie’s examples, she recounted a particular occasion when she went to see a local band play. Jodie felt she had to go to the gig because the lead singer (a friend) had recently lost his mother to ME. Jodie wanted to go to give him support and to show that she was still okay. However in going she faced a torrent of abuse from people claiming that she was feigning her illness. The fear of encountering the discriminatory attitudes of others once again left Jodie feeling trapped in the dwelling.

However being in the dwelling did not prevent this abuse. Jodie indicated that she was scared to sit in her garden in case she was seen by neighbours who would shout

over the fence, accusing her of faking her illness. Consequently Jodie no longer even felt protected from the abuse in her own dwelling. To be brief, the discriminatory and contemptuous attitudes of others came to have a negative impact on the meaning of the dwelling for Jodie.

(v) 'Care' dynamics

Jodie echoed the opinion of Louise on the benefits of direct payments. For Jodie direct payments enabled her to develop a close friendship with her carer. Jodie noted that she felt happier because she knew it would be the same person coming into the dwelling and would not have to explain her needs anew everyday and she knew that the person coming in was someone she could trust – giving her an increased feeling of security and esteem in the dwelling.

Direct payments also allowed Jodie more control in the dwelling. Jodie described how the rapport developed through employing the same person facilitated a position where Jodie's complex needs could be understood. Rather than just being 'cared' for direct payments enabled Jodie to start regaining control, and was assisted by a sympathetic carer to start to do activities such as cooking. Jodie indicated that the independence she obtained through the direct payments scheme helped her to "regain control over my life and my home". Direct payments also give Jodie a growing sense of freedom. The freedom to do as she pleased in her dwelling. As a result, the event of care dynamics in this case must be understood as having a positive impact on the meaning of the dwelling.

(vi) Emotional attachment

Jodie had gone to great lengths to give her dwelling a 'homely' feel. Through items of furniture, additional furnishings and sentimental bric-a-brac Jodie had made her dwelling a space in which she felt "comfortable and homely". As with John, Jodie was concerned that installing adaptations would turn her dwelling into a hospital. Like John, her refusal to install adaptations such as chair lifts meant that on days where she had little energy she would be confined to one floor of the dwelling. This for Jodie was preferable to the alternative of installing "ugly adaptations". Adaptations that would have distorted the appearance of the dwelling, reflecting not her ideas and values but what she could not do. Refusal to install adaptations became

a powerful symbol of self expression and her desire to maintain control over her dwelling.

As noted in Chapter 6, to avoid installing adaptations Jodie used every day objects around the dwelling to assist her movement. For example, the ironing board became a grab rail, pillows and cushions were used to avoid having specialist seats and large furniture served as props to rest on to save installing hoists. In doing so Jodie noted that she was able to keep her dwelling looking homely. It became clear that the inventive use of her possessions became a small victory for Jodie over ME and design barriers. Indeed the items that had dual functions came to take on elevated importance, they were items that Jodie was proud of, reflecting her desire to be 'normal'. In this way, the dwelling held a positive value, with a certain degree of emotional attachment to items in the dwelling developing.

In spite of this, it would be a mistake to say that Jodie was attached to her dwelling. She indicated that she had little by way of memories attached to it. In the four years she had lived in the dwelling her friends had visited only a handful of times; she said she had little to talk about and found it very difficult to eat in front of other people. The only memories it contained were that of frustration and boredom, a reminder of her confinement. As a 'psychic warehouse' the only memories the dwelling contained were negative ones.

However, in discussing her housing history Jodie noted that she had never formed an attachment to any dwelling she had lived in "the way that a lot of other people do". As noted in Chapter 6, Jodie did not seek to form any attachment to the dwelling and never had done. Rather, Jodie had a "special connection with the sea" and the coastal areas in general. For Jodie it was the coast that she was attached to, with the beach embodying her memories and biography. Jodie's personal identity meant that she simply did not seek to form any emotional attachment with the dwelling.

(vii) Relationship with co-habitants

Jodie shares the dwelling with her housemate, 'Ben'. This friendship was significantly important:

Jodie: ...[Ben] knows me. He knows when am having a bad day and what that means... We get along well, being trapped in here makes it so difficult to socialise so living with my friend makes sense!”

Living with Ben clearly meant a lot to Jodie. Indeed Jodie had built a room for him in her “dream house”:

Jodie: “A dream house should be just what you dream of... for me not being able to get out and speak to other people I would want to have a communal house where all of my friends would live with me. So [names of friends including Ben] would all live there with me.”

What is interesting to note here is that Ben is the only constant between the dwelling she currently lives in and her “dream house”. As the one constant, Jodie’s friendship with her housemate Ben became one of the few events that appeared to have a positive impact on the meaning of the dwelling for Jodie.

Using the three dimensional framework all seven events that impacted on the meaning of the dwelling are presented diagrammatically in Figure 7. 9:

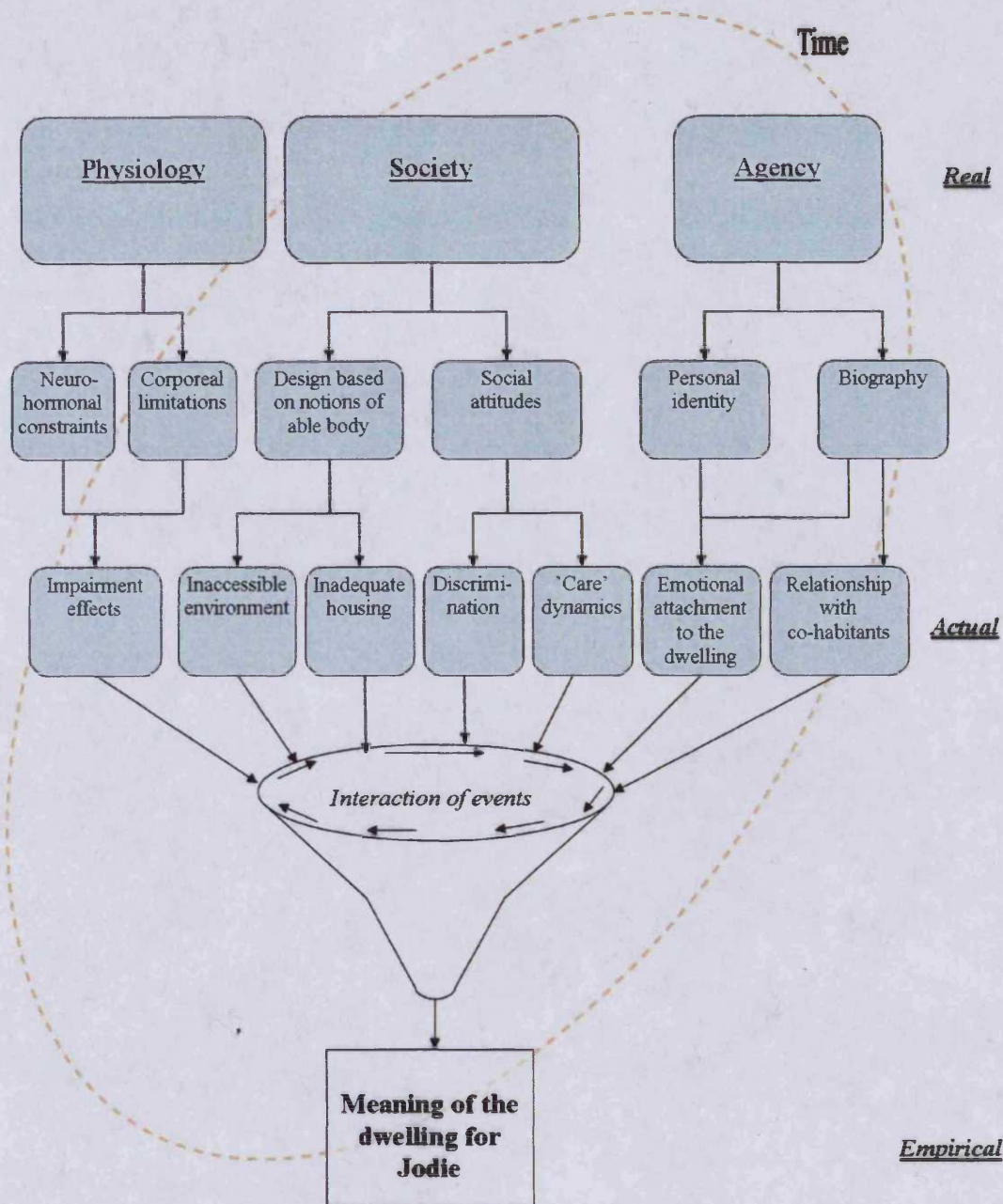


Figure 7. 9 –Structures, mechanisms and events identified in the determination of the meaning of the dwelling for Jodie.

