The choice agenda and the geography of housing for people with intellectual disabilities

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Abstract

The notion of choice is emerging as fundamental to new approaches to the provision of housing for people with intellectual disabilities. Choice is raised as a central theme in debates about state-funding distribution practices, allocation priorities, location, design and model of new housing developments and the overall aims of disability policy. For its advocates, this ‘choice agenda’ counters paternalistic traditions within the welfare state by offering individuals with disability more choice of where, how and with whom they live, respected as self-determining individuals in society. For its critics, the choice agenda is a neoliberal policy strategy to decrease government funding and responsibility for the provision of welfare services. In between, choice could be dismissed as empty rhetoric. My thesis examines these interpretations, aiming to offer a more coherent and critical understanding of choice as a basis for theory, policy and practice in housing for people with intellectual disabilities.

Three main themes are considered, giving rise to a more critical conceptualization of choice. First, debates about civil-rights and redistribution are revisited and considered as sources from which competing discourses of choice emerge. Second, the individuality implied by choice is considered in light of the ‘community-care’ ethos. Third, an institutional perspective is applied to examine the role of ‘choice’ as a logic of practice within state administration. I examine these themes with a case study - housing for people with intellectual disabilities in the State of Victoria. Interviews were conducted with over fifty people, both users and providers of services in various positions and locations. Analysis explores the implications of the choice agenda on practices and decisions concerning the location and design of new housing developments, and on allocation of placements. The choice agenda has affected these practices in a way that reshapes the geography of housing for people with intellectual disabilities in Victoria.
Declaration

This is to certify that

i. the thesis comprises only my original work towards the PhD,

ii. due acknowledgement has been made in the text to all other material used,

iii. the thesis is less than 100,000 words in length, exclusive of tables, maps, bibliographies and appendices.

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Glossary

**ABS** – Australian Bureau of Statistics

**Commonwealth Government** – the Federal Government of Australia.

**Community Visitors** – A branch of the Victorian Government Office of the Public Advocate. Community Visitors are mainly volunteers who visit people with intellectual disabilities at their accommodation settings and day programs to ensure services meet the standards of legislation.

**CRU** – *Community Residential Unit*, official term for a State-funded group home in Victoria. Also termed ‘Shared Supported Accommodation’.


**DHS** – *Department of Human Services*, the Victorian State Government department responsible for welfare services, including the Disability Services branch.

**DSR** – *Disability Supports Register*, the State Government’s register for housing and support services for people with disabilities.

**HREC** - *Human Research Ethics Committee*

**KRS** – *Kew Residential Services* – also known as ‘Kew cottages’, formerly an institution for people with intellectual disabilities in Melbourne, the largest in Victoria until it was closed down in April 2008.

**NIMBY** - *Not in My Backyard*. Refers in this thesis to local community opposition to the establishment of community care facilities.

**NGO** – *Non governmental organization*, non-profit.

**Support agency** – refers in this thesis to non-government agencies providing disability supports.

**SRS** – *Supported Residential Service*, a privately owned for-profit congregated facility for aged residents catering also for people with intellectual disabilities.
Chapter One
Introduction

During my two years as a Masters student in geography, between 2004 and 2006, I took part in community organizations in Israel that work with people with disabilities. Doing so, I came to know a number of people with disabilities living in congregated facilities. Two of them became close friends of mine. Both have cerebral palsy and lived at the same hostel. One was struggling at that time to move out of that place to a group home with some of his friends and was successful in doing so after almost two years of efforts and advocacy, despite the initial objection of his family. My other friend said then that she is actually quite happy to stay in the hostel where she had a partner, many friends and also a job at the kiosk. In 2007 she married her partner, and they decided to move out together. So far they have not been able to find an alternative place, and are still living in the hostel. Long conversations with both friends came to my mind while designing this research and inspired me to study the question of individual choice in housing for people with disabilities. What choice do they have? What is choice in this context, when so many external factors are involved in decision-making and options are so limited? As a student in human geography and later urban planning, my thinking about these questions tended to be in spatial terms and focused on questions of location and design of housing and how these affect choice. Eventually, such thoughts developed into a research question: what kind of geography would enable housing choice for people with disabilities, and what kind of geography would be created by a choice-based housing policy? I focused on people with intellectual disabilities, as their particular type and experience of disability opens up complex and challenging questions regarding choice and housing, and because it is a field of enquiry often neglected even within disability studies (Hall and Kearns 2001).

The notion of choice takes an increasingly important role in the literature on disability housing, in the discourse of professionals in the disability sector, and in disability policy (Bigby 2004b: 203). As will be
demonstrated throughout the thesis, choice has become in the last decade a central value by which different housing models are judged, compared and consequently prioritized in funding. For its advocates, this ‘choice agenda’ strives to offer individuals with a disability more choice of where, how and with whom they live, respected as self-determining individuals in society. For its critics, the choice agenda is no more than a policy strategy to decrease government funding and responsibility for the provision of services. In between, it could be dismissed as just empty rhetoric with no practical implications other than diverting attention from more systematic forms of oppression experienced by people with disabilities. Because of these competing interpretations, and because different actors in the disability sector use the notion of choice in different ways to raise contradictory claims, it is perhaps a notion too elusive to serve as the conceptual basis for policy and practice.

This thesis looks closely at these different interpretations of choice and the choice agenda. While I accept the critique of choice as a philosophy that is often used in ways that reinforce disadvantage for people with intellectual disabilities, I argue that choice should not be dismissed altogether, but rather reframed and reclaimed as a central value in the provision of housing. Acknowledging that people with intellectual disabilities have so little control over where, how and with whom they live, means that it is timely to find new ways to increase their choice in housing. Housing is but one aspect of people’s lives, but surely a significant one, in which choice is a significant factor. Yet, it should also be acknowledged that there are prices to be paid when choice is given precedence over other concerns. This study is thus an attempt to learn what these costs are, and what gains could be achieved by prioritizing choice as a central value in the provision of housing for people with intellectual disabilities. It aims to provide a more coherent and informed understanding of the notion of choice as a basis for theory, policy and practice in housing for people with intellectual disabilities, by studying the complexities and tensions inherent in choice and their implications in particular contexts.

This task entails revisiting some of the central debates in the literature about the provision of housing for people with intellectual disabilities, in search of different ways by which the notion of choice has been used, interpreted and
flagged as a value and concern. The knowledge offered by this literature on disability, housing, geography and choice, serves as the basis for a theoretical framework with which to rethink the implications of a choice agenda. At the same time, most of this literature does not address the question of choice directly but often carries interpretations of choice as implicit assumptions. Hence, revisiting this literature from a critical perspective with the question of choice in mind, may serve to regenerate debates which may seem to have lost some of their vigour in recent years. To be more precise, I refer to the theoretical debates about deinstitutionalization.

Deinstitutionalization has been a grand-scale movement, affecting the lives of people with disabilities in many different countries, and invoking much controversy. While generally supported by scholars, some have raised concerns regarding the path deinstitutionalization has taken and the severe consequences for many people who have been left homeless (Dear and Wolch 1987) and for families who have been caring for a person with a disability over a lifetime with very little support from government, and very unpromising prospects for the futures of those people. Deinstitutionalization has not yet achieved its major aim and some large state-run institutions and other congregated facilities are still operating in some countries. Moreover, it is questioned whether closing down institutions and replacing them with group homes has been the end goal of this movement or just a first step. In some ways, the choice agenda can be seen as another step forward in the progression of deinstitutionalization, by which the right to live in the community is further developed into (or, critics might argue, substituted by) a right to choice in housing. It is therefore important to return to those controversies and debates which have not been resolved to better understand their origins and implications, and to revive the discussion about the path of deinstitutionalization not as a thing of the past but as a present-day challenge.