Figure 7. 9 outlines the events and the underlying structures and mechanisms that impacted on the meaning of the dwelling for Jodie. These relational events interacted to produce a very unique meaning of the dwelling. The meaning of the dwelling for Jodie was a complex one with a number of events conspiring and conflicting to create a whole series of seemingly contradictory meanings. From the interviews with Jodie it became apparent that whilst the dwelling was a place of confinement, isolation,

boredom, dependency, and powerlessness it was also a space of freedom, control, security and a reflection of ideas and values. Understanding these conflicting meanings lies in understanding the interaction of the different events.

Jodie described her dwelling as “a colourful prison”. This phrase perfectly encapsulates the complexity of the meaning of the dwelling for Jodie. Events such as impairment effects, discrimination and the inaccessible environment conspired to produce a feeling of being trapped, bored and isolated in her dwelling. These negative meanings associated with the dwelling were then supported by the event of inadequate housing design which left Jodie feeling the dwelling made her both dependent and powerless. Clearly these meanings run counter to claims that the dwelling is a site of control, a centre of activities or a refuge from the outside world.

However, conflicting with these events was the event of care dynamics. With a new system of care in place through changing to the direct payments scheme Jodie gained a greater sense of freedom, control and security in the dwelling. Positive meanings were then reaffirmed through certain aspects of the event of emotional attachment. With Jodie using the dwelling as a site of self expression to reflect certain ideas and values, by investing time and emotional labour to a certain degree this helped to develop a level of attachment to the dwelling.

Given that the majority of events resulted in producing a negative meaning of the dwelling it come as little surprise that by and large the meaning was a largely negative one. The positive impact of the event of care dynamics and certain aspects of the event of emotional attachment were largely counteracted by other events such as impairment effects. Nevertheless, whilst the dwelling was a “prison” it was a “colourful” one, and some positive meanings did shine through. Explaining how such contradictory meanings sat side by side rests in recognising the fundamental role of time.

Time played a significantly important role in the meaning of the dwelling for Jodie. The impairment effects of ME were subject to rapid change. This left Jodie feeling trapped to one room in the dwelling one day, then able to slowly move around the dwelling the next day. Consequently meanings came to change very rapidly, and as

noted in Chapter 6, the different seasons came to bring different meanings to the dwelling. This explains why the meanings associated with the dwelling appear so contradictory- because events changed so rapidly the meaning of the dwelling fluctuated over short periods of time. The meaning of dwelling as a “colourful prison” occurred precisely because the meaning was constantly open to re-appraisal.

Moreover, the event of emotional attachment had a significant bearing on the meaning of the dwelling. Jodie came to obtain what can be understood as ‘ontological security’ not from the dwelling but rather from areas *outside* the dwelling – and most importantly from the sea and coastal areas. From her childhood coastal areas had held the most emotional significance for Jodie, being the place where she felt safe, comfortable and free. These areas embodied her most treasured memories and ambitions. As Jodie explained, she felt “at home” being by the sea. Consequently with the event of emotional attachment to the dwelling only weak, the dwelling was not that important to Jodie. It was never going to be a site of ontological security. As such its importance was diminished, enabling seemingly contradictory and conflicting meanings to lie in a curious temporally located harmony. The meaning of the dwelling then for Jodie must be understood as being not only complex but also entirely unique.

7. 5 Conclusion

This chapter has operationalised the analytical three-dimensional framework developed in Chapter 3 and presented an in-depth discussion of the findings from three participants to illustrate the complex and unique nature of the meaning of the dwelling for physically disabled individuals.

Principally, this chapter has emphasised the importance of recognising the interconnection of a variety of events on the meaning of the dwelling. Through retroductive analysis of the findings presented in Chapter 6, the case was made that it is impossible to explain experiences simply by reference to social arrangements. Rather it is necessary to understand events and mechanisms emerging from the structures of physiology, agency and society.

Acknowledging this, the three-dimensional framework developed in Chapter 3 was then operationalised to show how the different events emerging from the three ontologically distinct structures came to interact to produce the meaning of the dwelling. This framework facilitated a position whereby:

- the ontological reality of the impaired body and the ensuing impairment effects can be recognised but biological reductionism condemned,
- barriers arising from the structure of society such as the inaccessible environment, inadequate housing design, discrimination and ‘care’ dynamics can all be acknowledged without slipping into determinism,
- the important role of agency can be recognised and homogeneity and a uniform group identity rejected.

The central message of this chapter was that the meaning of the dwelling is a *complex, unique and temporally located* experience. It is the result of a number of different interacting, conflicting, competing and coinciding events, all distinctive to each individual. By advancing an explanation of the meaning of the dwelling as not just complex but also unique it becomes possible to develop a more complete understanding of the meaning of the dwelling, one that does not reduce disabled individuals to one homogenous group. Differences have to be acknowledged. In doing so it also becomes possible to offer an alternative to the host of literature which presents the experience of disabled individuals as one of loneliness, unhappiness, dependency and tragedy without discounting the fact that for some individuals such meanings were a reality.

As such there is no ‘meaning of the dwelling’ which could explain the experience for all individuals in this research. The meanings ranged from the dwelling as a site of confinement, isolation, boredom, dependency, insecurity, abuse and powerlessness to the dwelling as a space of control, freedom, self-esteem and a reflection of ideas and values. Indeed what became apparent was that an individual’s meaning of the dwelling may not just involve a single meaning but rather a set of fluctuating and often contradictory meanings. As a set of fluctuating meanings open to reappraisal any meaning of the dwelling has to also be understood as being temporally located.

Given this detailed analysis of the research findings, it now becomes necessary to reflect on how they address the research objectives identified in Chapter 1. It is to this final task that shall be the subject of the next chapter.

Chapter 8. Conclusion

Chapter 8

Conclusion

8. 1 Introduction

Through an appeal to critical realism and the three-dimensional framework this thesis has identified a range of events and generative mechanisms - each emerging from one of the three structures of either physiology, society or agency – that have an impact on the meaning of the dwelling amongst a sample of nineteen participants. Moreover, in doing so this research has also revealed that there is no universal meaning of the dwelling for disabled individuals. Rather what has been concluded is that any meaning (or set of meanings) must be understood as complex, unique and temporally located.

This concluding chapter will cover four key areas. Following this introduction the chapter will begin by addressing each of the five substantive research aims outlined in Chapter 1. Secondly, the chapter will outline the theoretical, methodological and empirical contributions, conclusions and implications that can be made from this research project. The chapter then offers a critical review of the research, reflecting on issues that have remained un-addressed and indicating how alternative research strategies may have yielded additional data. Finally, building on the arguments and conclusions made throughout this thesis, the chapter ends by outlining directions for future research.

8. 2 Addressing the research aims

In Chapter 1 five substantive research aims were identified. This section will return to these aims, explaining how this thesis has answered each one.

1. *To develop a critical understanding of the theoretical aspects of critical realism.*

Chapter 3 presented a detailed summary of the theoretical aspects of critical realism, noting exactly what critical realism was and was not. Through engaging with the work of Bhaskar, Archer and Sayer a thorough exposition of the critical realist philosophy was produced. The account presented however was more than just a

review. It sought to critically engage with some of the finer points of critical realist theory, seeking to theorise a way to bring in the largely overlooked physiological dimension. Being immersed in this way with the theoretical aspects of critical realism helped to facilitate a more focussed approach to the research, one that was able to question existing research from a particular theoretical position.

2. *To demonstrate the methodological potential of critical realism and establish its potential within disability and housing studies.*

As noted in Chapter 1 disability and housing studies have both remained largely untouched by critical realism, and as such there remains little published work discussing how this perspective can inform a research project in these fields. In Chapter 5 the methodological possibilities of critical realism were explained. From a summary of the intensive/extensive data collection approaches to a detailed discussion of the analysis process – including an original reading of Bhaskar’s DREI scheme - Chapter 5 sought to show precisely what is entailed in conducting a research project based on critical realism, the theoretical writings underpinning such directives and the benefits of adopting such an approach. By presenting this detailed account of how the research was conducted this thesis has added to Sayer’s (1992, 1997, 2000) exceptional contributions on the subject and demonstrated the methodological possibilities of critical realism not just for disability and housing studies but for social sciences as a whole.

3. *To advance an analytic framework through which to understand the impact of conflicting events on the meaning of the dwelling.*

Drawing on the ontological principles of critical realism, in Chapter 3 an analytical framework was developed, one that acknowledged the influence of the three structures of physiology, society and agency in explaining an experience. Of critical importance was that the framework stressed that any experience is the joint determination of events arising from the three structures and their emergent generative mechanisms. In summary, it was argued that structures give rise to particular mechanisms and when triggered these mechanisms give rise to particular events. These events will then have an impact on the experience. However the overall outcome is dependent on the interaction of *all* events that arise from the three structures of physiology, agency and society. Furthermore it was also asserted that

any experience is temporally located and any changes over time at the underlying level of the real would have an effect on events lying at the level of the actual and consequently on the experience lying at the level of the empirical. By doing so this 'three-dimensional' framework makes it possible to understand the impact of conflicting events on an experience, facilitating a non-reductionist position through an appeal to the irreducibility of an explanation to any one event.

Chapter 7 then sought to explain the research findings through this 'three-dimensional' analytical framework. Through retroductive analysis of the research findings and operationalising the three-dimensional framework it became possible to understand how the meaning of the dwelling comprises of the interaction of a number of competing and conflicting events from the three structures of physiology, society and agency and is subject to change over time. Indeed the case was presented that a strong emotional attachment to the dwelling can provide what Williams – albeit in a different context – has called a 'magical transformation', competing with events such as the inaccessible environment and inadequate housing design to make the dwelling somehow 'more tolerable, liveable or bearable' (2001a:58). By recognising the interaction of structures, mechanisms and events through the three dimensional framework the case was made that the meaning of the dwelling must be understood as being both complex and unique.

4. *To explore the range of events that can affect the meaning of the dwelling for physically disabled individuals.*

To uncover the events that impacted on the meaning of the dwelling, life history interviews were reasoned to be the most appropriate method. Full justification for this method was given in Chapter 5. Crucially it was asserted that by giving participants the opportunity to present their own accounts of the dwelling contextualised within their life story, this method could help bring to light the range of events in a way that no other method could.

In Chapter 6, the findings from the life history interviews were presented. This data revealed that a wide range of events impacted on the meaning of the dwelling, and in doing so provided a powerful challenge to accounts that have reduced explanations of the meaning of the dwelling to issues of inadequate housing design. Alongside

inadequate housing design the findings exposed the way in which the events of impairment effects, the inaccessible environment, 'care' dynamics, discrimination and emotional attachment to the dwelling all had a significant bearing on the meaning of the dwelling. Rather than just one event, the case was made in Chapters 6 and 7 that the meaning of the dwelling is instead the result of a range of different events, with the number of events present unique to the individual.

5. *To critique the social model of disability, asserting the need for a more experientially grounded understanding that is able to recognise the potentially disabling impact of impairment effects.*

"No theory emerges into the world fully formed, and getting the balance between the experience of impairment, and the experience of disability is a continuing endeavour."

(Shakespeare and Watson, 1997:268)

This thesis is part of this continuing endeavour. Chapter 4 presented a critique of the social model of disability offering a way of bringing the potentially disabling impact of impairment effects into a model that has cast impairment into the shadows. Central to this venture was an appeal to critical realism and the three-dimensional framework developed in Chapter 3.

In seeking to recognise the potentially disabling impact of impairment effects, physiology was presented as a real and distinct ontological structure. Indeed this claim becomes a fundamental assertion of the thesis. This however does not entail any biological reductionist or essentialist arguments. Rather, physiology and any emerging impairment effects become just one influence on disability alongside other events emerging from the structures of society and agency. By identifying the experience of disability in this way the disabling impact of impairment effects can be acknowledged without it becoming *the* explanation. Through such an understanding it becomes possible to avoid the extremes of both biological determinism and social constructionism and accept a more experientially grounded understanding of disability.

8.3 Contributions, conclusions and implications

This section is made up of three distinct parts: theoretical, methodological and empirical. Each part will outline the relevant contributions, conclusions and implications that emerge from this research project.

Theoretical

Critical realism has figured at every stage of this thesis. This thesis has made a clear theoretical contribution by locating critical realism within disability and housing studies. The work of Roy Bhaskar, Margaret Archer and Andrew Sayer has inspired a theoretically sophisticated research agenda, one that challenges existing boundaries in disability and housing research. Drawing on critical realism, this thesis has pointed towards a new direction for disability and housing research, asserting the need to integrate interdisciplinary contributions to help supplement existing arguments. Crucially, drawing on critical realist arguments it can be taken that contemporary housing and disability studies has been focussed on understanding events at the level of the actual and in doing so has missed out on understanding underlying explanations and importantly the connections between different events.

Building on critical realist arguments, the main theoretical contribution of this thesis is the development of the three-dimensional framework. This framework can enhance existing literature in a number of ways. To begin with, the framework has to be seen as contributing to critical realist theoretical writings by proposing an analytical schema whereby physiology is integral to the explanation of an experience. Whilst the role of physiology was recognised in the work of Bhaskar and Archer, it has remained under-theorised within critical realism and consequently its function has been neglected. By placing physiology as a key structure alongside society and agency the three dimensional framework is able to develop the theoretical writings of Bhaskar and Archer and offer an original proposition as to the role of physiology within critical realism.

With regard to literature within disability studies the three-dimensional framework breathes a new lease of life into some stagnant areas. As well as giving ontological depth to thought, in appealing to three deep underlying structures the three-dimensional framework provides a platform from which to question over-socialised

accounts within the social model. By adopting the three-dimensional framework it becomes possible to accept that an experience involves the complex interaction of events arising from physiology and agency as well as society. Through such an understanding, as explored in Chapter 4 the experience of disability can be broadened to account for the role of impairments alongside the very real disabling barriers created by society. The three dimensional framework thus allows the physiological body to be brought back in without discounting the influence of events emerging from the structures of agency and more importantly society. Understanding disability in this way through the three-dimensional framework marks an original and important theoretical contribution to the literature within disability studies.

By appreciating that structures are ontologically distinct - albeit significantly interdependent – and that an experience is made up of a number of events from these different structures, through the three-dimensional framework it becomes possible to recognise both differences and similarities without contradiction. In terms of the experience of disability this means recognising differing and particular impairment effects *as well as* shared events such as barriers in society without contradiction. In terms of the meaning of the dwelling this means recognising and making room for personal events such as positive experiences of the dwelling as a biographical accomplishment as well as collective experiences such as the inadequate design.

In short the three-dimensional framework illustrates a new direction for housing and disability studies: one that moves beyond static, over-socialised conceptions and values inter-disciplinary research and multifaceted explanations.

Methodological

This thesis has also made a number of methodological contributions. Firstly, at a general level, drawing on a previously un-explored passage of Bhaskar's work (1986:68) I asserted that analysis in critical realism runs beyond just retroductive analysis. Rather, it should be understood as a four-stage process comprising of description; retroduction; elaboration and elimination of alternative explanations; and identification of structures and mechanisms. Bhaskar has termed this the 'DREI' model of analysis. By adopting this over-looked approach and showing how the

DREI model of analysis works in practice this thesis offers an original contribution to critical realist methodological literature.