It is timely because today, perhaps more than ever before, there are pressing issues which call for urgent action. First, people with intellectual disabilities live far longer now than they would have lived in the early twentieth century or prior to it and unprecedented numbers of them are now being cared for by very elderly parents who are becoming too frail to continue doing so (Bigby 2004a). The urgent task of planning for this generation of people with
disabilities calls for a particular sensitivity to different choices they and their parents might favour (Gleeson and Kearns 2001). Second, an agenda calling for choice in housing is becoming increasingly dominant at the very same time that housing in the private market is becoming less affordable and thus practically inaccessible for most people with intellectual disabilities. This not only makes implementing the choice agenda a more challenging task, but also brings into question the political motivations behind it. It calls for an analysis that considers explicit and more subtle connections between the choice agenda and neoliberalism. This does not mean dismissing the choice agenda as a neoliberal plot, but rather carefully examining where both agendas intersect, where they diverge, and what it means for the choice agenda to be implemented in such a political climate.

There is a particular advantage in studying the relationship between neoliberalism and housing for people with intellectual disabilities. On the one hand, housing for people with intellectual disabilities is a domain where the seduction of ‘choice’ is most appealing, where the freedom of choice is not ‘just another word’, as implied by Harvey (p. 5), but a very real necessity to counter deeply embedded forms of oppression. On the other hand, people with intellectual disabilities, perhaps more than any other social group, may be disadvantaged by this agenda because of their particular vulnerabilities as citizens and consumers (Riddell et al. 1999).

Larner (2003: 510) calls on geographers to study the similarities between various forms of neoliberalism, as well as the particularities and ‘messiness’ of specific neoliberal projects. In this study I refer to the choice agenda as a neoliberal project because of a number of significant similarities and connections in its rhetoric and machinery. However, my aim is not to compare the choice agenda with other neoliberal projects. Rather, the main contribution of this study to the theorizing of neoliberalism, and more broadly to the theorizing of the state, lies in its detailed analysis of what Larner terms the ‘techniques of neoliberalism’:

[T]here was a virtual silence on the techniques of neoliberalism, the apparently mundane practices through which neoliberal spaces, states, and subjects are being
constituted in particular forms. Best practice, audit, contracts, performance indicators, and benchmarks are all techniques worthy of geographical attention, but these were rarely mentioned. When they were, their constitutive aspects were downplayed in favour of accounts in which they were seen as neutral ‘tools’. Although there was some discussion about neoliberal subjects, most often in the form of the rise of the entrepreneurial, self-responsible individuals, the implication was that state somehow ‘forces’ people to act in these ways. The complex appeal of concepts such as ‘freedom’, ‘empowerment’ and ‘choice’ was rarely acknowledged and even less likely to be theorized. The significance of these silences is profound. Because these issues were not explored, the tenacity of neoliberalism simply could not be explained (Larner 2003: 511).

This study joins Larner’s endeavor to fill such gaps in the geographic literature on neoliberalism. It presents an analysis of the ‘tools’ employed by the state as a means to achieve increased housing choice for people with intellectual disabilities. The spatial analysis that is presented is valuable in understanding the machinery of neoliberalism and its implications in particular geographic contexts. The study explores, to the fine details, how such tools are used, by whom, in what contexts and with what consequences. This allows an examination of the extent to which the choice agenda is significant beyond rhetoric, how it intersects with other policy agendas, how it is implemented within existing budgetary and other institutional constraints and how it is mediated by specific power-relations within and beyond state-bureaucracy. Thus, the rhetoric and logic of choice are analyzed as instruments that promote change not only in the lives of people with disabilities, but also in the structure and action of the state. The narratives of various actors in the disability sector demonstrate why the choice agenda has been adopted with such enthusiasm – even by those who hardly identified with neoliberalism – and thus help explain the ‘tenacity of neoliberalism’.
While housing for people with intellectual disabilities is not a typical urban planning issue and is rarely addressed as such, the theoretical perspective taken in this thesis draws much from urban planning thought. In the previous decades, much attention has been given in planning literature to the procedural aspects of how planning decisions are being made. Fincher and Iveson (2008: 5) emphasize the need to address also the normative aspects of planning – what decisions are made, with what consequences and for whom. The procedural perspective in planning literature often reflects a ‘fantasy of neutrality’ (p. 6), as if the planner is merely a facilitator without an agenda of their own. Hence, a normative perspective is necessary to bring into examination the values of the planners themselves and their influence on the outcomes of planning. In many ways, the choice agenda in housing for people with intellectual disabilities reflects a similar procedural perspective and a ‘fantasy of neutrality’ – an aspiration to see state officials acting as merely facilitators of a person-centred planning process directed by the choices of people with intellectual disabilities. In this thesis, I follow Fincher and Iveson’s call, and analyze the choice agenda from a perspective which is both normative and procedural – I look at how housing decisions are made, but also at their implications.

A reciprocal relationship exists between the theoretical debates and trends in the field of disability studies, and the professional and ideological debates occurring in the public arena. Academics and academic literature have played a significant part in the deinstitutionalization movement. Likewise, discussions and practices which have originally developed among professionals and clients within the sector are studied by scholars and debated within a more theoretical discourse. This study was designed with an aim to engage in this reciprocal relationship between academic research and professional practice and policy. It follows the tradition of case study research, and is focused on the disability sector in the State of Victoria, Australia. When dealing with a slippery notion such as choice, case study is a useful approach that connects the heights of abstraction (of theory as well as rhetoric) with the grounds of practice and experience. It enables an examination of the theoretical insights from multiple perspectives gathered from literature, with reference to the highly detailed specifics of a particular context. Various key-
actors in the Victorian disability sector have participated in this study – policy
makers in the State Government, staff and managers in support agencies, disabil-
ity rights advocates, advocates in parents’ associations, and people with intel-
lectual disabilities themselves. Their accounts are rich and diverse
descriptions of the sector, of the way it operates as a whole, and the way the
choice agenda is implemented within it.

For the participants of this study and for other people involved in the
disability sector in Victoria and other places, as clients, practitioners or
researchers, what I hope to offer in this thesis is also an opportunity to reflect
on the way they engage with the choice agenda as individuals and
organizations. I hope this would open up some new spaces of mutual
understanding where agreement could be achieved around the notion of
choice to allow the formation of new coalitions aiming to forge change in the
disability housing landscape.

The thesis is structured as follows:

Chapter Two reviews some of the literature on housing and choice for
people with disabilities, and literature on the geographies of disabilities in
general and literature on the geography of the state. It attempts to synthesize
both fields of enquiry into one theoretical framework which examines the
choice agenda from a geographic perspective. This framework is based on
three major themes: choice as a question of civil rights and redistribution of
resources; individualistic and communitarian perspectives on choice; and,
choice as a guiding principle in state administration.