Further, this thesis has shown how critical realism can be employed at a practical level. As noted in Chapter 1, disability and housing studies have remained largely untouched by critical realism and as a result there remains little published work discussing how this perspective can inform a research project. By discussing the possibilities and practicalities of a critical realist research project in detail in Chapters 3 and 5 this thesis sought to remedy this neglect. Principally, by outlining the critical realist approach to data collection and analysis this thesis demonstrated the specific methodological demands and implications of a research project based on critical realism. In doing so this research project paves the way for future research projects within disability and housing studies to adopt a critical realist approach.

By adopting a life-history approach to interviewing this thesis also contributed to a growing body of work seeking to bring this research strategy out of the margins and into the mainstream of disability and housing research (see Chapter 5). As well as offering support to this growing methodological practice within disability and housing studies, by discussing the limitations and benefits of the life-history interview within a critical realist research project this thesis has also made an innovative contribution to critical realist methodological literature and accordingly to social science research methods in general.

Finally, in moving beyond a 'wheelchair reductive' view of disability this research challenged the dominant research focus on experiences of wheelchair users. By exploring the experiences of individuals with a range of physical disabilities, both sensory and mobility, this thesis has also made a useful methodological contribution to the disability literature. This commitment to moving beyond a 'wheelchair reductive' view of disability meant ensuring that individuals with communication difficulties were not excluded from the research process. Doing so involved adopting a methodologically sensitive research strategy, one that allowed participants the time and space to respond to questions and express their thoughts (see Chapter 5). The development of such a strategy represents a possible methodological contribution to

the disability studies literature, signalling the way for future research with individuals with communication difficulties.

Empirical

This thesis has made a number of key empirical contributions to the literature on the meaning of the dwelling. The principal empirical contribution of this thesis was to contribute to understanding of the meaning of the dwelling for disabled individuals. Whilst this research has built on existing work on this subject - for example the innovative work of Imrie (2004a, 2006a) - importantly this thesis has sought to critically assess this existing literature and address the emergent gaps.

The results of the research on which this thesis is based supported Imrie's previous findings that inadequate housing design is at odds with conceptions of the dwelling as a place of independence, privacy, security and control. Given this finding the meaning of the dwelling has to be recognised as being intimately bound to housing design. However the evidence from this research also revealed that alongside inadequate housing design a number of other events impacted on the meaning of the dwelling. These events were identified as impairment effects, the inaccessible environment, 'care' dynamics, discrimination and emotional attachment to the dwelling. For example, carers in the dwelling left individuals feeling powerless and insecure thus having a very negative impact on the meaning of the dwelling, though this was shown to change when individuals received direct payments through which to employ their own carers. Further, emotional attachments to the dwelling became an important factor, with strong feelings of the dwelling as a 'psychic warehouse' or 'biographical accomplishment' having a beneficial impact on the meaning of the dwelling. This event of emotional attachment is an important one, bringing something new to the existing literature base. Through recognising this event of emotional attachment it became possible to acknowledge the previously silenced stories of happiness in the dwelling for disabled individuals.

The evidence in this thesis revealed that as well as being a *complex* experience - the outcome of not one but a number of events - the meaning of the dwelling for disabled individuals is also unique. For each participant the meaning of the dwelling was unique, the result of emergent events from underlying mechanisms that had been

triggered. Whilst one individual may have gained privacy, security and intimacy from their dwelling, another individual may have desired such meanings but these ideals may not have been realised because of certain events and particular (power) relationships that occurred within the dwelling. The way in which different events in attendance interact becomes central to the meaning of the dwelling. In short, a homogenous 'meaning of the dwelling' for disabled people does not exist.

Moreover, what the findings also revealed that an individual may not have just had one meaning of the dwelling. Rather than *the* meaning of the dwelling singular, it became meanings of the dwelling. The resultant meanings may have comprised of a number of seemingly contradictory experiences, with any meaning of the dwelling differing from room to room and from day to day. In such instances the overall meaning then became subject to rapid change and in a constant state of flux, dependent upon whichever event exerted the greatest force at any particular point in time. Conceptualising the dwelling as temporally located in this way becomes a significant empirical contribution, supporting previous work in this area by Gurney (1996). More importantly however, from the research what becomes apparent is that the meaning of the dwelling has to be understood not as a unitary category but rather comprising of a number of fluctuating and even conflicting meanings. In light of this finding I contend that previous work that presents a seemingly static and homogenous meaning of the dwelling should be reconsidered.

However, this thesis is much more than just an extended response to Imrie's 2004 paper *Disability, embodiment and the meaning of the home* (2004a)³⁵. It has made a substantial contribution to housing and disability studies, enriching a field where empirical findings have been focussed on highlighting and reiterating events that arise from the structure of society. The empirical findings from this research demonstrate that critical realism (and the three-dimensional framework) can offer an opportunity to redress the existing empirical imbalance and integrate opposing epistemological traditions in a non-hierarchical way. In doing so events arising from the structures of

³⁵ My interest in this area began in 2001 with subsequent funding for this research commencing in October 2002; two years before the publication of Imrie's article. What is interesting to note however is that both Rob Imrie's work and my work on this subject gained funding through the same source (Economic and Social Research Council) at the same time.

physiology and agency can become legitimate foci in explaining the meaning of the dwelling, enabling hitherto unappreciated concepts to be recognised.

8. 4 Critical review of the research

Reflexivity has been central to this research project and a reflection on the research process was presented in Chapter 5. Here the role of the researcher was reflected on, in particular with respect to the interpretation of research data. The argument was presented that despite having power and a given biography it was still possible to interpret texts in an objective fashion. Further, I also reflected upon some of the practical problems involved in interviewing individuals with communication difficulties, discussing at length the measures taken to ensure the involvement of previously silenced experiences.

Nevertheless, despite this reflective approach to research a number of aspects of the research still have to be addressed. These aspects fall under six points:

1. Inability to access the most isolated - To try and ensure a variety of experiences were explored this research looked towards recruiting participants from a wide range of organisations. However, a problem previously noted by Boucher in her work on homeless lesbians and bisexual women is that with any method of recruitment there will always be a problem of trying to reach and access the most isolated of people (2005:339). This research was no different. Consequently despite best efforts to counter this problem the experiences of the most isolated will be missing; experiences that could have revealed additional events that impacted on the meaning of the dwelling.

2. The quantity of data – The life-history interviews with nineteen participants produced over sixty hours of interview data. Transcribing this material was an exhausting and energy-sapping process. However, I feel doing this transcription gave me the chance to really grasp the data. The real frustration lies in how little of the data is actually shown in this research. Whilst all the data was used to inform the analysis and help understand the events that impact on the meaning of the dwelling, by squeezing the material into just two chapters inevitably only a fraction of the data

could be presented here. Accordingly I would like to take this opportunity to assure all participants that whilst not all the data has been presented in the thesis **all** the data was used to inform the analysis and all transcripts and subsequent analysis remain intact to be re-visited at a later stage.

3. The difficulty in representing concepts graphically – The intention of the three-dimensional framework figures (see Chapters 3, 4 and 7) was to present a complicated set of ideas in an uncomplicated fashion. As the aphorism goes, a picture paints a thousand words. However, the graphical representations fail to show the complexity of the arguments being made. The figures do not show the connection between the three structures and as such fail to show how particular events can be accounted for through reference to other structures. Further, whilst the oval overlay of ‘Time’ is used to show how structures change over time it does not convey the complexity and interplay of structure and agency and how the two impact on one another to produce change over time. Archer’s Morphogenetic sequence diagram shows this process far more effectively (1995, see Chapter 3). In short, the figures used in this thesis must be understood as *supporting* the text and not as an alternative to reading and engaging with the written material.

4. Loss of control over how the research is used - Reflexivity is not just about recognising the role of power during the research process, but also those at play after. Fine *et al* remind us that we have to anticipate how others will read/interpret/distort/report the research (2000). Indeed it is this that that represents the most significant potential to expose participants to harm (Hammersley and Atkinson, 1995; Kvale, 1996). I am aware that in arguing for an acceptance of a stratified three-dimensional framework that the research could be distorted to support just a medical model view, and as a result I may be confronted with many critics who argue that I am just another insensitive non-disabled researcher. Alternatively the research could be distorted to overplay the role of agency and lead to a decrease in resources available for housing adaptations/ design innovations, something that Allen encountered in his research on the need to recognise the role of agency in the housing and health debate (2000:63). This would be a complete misreading of the research. However if such a reading were to take place and impact on policy it could have a negative effect not only on the participants but to disability rights movements as a

whole. Misreading and the subsequent damage it could do to people's lives is beyond my control. What becomes important is to stress the importance of the social structures and the disabling mechanisms that they give rise to and be prepared to answer critics who may have misinterpreted the research.

5. Reproduction of power hierarchies - As discussed in Chapter 5, whilst this research cannot be described as an emancipatory research project (Stone and Priestley, 1996; Barnes, 2004b), it was nevertheless influenced by these writings. Specifically it is from an awareness on this work that attempts were made to question the dual researcher/researched and able-bodied/disabled power inequalities. However critics of this stance could argue that in singling out disabled individuals as requiring 'special treatment' I am actually *reproducing* power hierarchies rather than tackling them. Whilst I recognise the reasoning behind such an argument in response to this charge I would maintain that the attempts made to challenge the research hierarchy have in fact little to do with whether an individual is disabled or not. Rather it is couched in a more wide-ranging attempt to destabilise the power of the researcher and empower the participant.

6. The fallibility of knowledge – Despite the claims made in this research I acknowledge that the knowledge produced is ultimately fallible. As noted in Chapter 3 a critical realist perspective accepts that all knowledge claims are partial, fallible and have to be recognised as socially produced to a certain extent (Sayer, 1992, 2000; Collier, 1994; Yeung, 1997; Bhaskar, 1998; Cruickshank, 2002; Danermark *et al* 2002). Consequently it becomes necessary to understand the situated nature of the analysis and the ultimate fallibility of the structures and mechanisms identified in this thesis. However whilst recognising that the world can only be known in terms of available discourses and accordingly accepting ultimate epistemological relativism, critical realist accounts still reject any notion of judgmental or ontological relativism (see Bhaskar, 1998:57-58; also 1986:72-3 cited by Collier, 1994:90). In other words, whilst all knowledge is fallible, it is not all equally fallible (Sayer, 1992:68; Yeung, 1997:54). Although absolute truth becomes meaningless, Sayer's notion of 'practical adequacy' enables the possibility to distinguish good ideas from bad ideas, between more and less fallible accounts and between those whose inadequacy is already clear and those that have so far been proved to be adequate (1992, 2000; for discussion of

practical adequacy see Chapter 3). In seeking to move beyond a determinist account and recognise the importance of agency and physiology, the practical adequacy of this thesis lies in being able to explain the differing experiences of the meaning of the dwelling and hence generate knowledge about activities as they are ‘actually realized’ (Sayer, 1992:69). So whilst it has to be recognised that it becomes impossible to justifiably claim to ‘have discovered the *absolute truth*’ about the meaning of the dwelling for the participants involved and that as a fallible theory it is likely to be transcended by new theories, I contend that the knowledge produced, although fallible, is practically adequate (Sayer, 1992:67, italics in original).

Given this critical review, whilst the analysis can be regarded as ‘practically adequate’ this does not mean there is no room for improvement in the research. Although I maintain that life history interviews were a highly effective research strategy in raising the voices of the previously ignored and exploring the full experiences of the meaning of the dwelling I believe that an appeal to additional strategies may have produced even richer accounts.

One such strategy would have been to use non-verbal techniques of data collection. Such a technique has previously been used by Cooper Marcus, who asked participants to draw what their home means to them and then followed this up by asking them to discuss their drawing (1995). Gurney has previously argued that such a technique could prove to be a rich source of data for housing research (1996). Asking participants to make such drawings of past and present meanings their may have yielded some very interesting material. Additionally, asking participants to photograph important areas of their dwelling may also have provided further interesting material from which to draw upon (for previous use of such a technique in housing research see Hurdley, 2006b). At the outset of this research project such methods were ruled out over concerns that because some individuals may not be able to complete such tasks –owing to the nature of their disability- the data produced in this way would not have been comparable. The over concern here on what individuals could *not* do resulted in missing out on what individuals *could* do. Furthermore, the research was never meant to be a comparative study.

With the benefit of hindsight, the recruitment process could have been approached slightly differently. For whilst the research sought to explore the experiences of a range of disabilities, ultimately there was a disproportionate number of participants who relied on the use of a wheelchair. The problem here was one of perceived eligibility. Potential participants seemed to assume that it was only the experiences of wheelchair users that I wanted to hear. This is based on the comments of Jimmy, Jodie and Harry who on initial contact all asked if they could be involved in the research even though they were not wheelchair bound. Consequently the sample was not as diverse as wished for. On reflection a broader range of disabled experiences could have been uncovered by inserting a line into access letters saying words to the effect of “I would particularly like to hear from individuals with sensory impairments”. Further, whilst the research sought to gain a variety of experiences by using a range of agencies as gatekeepers, it may have been of benefit to try and also recruit participants through agencies that were not directly focussed on serving disability interests, for example asking to place speculative letters in public places such as libraries and sports centres. In doing so I believe a broader range of experiences would have been exposed.

8. 5 Directions for future research

The final section of this thesis will outline potential new directions for research that transpire from the arguments and conclusions made in this thesis. Directions that outline my future research agenda and indicate possibilities for researchers working in variety of research areas.

At a general level the three-dimensional framework provides an important and sizeable platform for further research. The framework provides an opportunity to rethink a vast range of existing debates by looking to acknowledge the roles of physiology, society and agency and their emergent events in a dynamic and non-reductionist way. Doing so offers an exciting and original direction for research, not just in housing and disability studies but in *all* areas of the social sciences. It also paves the way for truly multi-disciplinary research projects, ones that are informed by researchers, academics, policy makers and additional interested stakeholders from disparate and contrasting research backgrounds and traditions. It would not be a

research agenda, but rather an analytical framework underpinning a variety of research projects.

Time was recognised as an important factor in explaining the meaning of the dwelling and had a central role in explaining experiences in the three-dimensional framework. However given space restrictions in this thesis it was not possible to fully explore the possibilities that temporal understandings can bring. I believe that by forging links with the burgeoning literature on time, biographically informed research could be profitably pursued and applied to a number of aspects in both disability and housing studies. Of particular interest I believe would be to take understandings of disability further using this temporal dimension. Whilst there has been work on the time taken to 'adjust' to disability (see Chapter 4) there has been little else within disability studies engaging in debates on time. For example it is very difficult to find any research which recognises the way in which impairment effects can vary over time – both short and long term. In light of new debates and the material developed in this research project I contend that the time has come to stimulate such a discussion.

At a more specific level, the empirical findings of this research point towards the need for an alternative research agenda in housing studies – one that looks to explore not the home but the *dwelling*. With the physical product of the house becoming intimately tied to the notion of home (through inadequate design) the term 'home' becomes a dubious one. To draw on critical realist terminology I would argue that the term 'home' in this context is in fact a bad abstraction in that in neglecting the physical aspects of the house it is dividing what is in effect indivisible (for more on the notion of 'bad abstraction' see Sayer, 1992, 2000; Fitzpatrick, 2005).

Acknowledging the influence of the physical structure of the house on the 'home', King (2004) and Imrie (2006a, 2006b) have elsewhere suggested the need to talk about dwellings rather than houses/homes. By operationalising the notion of the dwelling this thesis provides a starting point for this new research endeavour and paves the way for promising avenues of future work in this area.

As was made clear in Chapter 1 the focus of this research project was on exploring the impact the neglected variable of disability had on the meaning of the dwelling. Given this explicit focus on an under-explored issue, no attempts were made to explore the

impact that additional variables such as class, income, gender, ethnicity, sexuality or tenure had on the meaning of the dwelling. The focus for future research in this area therefore lies in seeking to remedy this neglect and understand the impact of these additional variables *alongside* disability. For example, given Rae's (1993) previous suggestion that having female carers in the dwelling can threaten a disabled women's marital relationship and domestic role in the dwelling, does gender have a compounding affect on the meaning of the dwelling? Further does low income, and with it the need to rely on inaccessible public transport and the need to engage with the assessment process contribute to feelings of isolation and loss of control over the dwelling? Such questions need to be empirically explored before any assertions can be made, and herein lies scope for further research – research that could reveal a great deal about how different variables can affect the meaning of the dwelling. Similarly whilst the decision was made not to look at the assessment process given the wealth of literature already on this subject, on reflection it may have produced an interesting avenue of research and highlighted events that may have been missed.