Chapter Three describes the methodological approach taken in this
research, following the tradition of qualitative case study research in
geography. It provides details on the design of the empirical investigation, the
recruitment procedure, the field work undertaken and the way the material has
been coded and analysed. Further, a suggestion is made in the chapter that
the geography of housing for people with intellectual disabilities may be
described from three perspectives: ‘where’, ‘what’ and ‘for whom’. The
structure of the empirical chapters that are to follow is based on this logic, and
separate chapters respond to each of these three perspectives.
Chapter Four provides a brief informative overview of the disability sector in Victoria, which was chosen as a case study.

Chapters Five is the first among the four chapters that lay out the empirical work that has been conducted in Victoria. It addresses the question of location ('where') in housing for people with intellectual disabilities. A central theme in this chapter is the institutional construct of ‘regions’ in Victoria’s disability services and how they affect the location of housing. A second theme is the legacy of State-run institutions in the past and its affect on the current location of housing and services for people with intellectual disabilities today. The third theme is the tendency to locate housing for people with intellectual disabilities in areas considered as ‘locations of disadvantage’, mainly due to a chronic shortage in resources for disability services.

Chapter Six, as the previous, is still focused on the question of location and its relationship with housing choice, but discussed a different theme: the way community inclusion and exclusion affect the location of housing for people with intellectual disabilities, and the implications in terms of choice.

Chapter Seven moves from a focus on the question of location ('where') to the question of housing models ('what'). The chapter discusses the complex relationship between the choice agenda and the use of particular housing models in the disability sector in Victoria. It shows that some interpretations of choice (‘idealistic’) are used to promote smaller, more dispersed housing models, while other interpretations (‘realistic’) are used to encourage clustered and congregated developments.

Chapter Eight explores the way people with intellectual disabilities are categorized in policy narratives and the way such policy-constructed identities shape their actual geographies in terms of who gets to live where. The chapter discusses how the logic of choice intersects with categorizations based on need and social compatibility, to produce particular identity groupings and geographies.

Chapter Nine concludes this dissertation with a reflection on the implications of the research findings in the broader theoretical narratives about housing for people with intellectual disabilities, and discusses an alternative ways to conceptualize choice as a basis for policy and practice.
Chapter Two
Geographies of disability, housing and choice: between neoliberalism and the disability rights movement

The notion of choice seems as too shaky a ground on which to base disability policy. It may be interpreted in various ways and towards various goals, often contradictory. In particular, a distinction could be made between interpretations of choice rooted in neoliberal philosophy, and interpretations rooted in the tradition of the disability rights movement. This chapter examines such competing interpretations of choice which are expressed explicitly and implicitly in scholarly literature. It offers a theoretical framework which explains some of the tensions and contradictions embedded in this notion, and their possible implications when choice is employed as the central logic of state policy in particular contexts.

One central feature of choice is probably undisputed: in its most basic sense, choice means an uncoerced selection of a preferred option between at least two alternatives (Stancliffe 2001: 92). However, this seemingly simple definition of choice leaves many other questions unresolved. What level of control by an individual over the decision is implied by choice? Is choice between a number of undesirable alternatives still a choice? Is choice a right, and if so – a civil right or a welfare right? Various approaches and answers to these questions are discussed in this chapter. The aim is not to endorse any specific definition of choice, but rather to understand how different interpretations of choice inform the agency of various actors in the provision of public services in general, and housing for people with intellectual disabilities in particular.

Three theoretical perspectives are explored in this chapter. First, theoretical discussions concerning the tension between the rights-based approach and the distributive approach to social justice (Young 1990), are revisited and considered as points of departure from which competing discourses of choice emerge. Second, theoretical discussions about
community and disability are engaged to consider a tension between the individuality implied by choice and the community ethos of disability housing. Finally, an institutional perspective is applied to examine the role of ‘choice’ as a logic of practice within state bureaucracy – the structural changes that are typically adopted by the state as a means to increase individual choice for welfare clients and citizens. Addressing the three theoretical perspectives, this chapter lays a framework which helps understand how cultural and discursive notions of disability, community and choice come to play within broader political, social, bureaucratic and spatial processes to produce particular kinds of homes for people with intellectual disabilities.

Discussions and examples in this chapter are based on sources from various bodies of literature within the disciplines of geography, disability studies, sociology and others. Most of this literature has been written in the US, UK, Canada and Australia. The reason for focusing on these contexts is twofold: first, availability of English publications; second, their central location in what Clarke (2006: 424) terms a network of ‘Anglophone neoliberalism’.

The structure of this chapter is as follows. Section 2.1 examines the emergence of choice as a central discourse in State policy – in the disability sector and beyond it. Section 2.2 offers a brief overview of the geographic literature on disability in general, and disability housing in particular, to explain the importance of the spatial perspective, and also to suggest where this study belongs within the broader corpus of geographic scholarship in terms of its analytical approach. Section 2.3 presents the three theoretical perspectives mentioned above with particular attention to their spatial dimensions. I conclude by linking this theoretical framework to the design of this study which is presented in the following Chapter Three.

2.1 The emergence of a choice agenda

Historically, the increased emphasis on choice in disability policy – which I term here the choice agenda - can be seen as evolving from the disability rights movement, on the one hand, and the philosophy and policies of neoliberalism, on the other. In this section I briefly introduce these movements
and their connection with the choice agenda, a discussion that will be further developed and elaborated along this chapter and the rest of this thesis.

While I argue that the choice agenda finds its roots in the history and philosophy of the disability rights movement, it has nevertheless not been a central feature of the social model of disability and deinstitutionalization (in its primary phase) – two of the movement’s most celebrated achievements. Deinstitutionalization was initially supported by a discourse which condemned the abuse of rights in institutions and emphasized the right for community living and normalization. Choice was not a central notion in this movement at its early stages, and it seems to have emerged as such in places where community-based models had already become a norm in disability services. The principle of normalization guiding deinstitutionalization was defined by Nirje, its central theorist, as making available to all intellectually disabled people ‘patterns of life and conditions of every day living which are as close as possible to the regular circumstances and ways of life of society’ (Nirje, 1973). It may be argued that the individuality implied by choice is contradictory with the aspiration for normality. In contrast, it could be argued that making choices is part of a ‘normal’ way of life. Either way, the notion of choice was not central in the discourse of normalization at the early stages of deinstitutionalization. Similarly, the discourse of ‘community care’ has not emphasized the choices of individuals as much as it offered an integrationist agenda for people with disabilities.

Nor is choice a central value in the social model of disability. The social model views disability as a collective experience of an oppressed social group (Oliver 1996), and is therefore alien to the individualistic nature of the choice agenda. Nevertheless, like the social model of disability, the choice agenda too challenges the authority of professionals and experts to make decisions on behalf of people with disabilities (Clarke 2006: 437), and therefore some significant lines of alliance and intersection are found between the two.

The choice agenda in housing for people with intellectual disabilities finds its roots in three other streams within the disability rights movement: the Independent Living and the self-determination movement (Wehmeyer 2002) and the Person Centred Planning movement (Holburn and Vietze 2002). The
choice agenda also finds roots in the Quality of Life thread in social work literature on housing for people with intellectual disabilities.