Additionally, there is also a need to explore the many different types of disability not covered in this research, in particularly individuals with mental health difficulties or learning disabilities. The possibility for research on this variable was identified but not empirically explored in this research project. As a result of Asbergers Colette had become Deaf. As this research project was focussed on uncovering events connected to physical disabilities the research concentrated on exploring how Colette's deafness impacted on the meaning of the dwelling. However what became apparent from the interview was that Asbergers also had a significant impact on the meaning of the dwelling in its own right. For example, it led to Colette not wanting to be around other people, with her dwelling coming to take on extra significance as a refuge from the outside world as a result. Unfortunately exploring the meaning of the dwelling for individuals with mental health difficulties was regarded as being outside the scope of this thesis. Indeed, exploring the voices of a group marginalised even within the disability studies literature is the subject for a whole new PhD thesis.

The thesis opened with a series of popular aphorisms on the home. These aphorisms were intended as nothing more than a crisp scene setting introduction to the research. However reflecting on these sayings, in light of the material revealed over the last

eight chapters it seems that a reworked version of this opening expression actually offers a neat conclusion to the arguments and experiences presented in this thesis. Modified to express the experiences of the nineteen disabled individuals who participated in the research this extract can be adapted to read as: *The dwelling. It can be a prison. It can be where charity is experienced. It can also be where the heart is.* It is the ambiguous and contrary nature of this expression that not only summarises the conclusions of this research, but also explains why the dwelling has been - and will remain - an attractive, alluring and above all absorbing concept.

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Appendix 1

Design specifications

1. Part M building regulations

The Part M building regulations have been highlighted by Carroll, Cowans and Darton (1999:10-11). The requirements for a new house are as follows:

The approach to the house should be wide enough for wheelchair users, even when there is a parked car. This translates as an additional 900mm added to the space given for a car.

The approach should not be too steep, ideally it should be level. If the plot gradient is less than 1:20 then no part must be steeper than 1:20. If the plot gradient is between 1:15 and 1:20 then individual slopes of 5m or less may have gradients up to 1:12 and individual slopes 5 to 10m in length may have gradients up to 1:15. Paths should be at least 900mm wide.

An accessible threshold at entrance level should be provided.

Doorways and corridors should be wide enough to allow wheelchair users to manoeuvre into and out of rooms. The entrance door must always be 775mm in width. Internal doors and corridors conform to the following table:

Doorway clear opening (mm)	Corridor passageway width (mm)
750 or wider	900 (when approach head-on)
750	1200 (when approach not head-on)
775	1050 (when approach not head on)
800	900 (when approach not head on)

Communal stairs in blocks of flats should provide ease of access to ambulant disabled people. Handrails should extend 300mm beyond top and bottom step and be 900mm from nosings.

A steeped change of level within an entrance storey should allow ease of access to ambulant disabled people, with flight clear width of 900mm and suitable continuous handrail on each side where there are more than three rises.

Wheelchair users should be able to use any lift provided in a block of flats. There should be clear landing entrance 1500x1500mm, lift controls between 900 and 1200mm from the floor.

Switches and sockets at a convenient height for all, between 450 and 1200mm from finished floor level.

All homes should have an entrance level WC that is useable by a wheelchair, with clear useable space between the front of the WC and opposite the wall/door of at least 750mm.

2. Lifetime Home building regulations

Lifetime Homes designs call for building regulations that are above those outlined in the Part M regulations. Replicating the summary presented by The Joseph Rowntree Foundation, the sixteen standards can be seen in the table below (see also Carroll, Cowans and Darton, 1999:10-11; Imrie, 2006a)

Table 1: Lifetime Homes standards

Lifetime Homes standards	Specifications and dimensions which meet Lifetime Homes standards	
1 Where there is car parking adjacent to the home, it should be capable of enlargement to attain 3300mm width	The general provision for a car parking space is 2400mm width. If an additional 900mm width is not provided at the outset, there must be provision (e. g. a grass verge) for enlarging the overall width to 3300mm at a later date	
2 The distance from the car parking space to the home should be kept to a minimum and should be level or gently sloping	It is preferable to have a level approach. However, where the topography prevents this, a maximum gradient of 1: 12 is permissible on an individual slope of less than 5 metres or 1: 15 if it is between 5 and 10m, and 1: 20 where it is more than 10m.* Paths should be a minimum of 900mm width	
3 The approach to all entrances should be level or gently sloping	See standard 2 above for the definition of gently sloping	
4 All entrances should: a) be illuminated b) have level access over the threshold c) have a covered main entrance	The threshold upstand should not exceed 15mm	
5 a) Communal stairs should provide easy access and b) where homes are reached by a lift, it should be fully wheelchair accessible	<p><i>Minimum dimensions for communal stairs</i> Uniform rise not more than 170mm Uniform going not less than 250mm Handrails extend 300mm beyond top and bottom step Handrail height 900mm from each nosing</p> <p><i>Minimum dimensions for lifts</i> Clear landing entrances 1500x1500mm Min. internal dimensions 1100x1400mm Lift controls between 900 and 1200mm from the floor and 400mm from the lift's internal front wall</p>	
6 The width of the doorways and hallways should conform to the specifications in the next column .	<p><i>Doorway clear opening width (mm)</i></p> <p>750 or wider</p> <p>750</p> <p>775</p>	<p><i>Corridor/ passageway width (mm)</i></p> <p>900 (when approach is head- on)</p> <p>1200 (when approach is not head- on)</p> <p>1050 (when approach</p>

	<p>is not head- on) 900 (when approach is not head- on)</p> <p>900</p> <p>The clear opening width of the front door should be 800mm. There should be 300mm to the side of the leading edge of doors on the entrance level</p>
7 There should be space for turning a wheelchair in dining areas and living rooms and adequate circulation space for wheelchair users elsewhere	A turning circle of 1500mm diameter or a 1700x1400mm ellipse is required
8 The living room should be at entrance level	
9 In houses of two or more storeys, there should be space on the entrance level that could be used as a convenient bed- space	
10 There should be: a) a wheelchair accessible entrance level WC, with b) drainage provision enabling a shower to be fitted in the future	<p>The drainage provision for a future shower should be provided in all dwellings</p> <p><i>Dwellings of three or more bedrooms</i> For dwellings with three or more bedrooms, or on one level, the WC must be fully accessible. A wheelchair user should be able to close the door from within the closet and achieve side transfer from a wheelchair to at least one side of the WC. There must be at least 1100mm clear space from the front of the WC bowl. The shower provision must be within the closet or adjacent to the closet (the WC could be an integral part of the bathroom in a flat or bungalow)**</p> <p><i>Dwellings of two or fewer bedrooms</i> In small two- bedroom dwellings where the design has failed to achieve this fully accessible WC, the Part M standard WC will meet this standard</p>
11 Walls in bathrooms and toilets should be capable of taking adaptations such as handrails	Wall reinforcements should be located between 300 and 1500mm from the floor
12 The design should incorporate: a) provision for a future stair lift b) a suitably identified space for a through- the- floor lift from the ground to the first floor, for example to a bedroom next to a bathroom	There must be a minimum of 900mm clear distance between the stair wall (on which the lift would normally be located) and the edge of the opposite handrail/ balustrade. Unobstructed 'landings' are needed at top and bottom of stairs
13 The design should provide for a reasonable route for a potential hoist from a main bedroom to the bathroom	Most timber trusses today are capable of taking a hoist and tracking. Technological advances in hoist design mean that a straight run is no longer a requirement
14 The bathroom should be designed to incorporate ease of access to the bath, WC	Although there is not a requirement for a turning circle in bathrooms, sufficient space

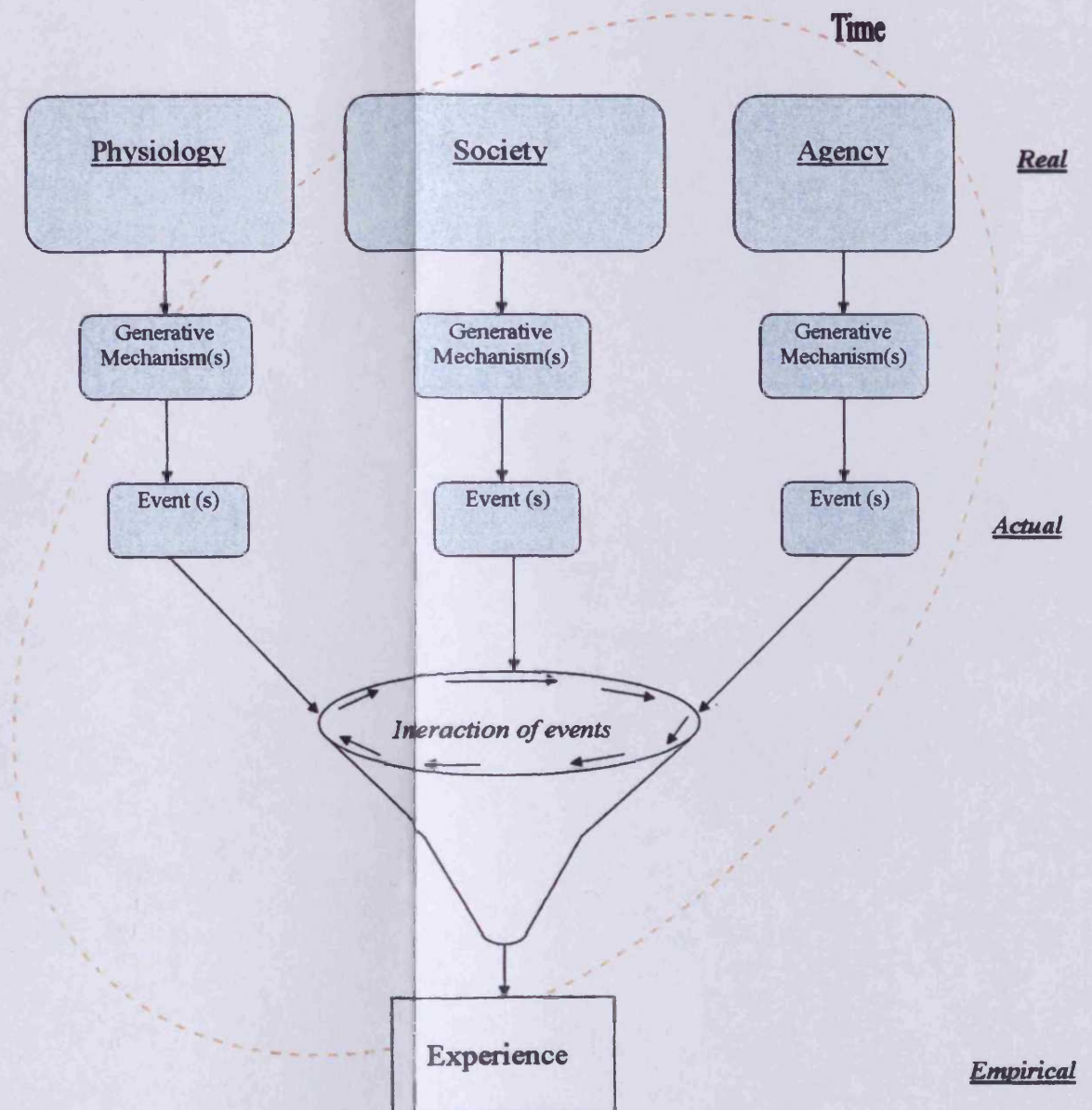
and wash basin	should be provided so that a wheelchair user could use the bathroom
15 Living room window glazing should begin at 800mm or lower and windows should be easy to open/ operate	People should be able to see out of the window whilst seated. Wheelchair users should be able to operate at least one window in each room
16 Switches, sockets, ventilation and service controls should be at a height usable by all (i. e. between 450 and 1200mm from the floor)	This applies to all rooms including the kitchen and bathroom

Source: Joseph Rowntree Foundation, 2006

Appendix 2

Three-dimensional framework

Diagrammatic representation of the three-dimensional framework:



Three dimensional framework for explanation of an experience over time.

Appendix 3

Sample access letter to organisations

Dear X

Hello, my name is Andrew McKechnie, and I am a PhD student at Cardiff University. We spoke on the telephone on Wednesday 11th February where we discussed the possibility of conducting research with X Housing Association.

I have recently secured funding for the next three years to conduct research into the meaning of home for those with disabilities and the wider impacts this can have on social exclusion and citizenship. The central concern of this research will be to explore how physically disabled individuals adapt to their housing circumstances and their immediate environment. The benefits of such a study would hopefully be to highlight the variety of problems the environment poses to severely disabled people and their families, and the need for more flexible responses as well as increased resources.

In our telephone conversation you asked me to explain how you could help in the research. I would greatly appreciate the opportunity to learn from your experience and engage with you in conducting research to facilitate a greater understanding of the home for disabled people, and explore the wider implications for social exclusion and citizenship. What would be particularly helpful would be if I could talk to some of the staff engaged in supporting people and helping them to live independent lives. It would also be very useful for the research if I could talk with the individuals who live in your houses and flats.

Before becoming a PhD student I studied a MSc course entitled Social Science Research Methods. As part of the course I completed a dissertation which explored alternate frameworks for conducting research into disability issues. A central theme of the dissertation was on emphasising the necessity of developing a research agenda that stressed the importance of partnership based research and emphasised the importance of confidentiality. Ensuring privacy and confidentiality will be of utmost priority in conducting the research and I will assure any individuals involved that anything they say will only be heard by me, and also that anything that I do report in the dissertation will be, and will

remain, anonymous. Any research that I conduct will be conducted following the British Sociological Association's statement on ethical practices. Ethical considerations will be of paramount concern to the research, with an on-going endeavour to respect the privacy and confidentiality of everyone involved in the research.

I hope you feel able to assist me, at any level, in the research. I am happy to meet or talk over the telephone with you, and discuss my research plans in more detail, and answer any questions you may have. You can contact me at 029 208 75169, via email mckechnieaj@cf.ac.uk or via post at Cardiff University, Glamorgan Building, King Edward VII Avenue, Cardiff, CF10 3WA. Alternatively please feel free to contact my supervisors Bridget Franklin (029 208 76223 or FranklinBJ@cardiff.ac.uk) or Craig Gurney (029 208 76231 or Gurney@cardiff.ac.uk) if you have any questions. I look forward to hearing from you.

Yours sincerely,
Andrew McKechnie

Appendix 4

Specific access letter to Katy

Dear Katy,

Hello it's Andrew McKechnie from Cardiff University. Thank you for indicating your willingness to be involved in the research.

As I indicated in the previous letter, the aim of the research is to explore experiences of the home. The aim is to work towards tackling and bringing down barriers and stereotypes, as well as arguing for the need for increased resources.

I am free throughout much of July, the latter half on August and throughout September. I have written a list of all the dates on which I am free, If you would like to circle a date that is good for you and write in a time I would be happy to meet you at your house to conduct the interview then. If there is anything further that you would like to know about the research please do not hesitate to ask.

Regards,

Andrew McKechnie

Dates for interview

July

Monday 19 th	Time:
Tuesday 20 th	Time:
Wednesday 21 st	Time:
Thursday 22 nd	Time:
Friday 23 rd	Time:

Wednesday 28 th	Time:
Thursday 29 th	Time:
Friday 30 th	Time:

August

Monday 2 nd	Time:
Tuesday 3 rd	Time:
Wednesday 4 th	Time:
Thursday 5 th	Time:
Friday 6 th	Time:

Friday 20 th	Time:
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Monday 23 rd	Time:
Tuesday 24 th	Time:
Wednesday 25 th	Time:

September

From Tuesday 7th Date: Time:

- Please circle if you would like to write / type your responses
- If you would like to conduct the interview any other way please describe:

Appendix 5

Biographies

All details refer to information given at time of interview. Pseudonyms have been given to preserve anonymity. All participants lived in the South Wales area.