The Independent Living movement, led by activists with disabilities who struggled for increased rights, first in the US and later internationally, have emphasized self-determination, independence and choice as major values on which their movement was based. Very much due to their efforts, since the 1990s, the notion of self-determination has become ‘a focal point for designing supports in disability services’ (Wehmeyer 2002: 51). Self-determination debates revolve around the question of how to achieve greater personal control for people with disabilities over resources, services and supports. However, as Oliver (1989) claims, when disability rights advocates and professionals talk about independence, they often mean different things. While professional often think about independence as ‘self-care’ in the sense of doing things alone, disability rights advocate independence in terms of being in control and making decisions over one’s life (Oliver 1989; Reindal 1999). While the first interpretation of independence may lead to reduction in welfare services, the second interpretation aims towards reforming the way such services are designed, controlled and accessed. Therefore, one of the major ideas advocated by self-determination advocates is individualized funding – allocation of public funding directly to individuals rather than to services, to allow them more individual control and choice (Bostock et al. 2004; Harrison and Davis 2001; Wood 2004).

O’Brien and O’Brien (2002) argue that Person Centred Planning – an umbrella term for a variety of individualized planning approaches in disability services – was first developed within a ‘community of practice’ that functioned between 1973-1986 in North America and the UK to promote the principles of normalization (p. 4). Increasing choice in the daily lives of people with intellectual disabilities is one of the major aims of person-centred planning (Amado and McBride 2002; Malette 2002).

Choice has also emerged as a central notion in much of the literature examining disability services from a Quality of Life perspective (Felce et al. 2002; Magito-McLaughlin et al. 2002). O’Brien (1987) argues that choice is one of the five main quality of life principles. As a quality of life indicator, choice can be both subjective and objective: in subjective terms, a sense of
being self-determinant and having choice; in objective terms, the existence of choice-making opportunities in the living environment. Various Quality of Life studies attempt to understand the extent to which residents in particular housing models experience choice in their daily lives (Emerson 2004; Emerson et al. 2000; Wood 2004). Such studies often advocate the closure of large scale facilities and institutions by presenting quantitative evidence to the superiority of smaller facilities. Stancliffe (1997; 2001), for example, argues that living environments that are smaller allow more choice making opportunities for their residents. Some, however, contest the objectivity implied by Quality of Life measurements, and propose an argument that people with disabilities should have a choice about which option they prefer and that over-reliance on formulaic models such as the group home cannot meet the diversity of preferences and needs of service users (Bostock et al 2004: 47). In some cases, this line of argument is developed to justify the continuing existence of large scale facilities, clusters or ‘village’ models (Cummins and Lau 2003; Cummins and Lau 2004), in contrast with the way most Quality of Life studies use choice to advocate smaller and more dispersed facilities. More elaborate discussions on these studies and debates are presented in the following sections, as well as in Chapter Six about the disability housing model debate.

At the same time, the choice agenda also finds roots in other trends which seem remote from the history and philosophy of the disability rights movement. In particular, choice is a well represented notion in the lexicon of neoliberalism. The notion of a ‘choice agenda’ is not exclusive to disability services, but is commonly used with reference to neoliberal policy interventions in other public domains, mainly education and healthcare (Jordan 2006; Kershaw 2004; McIntosh and Phillips 2001; Weiss 2001). A choice agenda is also evident in public and social housing in Europe, where choice-based models of allocation have been implemented, such as choice-based-lettings in the UK and the Delft model in the Netherlands (Kullberg 1997; Kullberg 2002).

Geographers have not been closely involved in the rise of the choice agenda in disability literature. The work of geographers may be used to challenge and move beyond simplistic spatial equations such as ‘larger facility
equals fewer choice making opportunities for residents’, and offer a more sophisticated spatial analysis of choice. The following section reviews some of the work carried out by geographers on disability, a tradition which informs my current study as well.

2.2 Geographies of disability: structure and nuances

Until the 1980s, studies in human geography most commonly approached disability as a medical rather than a social problem (Park et al. 1998: 210). Nevertheless, due to the nature of geography, these studies focused on the environmental determinants and not on individuals, an approach that could be seen as a divergence from the classic bio-medical model of disability which focuses on individuals. Geographers used quantitative surveys, to study the spatial distribution of ‘incidents’ of disability, as well as the delivery of public services (p. 210).

With the movement of deinstitutionalization, many geographers turned to study community opposition to community-based mental health care facilities (Dear 1977; Dear et al. 1980; Joseph and Hall 1981; Taylor et al. 1979; Wolpert et al. 1975). Some geographers have tried to expose the disabling nature of the built environment in terms of physical accessibility (Hahn 1986). However, in the 1990s, this focus on physical access was critiqued for being too mechanistic and positivistic (Gleeson 1999; Imrie 1996; Kearns 1994; Kearns 1993; Park et al. 1998). Several scholars – in particular Imrie, Gleeson and Kearns - have called on geographers to look at more systematic forms of oppression where the disabling features of the built environment are intertwined with the ableist norms of society, beyond physical barriers, and to explore ‘the social, institutional and political processes that produce disabling spaces’ (Imrie and Edwards 2007: 626). Rob Imrie (1996), for example, in his book ‘Disability and the City’, examined the way disabling environments are being produced and reproduced through planning practices. Brendan Gleeson (1999) contributed to the understanding of the socio-spatial construction of disability, by comparing the social spaces of disability in
Feudal, Industrial and contemporary cities. Robin Kearns (1993; 1994) called for a more holistic conceptualization of disability – and health studies in general - through a focus on the notion of place.

The notion of place can help understand the oppression and exclusion experienced by people with disabilities beyond physical inaccessibility. Certain groups face disadvantage because of their location in particular places which are less advantaged in terms of access to physical and social infrastructure, jobs, education opportunities and recreational facilities (Fincher 1991: 132). As argued by Fincher and Iveson (2008: 32), locational advantage and disadvantage are often discussed in terms of physical access and distance. Moreover, notions of locational disadvantage are often used in ways that portray place as a static container of services, rather than focus on the mobility of people as a source of opportunity (p. 34). Nevertheless, an appreciation of locational disadvantage may be useful and positive in guiding redistribution. People with disabilities, in particular, are significantly affected by locational disadvantage: a 1970 commission of Inquiry into poverty by the Australian Government found that location was a major determinant of the levels of poverty experienced by people with disabilities (Gleeson 1999: 200).

A focus on place also helps understand the political aspects of disability, and geographic literature provides the necessary conceptual framework to analyze the role of place in such political processes. Many geographers have studied what happens to political movements and organizations in the context of a particular place. On the one hand, political organizations which are place-based, are often parochial and exclusive, unable to engage with larger political projects of socio-structural change (Fincher, 2001). On the other hand, the local scale often allows interactions which are more flexible and less formal than those in a non-local context, providing an opportunity for a more open discussion in which voices which are not often heard could be raised (Permezel 2001). Place could be a familiar arena in which one may feel more comfortable to act towards change (Wekerle 1998). In place, people’s needs could be understood in their context, and the local strengths and social capitals may be used in order to provide solutions. Place has the potential to bring different people to act together for shared local interests (Ife 1995; Kenny 1997) and a sense of local belonging,
a commitment that might be deeper and more long-lasting than just sharing an interest. People living together in a place may also share a sense of belonging and affinity to each other, through ‘values of care, nurturance, and relatedness’ (Friedman 1995:188) and a sense of community.

Wilton and Kitchin (2003), for example, describe the politics of the disability rights movement from a spatial perspective, examining the way disability rights organizations in Ireland and Canada ‘jump scales’ strategically, back and forth, from local place-based politics to regional and state level politics. Wilton and Kitchin’s approach which goes beyond the local scale of place, accords with Dorn and Laws (1994) in their call on geographers to take into consideration various scales of place, which are both subjective and material. Similarly, Wolch and Philo (2000) call for an approach that would help us ‘understand nuanced place-specific happenings as well as more structurally-determined space compressing processes’ (p.150).

These questions on the approach to be taken by geographers in disability studies relate to a broader movement within the discipline often termed the cultural turn in human geography – ‘a shift from more structural conceptions of social processes to a more intimate and complex geography of meanings, identities and the body’ (Hall and Kearns 2001: 238; see also Cook et al. 2000; Pile and Thrift 1995). From this perspective, the asylum, for example, is examined as a ‘landscape’, with a focus on its symbolic role which goes beyond its functions as a place of residence. The asylum is depicted as a symbol of a social fantasy of a ‘eugenic project’ (Radford and Park 1995; Smith 2005) and a cultural will to separate the deviant body that challenges established social norms (Dorn and Laws 1994: 107). This more intimate perspective also turned to look at the home, as a site with both material and discursive meanings, to study how the home interacts with the body of a person with a disability to produce ‘paradoxical and contradictory spaces’ (Imrie and Edwards 2007: 627). Dyck et al (2005), for example, discuss what happens to the home when it becomes a site of care by outside paid workers. The entrance of a carer into the home changes its materiality, its meanings and the way it is used by its residents.

Much geographical research in disability might be termed ‘counter-policy research’ that involves critiquing policies which affect people with disabilities.
However, the scope of such studies goes beyond any particular policy initiative, and their aim is to deconstruct the concepts by which such interventions build upon and understand the spatial contexts in which they take place (Imrie and Edwards 2007: 632).

The challenge of geography (and geographers) is, we would argue, to extend and develop the theoretical insights of a Lefebvrian-inspired understanding of the production of space, and continue to combine it with the commitment to dialogical social inquiry. Such an inquiry…is not best served by the construction of static categories (i.e. social/medical, disabled/nondisabled, oppressor/oppressed) that have tended to characterize debates regarding the conduct of disability research and theory. Rather, it is one which ought to be intimately connected to space and place, that is, to the specific values and contexts of conduct, the diversity of lived encounters, and embodied experiences, of disability, and the temporal/spatial fluidity of (disabled people’s) identities. (Imrie and Edwards 2007: 635)

Furthermore, over the last two decades geographers have increasingly stressed their own role in their relationships with people with disabilities who were the subjects of their research, and emphasized their political commitment as researchers, calling for emancipatory approaches such as Participatory Action Research where researchers engage in the political arenas and movements of people with disabilities (Gleeson 1999: 202-205).

**Geographies of intellectual disability**

While geographic attention is often focused on mental illness and physical disability, very few studies address intellectual disability (Hall and Kearns 2001: 239; Park et al. 1998). One reason for this, suggested by Hall and Kearns (2001), is the absence of people with intellectual disabilities in the academic world, as opposed to people with physical disabilities and mental illness. While the latter two groups are far from being well represented in
academia, their presence and scholarly activity has been a major force driving the acceptance of the social model of disability by academics.

Wolpert (1980) presented one of the few early studies in human geography addressing intellectual disability, examining some of the socio-spatial implications of the deinstitutionalization movement. Two main analytical approaches were adopted by geographers: the first, a focus on the location of group homes, particularly in North America (Joseph and Hall 1985; Metzel 2005; Radford 1985); the second, a focus on the everyday geographies of people with intellectual disabilities (Hall 2004; Laws and Radford, 1998). Laws and Radford define their paper as a response to Kearn’s (1994; 1993) call for place based research in disability. They are concerned with the way people with intellectual disabilities perceive their environments and the extent to which such perceptions are shaped by their lived everyday experience. Their findings are very closely related to the questions that are raised in my study about choice in housing:

When choices are available, people often choose to develop their identities in accordance with particular places: the downtown-living yuppie, the suburban family, the seashore retiree. These identities are also imposed by social relations and practices over which individuals have little control. Our interviews suggested that people labeled as disabled rarely have choices available to them. Several respondents expressed the desire to live elsewhere, to have a different home, to live in a different part of town. But the identity that has been thrust upon them restricts the places where they can live. (Laws and Radford 1998: 100)

I see my research as continuing in many ways the path paved by the geographers mentioned above, aiming to push the enquiry even further by applying an even more nuanced understanding of the variety of identities among people with intellectual disabilities, and how these relate to their location in different kinds of homes and everyday geographies as well as broader political, social and spatial processes. A central actor in all of these processes is the state. Thus, before attending to the specific discussions
related to choice in housing for people with intellectual disabilities, the following section addresses some of the broader challenges in conceptualizing the state, once again mainly from a spatial perspective.

2.3 Geographies of the state in the context of neoliberalism

Making sense of the state, and more specifically the liberal-democratic state, as a unique entity separated analytically from other facets of society, is a major conceptual challenge. In this section I explain the approach adopted in this thesis, with reference to some of the geographic and political-science literature addressing this question.

One theoretical approach views the state as ‘a cipher’ that simply mirrors existing power relations in society (Dunleavy and O’Leary 1987: 51). From this perspective, the actions of state bureaucracies are understood as the outcome of power contests between various pressure groups. The structures of state bureaucracies are considered highly responsive to changes in power-relations, and are thus in constant flux. Nevertheless, the state does not affect social change as much as reflect it (p. 43-44).

In contrast, the state is often understood as a more active player in the power contests between various groups. Some theorists see the state as an active player, yet one that is neutral in its approach, seeking to mediate conflicts of interest and to achieve consensus by promoting the ‘public good’ (p. 46), and acting as ‘a regulator and an arbiter – even a ‘cash register’”(p. 6). Here a distinction could be made between critical theory of what the state is and a more ethical position about what the state should be. For example, while Titmuss (1987) does not suggest that the welfare state has always been successful in promoting the public good, he does strongly advocate that this should be its major role.

Other theorists, however, question the notion of state neutrality. Marxists, for example, see the state as an actor that actively promotes the narrow interests of a dominating economic class. Harvey (2005), for example, describes the emergence of neoliberalism as a response by various states to
the surging inflation and unemployment during the 1970s. Deng Xiaoping, Margaret Thatcher and Ronald Reagan’s 1978-1980 economic reforms are viewed by Harvey as a ‘revolutionary turning-point in the world’s social and economic history’ (p. 1), and mark the rise of neoliberalism. Harvey suggests that neoliberal philosophy is founded on an aspiration to ‘bring all human action into the domain of the market’ (p. 3), assuming that this would maximize economic and social good. The role of the state in neoliberal philosophy, as summarized by Harvey, is to create the institutional framework that would promote these goals:

The state has to guarantee, for example, the quality and integrity of money. It must also set up those military, defence, police, and legal structures and functions required to secure private property rights and to guarantee, by force if need be, the proper functioning of markets. Furthermore, if markets do not exist (in areas such as land, water, education, health care, social security, or environmental pollution) then they must be created, by state action if necessary. But beyond these tasks the state should not venture. State intervention in markets (once created) must be kept to a bare minimum because, according to the [neoliberal/neo-classical] theory, the state cannot possibly possess enough information to second-guess market signals (prices) and because powerful interest groups will inevitably distort and bias state interventions (particularly in democracies) for their own benefit. (Harvey 2005: 2)