Finn – Male. 21 years old. Has lived in current Housing Association dwelling with family for eleven years. Uses direct payments scheme. Has had Muscular Dystrophy since birth leaving and uses a wheelchair.

Martin – Male. In his 40s. Has lived in current Housing Association dwelling on his own for fourteen years. Uses direct payments scheme. Had a brain haemorrhage fourteen years ago now has speech difficulties and uses a wheelchair.

Jimmy – Male. 43 years old. Has lived in current owner occupied dwelling on his own for the last twenty years. Does not need care assistance. Had a brain haemorrhage fourteen years ago. Originally he was paralysed from the shoulders down but now has regained the use of limbs, walking with a stagger and having difficulty writing.

Jodie – Female. Has lived in current privately rented dwelling with her friend for four years. Uses direct payments scheme. Has had ME since a teenager.

Carrie – Female. In her late 60s. Has lived in current owner occupied dwelling for last forty two years. Currently lives on her own but previously used to share the dwelling with her mother. Uses direct payments scheme. Has had Spina Bifida since birth and uses a wheelchair.

Louise – Female. In her 60s. Has lived in current owner occupied dwelling with husband for the last thirteen years. Uses direct payment scheme. Diagnosed with Multiple Sclerosis twenty three years ago and uses a wheelchair.

John – Male. 67 years old. Has lived in current owner occupied dwelling with wife for sixteen years. Does not receive any care assistance. First signs of Multiple Sclerosis came five years ago and is now a wheelchair user.

Alison – Female. 64 years old. Has lived in current owner occupied house for twenty one years. Currently lives on her own but previously used to share the dwelling with her husband and children. Uses direct payments scheme. Diagnosed with Motor Neurone Disease three years ago has restricted use of limbs using a wheelchair and has difficulty communicating verbally.

Katy – Female. In her early 40s. Has lived in current Housing Association dwelling on her own for sixteen years. Does not need care assistance. Has had Cerebral Palsy since childhood leaving her unable to communicate verbally and restricted use of hands.

Melissa – Female. 38 years old. Has lived in current owner occupied house with sister for the last ten years. Uses direct payments scheme. Has had osteogenesis imperfecta since birth and uses a wheelchair.

Sam – Male. 55 years old. Lived in Housing Association residential setting. Did not require any care assistance. Diagnosed with Multiple Sclerosis thirty years ago, mobility restricted and uses a wheelchair.

Sissy – Female. In her 60s. Has lived on her own in current Housing Association residential setting for last twelve years. Does not need care assistance. Went into hospital twelve years ago but in the theatre choked on own vomit, the body panicked leaving in her in a coma for six months. Now has a speech impediment and uses a wheelchair.

Steven – Male. In his 60s. Has lived on his own in current Housing Association residential setting for last four months. Does not receive any care assistance. Has had ‘terrible arthritis’ for the last sixteen years, leaving his mobility restricted.

Deirdre – Female. 66 years old. Has lived with her daughter, son-in law and granddaughter in owner occupied dwelling for four years. Receives care from social services. Diagnosed with Multiple Sclerosis twelve years ago and now uses a wheelchair.

Sharon – Female. In her 30s. Has lived in current owner occupied house with her husband for the last four years. Does not receive any care assistance. Has had a rare condition since birth, affecting her muscles, bones and also leaving her partially sighted.

Harry – Male. In his 70s. Lived in owner occupied dwelling with wife for last six years. Does not receive any care assistance. Contracted Parkinson’s fifteen years prior to the interview.

Valerie - Female. 84 years old. Has lived in owner occupied dwelling for ‘about thirty years’. Currently lives on her own, but previously shared the dwelling with her family. Does not receive any care assistance. Has been visually impaired for last four years.

Colette - Female. 52 years old. Has lived in current owner occupied dwelling with her husband for nine years. Does not receive any care assistance. Has had Asbergers since birth, affecting her hearing.

Mick - Male. In his 50s. Has lived on his own in current Housing Association residential setting for last three years. Does not receive any care assistance. Had a stroke years ago leaving him with speech difficulties and unable to use his left hand.

Appendix 6

Interview schedule

Interview name:

Date:

Time Started:

Time Completed:

Follow up interview arranged?

Introduction *(to be read out before interview)*

The recording and subsequent transcripts of this interview will only be used for the purposes of my research. The information from this interview will be treated in the strictest of confidence.

The purpose of this interview is to explore your experience of the dwelling and understand the various events that come to impact on this experience.

Before we start is there anything you would like to know about me, the research I am conducting or anything about the interview?

Section 1: Life History

1. Could we begin by you telling me about your life and some of the changes that have happened?

Prompt about:

- *Family*
- *Age*
- *Jobs have had; the reasons for leaving*
- *Marriage history*
- *Children*
- *Interests*
- *Life changing experiences*
- *Type of disability*
- *Onset of disability*
- *Episodic issues*

2. Could you tell me about any barriers you face in the wider environment. To what extent do these affect your life?

Section 2 : Assistance/ care received

3. Please could you tell me a little about any care support you receive, and explain how it works.

4. What is the nature of your relationship with your carer(s)?

5. What are the positive and negative aspects of this service?

6. Do you feel the service gives you/leaves you : (i) independence/dependent?
(ii) power/ powerless?
(iii) emotional support/ emotionally neglected?
(iv) privacy / unsafe?

7. Can you help me understand why you feel like this?
8. Related to this, can you tell me what independent living means to you?

Section 3: The dwelling

I'd like to move on now and ask you some specific questions about your current dwelling and your housing history.

9. Firstly, could you tell me about the different dwellings you have lived in over your life, including who you lived with, how long you lived there and the tenure of each property.
10. Why did you move into this dwelling?
11. How long have you lived here?
12. Can you tell me a little about the factors that influenced moving into this dwelling.
12. Did you look at any other dwellings before you chose this one?
If yes: Why did you decide not to chose them?
If no: Why did you not look at any where else?
14. How do you feel about moving into this property?
15. How do you feel about your old property?
16. Could you tell me a little bit about this dwelling, detailing for example how many rooms it has, whether you have any outside space and who else lives here?
If other people live there: Can you tell me who does what and who will make decisions on a typical day?
17. Do you have access to all the space in the dwelling? Is there anywhere that you cannot access?
If there is space cannot access: *Can you explain how you feel about no longer being able to access this area.*
18. Have you had to install many adaptations to this dwelling? Can you tell me about them.
19. How did this make you feel?
20. Did you encounter any difficulties in obtaining adaptations/ getting funding for adaptations?
21. Have you done many jobs on the house since the adaptations were installed?
22. Are you happy with the state of repair and decoration of the house at the moment?
23. Is there anything you would like changed?
24. Are you able to carry out these changes?
If no: Can you explain how this makes you feel?

25. Have there been any periods where you have been confined to the dwelling/ a particular space within the dwelling?

If yes: Can you explain for how long, and how this made you feel

26. Who do you let into your dwelling?

27. *IF HAS CARERS:* How do you feel about carers coming into the dwelling? Do you have any control over who comes in?

28. How does this make you feel?

Probe about issues of security and privacy

29. Does anyone else have a key to the dwelling?

30. Do you feel safe with this?

31. Is there anywhere you seek privacy away from here?

If yes: Could you help me understand better why you feel like this?

32. Do you have any relatives/friends living in the local area?

33. When was the last time any of your relatives/friends visited you here?

34. When was the last time you met up with one of your relatives/friends? Where did you meet?

35. Can you explain to me if there are any limits to meeting up with relatives/friends outside your dwelling.

36. How does this make you feel?

37. Do you ever feel isolated in the dwelling?

38. Some people say that house and home mean quite different things. What does your home mean to you?

*Prompt about: Descriptions of home life,
Happiest/ saddest moments,
Particular events
Setting up home
Positive aspects of home life
Negative aspects of home life*

39. Do you have any current plans to move out of this dwelling?

If yes: why do you want to move? Where do you want to move to?

If no, how long do you think you will live here?

40. Finally, do you have any questions you would like to ask but haven't had the chance to ask yet?

Closing: *(to be read out)*

Thank you, and may I remind you once again that all information given in this interview will be treated with the utmost level of privacy and confidentiality, and only I will have access to the tapes and their subsequent transcriptions.