Harvey’s interpretation suggests that neoliberal philosophy is contradictory with regards to the state: it supposedly distrusts state power at the same time as it calls for strong coercive action by the state to implement an all-encompassing market model (p. 21). In any case, for Harvey, the theoretical foundation of neoliberalism is significant only as a rhetorical, seductive justification for the political project of neoliberalization, through which the state actively helps restore the power of an economic elite (p. 19).
In contrast with both Marxist theory of the state and the notion of state neutrality, institutionalists understand state action as driven by contests of power within its own institutions and apparatuses as much as by contests of power among pressure groups which are external to the state. The state, from this point of view, is not a unified organization, clearly distinct from the rest of society, but consists of multiple coalitions within the formal bureaucracy of the state and extending outside of it. Mountz (2003) suggests that such coalitions should not be viewed only through the perspective of formal groups with shared political interests (as may be implied by the terms ‘interest groups’ or ‘pressure groups’), but rather in more fluid, subtle, spatial and mundane terms. Mountz understands state action as driven by ‘the people who comprise it [the state], their everyday work, and their social embeddedness in local relationships’ (p. 640). For example, Mountz describes how the positions and decisions of Canadian officials involved in human smuggling policy are influenced by their location within State bureaucracy. Officials who have had – due to their particular professional roles and geographic location – closer personal contact with migrants, presented very different positions than those officials whose roles and locations detach them from the subjects of the policies they construct.

As in the example above, Mountz’s approach opens up an opportunity for geographic research that not only explores ways by which the state shapes local and regional communities, but also examines how the state itself is shaped by geography (p. 628). Much of the analysis presented in the empirical chapters of this thesis follows Mountz’s understanding of the everyday geographies of the state. Seemingly mundane and quotidian bureaucratic decision making practices of state officials in the Victorian disability sector are examined in their specific geographic contexts. Analysis provides a number of telling examples of how State policy - in this case ‘the choice agenda’ - is negotiated between various actors within and outside formal government agencies. Such negotiation often takes place through both formal and informal everyday local interactions.

Theorizing the state as comprised of coalitions within and beyond formal government institutions, makes the role of non-government non-profit agencies contracted by the state to deliver services more difficult to define.
They are both part of the state and external to it. Wolch (1990) uses the term ‘shadow state’ to signify this peculiar position: ‘a para-state apparatus comprised of multiple voluntary sector organizations, administered outside of traditional democratic politics and charged with major collective service responsibilities previously shouldered by the public sector, yet remaining within the purview of state control’ (p. xvi)

The expansion of the voluntary sector since the 1980s in various states has further complicated the analytical task of defining this sector’s role within or in conjunction with the state. Wolch describes the expansion of the voluntary sector in the US and the UK as driven by both ideological and practical motivations. From an ideological perspective, the political right has promoted voluntarism as a means to achieve greater freedom through an alternative to state monopoly (p. 5). The political left has promoted voluntarism as a means to achieve social change and greater power for disadvantaged groups (p. 6). From a pragmatic perspective, voluntarism appeared to state officials as simply a cheaper, more efficient and more flexible form of service provision, stimulating competition and promoting economies of scale (although, I would argue that such reasoning, too, is not purely pragmatic but entrenched in neo-liberal ideology).

For Clarke and Newman (1997), whose study focuses on the British context, the expansion of the voluntary sector has been tied with broader changes in the welfare state and in the structure of public administration in general. They refer to these changes as the rise of the ‘managerial state’ (p. 18). The relationships between different state departments and agencies, within formal government institutions and beyond them, have been transformed. Rather than hierarchical trustee-beneficial relationships, a network based on contractual relationships has developed. Similarly, the structural distinction previously made between planning and provision, gave way to a distinction between purchasers and providers, to resemble a quasi-market structure facilitating competition between various providers (Clarke and Newman 1997; Dunleavy and Hood 1994: 9).

Increasing consumer choice has been flagged in policy narratives as a major aim of such restructuring of state institutions. A discourse of choice ‘has been able to speak for and offer positions to a variety of individuals and
groups who were critical of the old ways of doing things. Their consent may be partial and conditional, tempered by concerns over resources or how far the rhetorics are realized in practice, but they are positioned within the transformative project’ (Clarke and Newman 1997: 50).

The restructuring of the state complicates the question of how to interpret power relations within and beyond the state. On the one hand, it may be argued that contracting out services signifies the state’s withdrawal from some of its roles and responsibilities, a decrease in its size and power. Such an argument about the weakening of the state is put forward in much of the literature written about globalization, describing the decline of the nation-state and displacement of its power to local and supranational institutions (p. 23). On the other hand, such restructuring may be interpreted as an expansion of the state. Indeed, through sub-contracting, the state delegates power to a host of other agents – service providers as well as users of services who now have more choice as ‘consumers’. At the same time, such agents are also able to mobilize other sources of power – not only that which was delegated to them by the state. Thus, state power is retained, exercised through indirect rather than direct agency and through new forms of governance. Indeed, there are even signs of further centralization of state power in terms of tighter fiscal control, more intensive auditing, and the state’s power to name and prioritize ‘legitimate partners’ (p. 23, 26). Similarly, Wolch (1990) claims that while the expansion of the voluntary sector may serve to democratize the provision of human services and promote a more open public discourse towards social change, the deepening dependency of voluntary organizations on state contracts and grant funding undermines their ability and motivation to take confrontational action against government policy towards social change. Rather, their activities are consequently more narrowly defined to respond to the terms of government policy. (p. 216)

In geographic terms, Wolch focuses on the spatially uneven development of voluntarism to understand its relationship with the state. Wolch examines three ‘common wisdom’ explanations for this uneven development of the voluntary sector: first, variance in social needs between places; second, variance in economic prosperity; and, third, contrasts in regional histories and cultures. However, the empirical work conducted by
Wolch in the US and the UK, suggests that none of these factors alone provides a sufficient explanation to the actual geography of the voluntary sectors in both countries (p. 115-116). The author suggests an alternative explanation, based on an analysis of local institutional dynamics between 'local state' institutions, the market, charitable sources and voluntary agencies which, over time, form diverse local patterns and result in an uneven development of the voluntary sector (p. 150).

While Mountz (2003), discussed above, seeks to understand how diverse local institutional dynamics are eventually translated into a seemingly coherent and unified policy discourse, Wolch highlights how such dynamics constitute the uneven geography of the voluntary sector. The analysis presented in this thesis draws much from both Mountz’s and Wolch’s work. It provides a detailed exploration of the localized institutional dynamics within and beyond the disability sector in Victoria. It further examines how such dynamics affect, and are affected by, the uneven development of a geography of housing for people with intellectual disabilities, on the one hand, and state policy and ‘the choice agenda’, on the other.

The choice agenda in housing for people with intellectual disabilities is thus examined in this thesis as a state-driven political project. I interpret the motivations, machinery and outcomes of the choice agenda from an institutional theoretical perspective. I analyse the choice agenda as a political project driven by the power contests among actors both within formal state institutions and beyond them. I examine the role played by the state as a ‘referee’ that, through the choice agenda, mediates contests of power between various stakeholders in the community but at the same time is, itself, a major stakeholder. I analyse the role of the state as a ‘cash register’ that redistributes material resources in a way that not only reflects such power contests, but actively affects them. And I explore the spatialities of the bureaucratic structures by which the state’s agency is enacted. The three themes discussed in the following section respond to these various roles of the state.
2.4 Three perspectives on choice in housing for people with intellectual disabilities

This section presents and discusses three themes or theoretical perspectives on the question of housing choice for people with intellectual disabilities. While these three perspectives are not fully comprehensive and are in many ways overlapping, each raises a set of very specific and unique theoretical questions about the provision of housing for people with intellectual disabilities, about individual choice and about the role of the state in facilitating both.

The first theme relates to the state’s roles as a legislator, defender and in many cases abuser of civil rights, and its role in the redistribution of material resources. Section 2.4.1 examines how an appreciation of these roles, which are often contradictory, may help in the analytical task of defining the choice agenda as a practice of the state. The second theme relates to the state’s role as a mediator in conflicts of interest among various stakeholders in the community. Section 2.4.2 examines how such conflicts may affect the outcomes of the choice agenda, and how the choice agenda may be used by the state as a tool in its attempt to mediate such conflicts. The third theme, discussed in section 2.4.3, relates to the institutional structures within state bureaucracy and how these affect and are affected by the choice agenda. It raises questions about the nature of transformation and flexibility within state institutions to discuss the potential of any policy agenda, and particularly one which is concerned with individual choice, to inflict change.

Each of these themes is discussed with reference to a wide range of scholarly sources, from feminist philosophy, through social work, to sociology and political science. However, particular attention is given to geographic literature, to discuss the spatial aspects of each of the three themes and to help develop specific hypotheses for this study regarding the spatial manifestations of the choice agenda in housing for people with intellectual disabilities in Victoria.
2.4.1 Civil rights and redistribution of resources

Perhaps the most immediate interpretation of choice in disability services is that of a civil right. Choice, in this context, encompasses an even greater demand for individual rights than that raised by the deinstitutionalization movement - not only one’s right to non-institutional housing in the community, but also one’s right to choose one’s home. However, there are different kinds of rights. Civil and political rights emphasize individuals and their freedoms, as opposed to economic and social rights which emphasize redistribution of resources (Ife 2006: 297). It could be questioned, thus, to what extent choice in housing is a matter of a freedom to choose, to what extent it is a matter of redistribution of resources and services, and whether or not both types of rights can co-exist. Imrie (1996) argues that the individualistic essence of civil rights and the assumption embodied within the civil-rights system that the status-quo is natural and good (p.65) undermine the recognition of disability as a social wrong, rather than an unfortunate medical condition experienced by an individual. Moreover, seemingly positive – even radical – advances in civil rights legislation often seem to be accompanied by significant cut backs in the distribution of resources for the very same populations allegedly protected by such rights. In this section I elaborate on the questions of why this tension between distribution and formal rights appears, and how it relates to choice in housing for people with intellectual disabilities.

Redistribution often clashes with civil rights because of the practices through which it is enacted, mainly the welfare state. The welfare state has traditionally aimed to protect and maintain the system of social relations where this is not achieved by market forces (Dear and Wolch 1987), and so far as it does not threaten ‘free’ market activity (Jamrozik 2005), by redistribution of services and goods. Welfare agencies in the forms of institutions such as state-run hospitals, schools and social insurance were established in order to service all groups in society, with particular orientation towards material support for lower income groups. In addition to redistributing resources, the welfare system has aimed to reduce or at least partially control social conflict by institutionalizing it (Dear and Wolch 1987: 15-17).
Distribution of services to people with disabilities through the welfare state has traditionally been dependent upon a determination of need based on pathologizing medical notions of dependency. For example, provision of cash benefits for people with disabilities is done in most countries following very particular criteria of entitlement. Such criteria are often defined by medical categories of impairment and of the degree of inability to work these impairments cause (Dixon and Hyde 2000). By that, such programs reinforce the bio-medical model of disability and the oppressive relations embodied within this model. They are also often critiqued for promoting unemployment among people with disabilities as employed people may lose their entitlement.

Young (1990) suggests that welfare systems have failed in delivering improved social justice because of their reliance on a ‘distributive paradigm’, which reinforces social relations and oppression by depoliticizing ‘issues of organization of production, public and private decision making structures and the social meanings that confer status and reinforce disadvantage’ (p. 66), leaving these to the authority of professionals in the welfare system. Young argues that social thinking is fixated with an assumption that justice is to be evaluated solely by the distribution of different kinds of goods. She acknowledges the importance of distribution, but reminds us that many other factors of Justice cannot be conceptualized in distributive terms, such as autonomy and decision-making power.

Such critique of the paternalistic structures of the welfare state and the ways that individual rights are being infringed within it finds roots in the civil rights movement. This movement first emerged in the US and soon internationalized. The emergence of the feminist movement and the civil rights movements during the 1960s created an opportunity and inspired people with disabilities in the US to start a struggle of their own which emphasized rights as its main strategy and central goal. The return of thousands of wounded veterans from the war in Vietnam – angry and confrontational - pushed the movement forward.

One of the first targets drawn by the disability rights movement was the welfare state, and particularly the institutions in which people with disabilities were housed. The movement called for deinstitutionalization - moving people with disabilities out of large-scale institution-based care into small-scale
community-based facilities. This was driven by growing evidence of the abuse of human rights in institutions - particularly, a book titled ‘Christmas in Purgatory’ which included photographs from one institution in the US (Blatt and Kaplan 1966) - as well as a new philosophy of care termed ‘normalization’ advocating for a community-based approach (Nirje 1973; Smith et al. 2005).

Civil rights, however, have proved a very weak substitute for services. Equal-opportunities and anti-discrimination legislation was constituted in many countries, but failed almost completely to deliver any improvement in outcomes. It became clear that such legislation lays most burden on the ‘victim’ to prove discrimination, case by case, as if each case is an exception rather than the norm (Imrie 1996: 168; Young 1990: 196; Cooper 1999: 220). Only 2 percent of all discrimination complaints lodged at the Human Rights and Equal Opportunities Committee in Australia make it to the tribunal stage of the resolution process (Handley 2001: 523; Thornton 1997: 185). In the Australian context, these vulnerabilities are even more problematic. A 1995 High Court decision held that the Human Rights and Equal Opportunities Commission, the federal agency responsible for the implementation of the Equal Opportunities Act, should have no powers of enforcement, as that would be unconstitutional (Handley 2001: 524). A review of the Disability Discrimination Act 1992 in Australia has also found that people with intellectual disabilities are even less likely to enjoy the benefits of such legislation than people with other kinds of disability (Productivity Commission 2004). For Handley, ‘whilst the disability movement has welcomed the neoliberal critique of paternalist welfare policy (for example, in the form of institutionalization) on the one hand, they maintain the necessity for welfare in the form of adequately funded means to seek redress for discrimination on the other. There is no neat fit between these two ideals in the current political and economic climate.’ (p. 523).

Disability rights legislation in the US has particularly demonstrated this tension. The most notable legislative achievement of the disability movement world-wide has been the signing of the Americans with Disabilities Act of 1990 (the ADA). This legislation is widely considered the most radical and sweeping piece of legislation concerning the civil rights of people with disabilities, with international impact of consequent legislation in various countries, including
Australia, within less than a decade. Before its signing, the ADA draft could have been seen as a ‘dreamy, pie-in-the-sky’ (Shapiro 1993: 6) piece of legislation for two major reasons: first, it maintained that private businesses should, at their own expense, modify their locations in order to make them physically accessible for people with disabilities, exposing them to potential lawsuits; Second, it was initiated by a conservative Reagan Government replaced by a similarly conservative Bush Government, both highly attentive to private investors’ interests. George H. W. Bush seemed ‘strangely cast to become the shining knight for the disability rights movement.’ (p. 120). In most of his previous engagements with the disability movement he ‘seemed to be its most formidable enemy’, hoping to deregulate former legislation achieved by the movement. But supporting the ADA legitimized the Government’s withdrawal from much of its welfare expenses and responsibilities: ‘When you add together state, local, and private funds it costs almost $1200 billion annually to support Americans with disabilities, in effect to keep them dependent’ (Bush quoted in Imrie 1996: 64).

The relationship between the libertarian approach to rights, and the neoliberal philosophies under which cut-backs in funding are practiced by governments today, is not coincidental. Woodiwiss (2005) argues that historically, rights – and particularly the right to property - were developed in order to protect capitalist interests (p. 139). Rights emerged with capitalism, as its means to legalize and institutionalize power, property and labour. However, ‘the formulation of a right to property implied an individual identity and a certain freedom that were in theory available to all’ (p. 31).

A right to choice, however, when related to public services, is not entirely a matter of freedom. It is not only about being free to choose an opinion or even express it. Choosing a public service means that one’s fellow citizens are required to pay for this service with their taxes, and that the government should provide this service. In this sense, welfare rights are different and often more controversial than rights related to freedom (Wilmot 2007). A right to choose a service is thus a combination of two kinds of rights – the right to choose as a freedom, as well as the welfare right to public services. Wilmot argues that the combination of both rights is not easily justifiable, as providing welfare for one often impinges on the freedoms of
another – particularly when taxation needs to be levied (p. 64). Wilmot offers an alternative justification for a right to choice in welfare services, suggesting that it is not a right to freedom as much as an essential condition of welfare rights. The outcomes of welfare services may only be assessed in terms of particular values and priorities which differ from one person to another. One person may prioritize life-expectancy, and another a pain-free life. Because it is difficult to predict the values and priorities of any individual, it is only possible to rely on their own judgment, hence their own choice (p. 64-65).

While Wilmot’s argument refers to health-care services, it is worthwhile to examine whether it could be generalized to other domains of welfare provision, such as housing and support for people with intellectual disabilities.

In public services, also beyond the disability sector, the right to choose has become a central agenda underlying contemporary discourse and policy in various countries. Such choice agendas are based on an assumption that individual clients of public services are economically-rational and mobile beings who, if allowed, will ‘vote with their feet’ and choose the services that are most beneficial for them. ‘Each residential and productive community would offer a different set of amenities, and those who chose to join as members could in this way express their consensus about levels of taxation and quality of provision’ (Jordan 2006:151). This approach stands in stark contrast with welfare philosophies that question whether choices made by individuals best serve their own good and particularly the social good. Titmuss (1987), for example, argues that the notion of consumer choice is not necessarily relevant to welfare services, particularly to medical services, which are essentially different from other types of consumption goods, and provides a long list of distinctions such as the idea that ‘medical care can seldom be returned to the seller, exchanged for durable goods or discarded’ (p. 166). Titmuss, as more recent commentators, criticizes choice agendas for increasing disadvantage by favouring those who are in a better position to utilize their choices (Buscall 2006; Kershaw 2004; Macintosh 2007; Molnar et al. 1996; Redfern 2006; Weiss 2001). Wilton (2004), for example, addresses the notions of choice and flexibility in relation to employment for people with disabilities, and concludes that:
In the discourse of flexibility characteristic of the contemporary economy, disabled people are ‘free’ to seek out those employment opportunities that are most appropriate to their skills and relative abilities. On the other hand, there is a need for recognition that disabled people continue to be constrained in occupational choices by a range of structural and attitudinal barriers. Individuals are often unable to seek new opportunities [...]The assertion that disabled people are responsible for ‘choosing’ appropriate jobs reproduces an exclusive focus on the limitations of individual workers rather than the ‘disabling’ organization of work (Wilton 2004: 430)

In housing, a right to choice opens an opportunity for any person with a disability to demand more than they have done before – not only a right for non-institutional housing, but also a right for choice in housing. However, the right to choice also stands for social relations of a kind in which people with intellectual disabilities are often even more disadvantaged as ‘flawed consumers’ (Bauman 2007; McDermont 2007: 90-91) at the bottom of the capitalist chain.

Geographically, a focus on redistribution highlights the lack of resources accessible to people with disabilities, on the one hand, and the spatial aspects of particular welfare practices under which redistribution takes place, on the other. Welfare agencies redistribute public resources through the delivery of services. However, such agencies also attempt to save costs in service provision using two main spatial strategies: first, by locating their services in low-income neighbourhoods; second, through economies of scale. In the empirical chapters of this thesis, I show how the tension between redistribution and a right to choice is manifested in Victoria as a policy dilemma between ‘more resources for fewer people, or fewer resources for more people’, and I show how location and economies of scale are used as cost saving spatial strategies to address this dilemma, thus playing a significant role in housing choice for people with intellectual disabilities.
2.4.2 Individual choice and community care

An ethos of ‘community’ is strongly embedded within the current thinking and discourse about disability housing and long term care. The links between the choice agenda and this community-ethos are complex, because it is clear that the choices of individuals with intellectual disabilities are often in conflict with the choices of others in the community.

It is questioned whether choice-making is a purely individualistic process. Any person’s choices, particularly when it comes to major life decisions, are negotiated with other people and are constrained by circumstances (Smith et al. 2005: 228). But people with intellectual disabilities have particular disadvantages that further undermine the individuality of their choices. Contrary to common perception, the major barrier to choice is not necessarily their lack of capacity to understand what options exist and to express their preference. Various studies suggest that it is possible to overcome this barrier through practices, such as Person-Centred Planning which enable people with intellectual disabilities to make an informed choice despite their impairment (Davis and Faw 2002; Holburn and Vietze 2002; McGlaughlin et al. 2004; Riddell et al. 1999). An important aspect of Person-Centred Planning is the involvement of a network of relatives and other members of the community when planning supports for a person with an intellectual disability, in order to support that individual in making choices and plans, and also to maintain this network as a source of informal support that would enable the implementation of the plan. Such involvement of other people is essential to the planning process, but at the same time challenges the individuality of the choices made by people with intellectual disabilities.

Beyond Person-Centred Planning, such involvement of other people in the lives of people with intellectual disabilities is an essential feature of the ‘community-care’ ethos that has guided deinstitutionalization and the development of housing models such as the group-home and supported independent living. The explicit overarching aim of community-care is to ‘promote the integration of dependent peoples into the broader community’ (Gleeson 1999: 153). Moreover, long before and long after the notion of ‘community care’ was introduced as a formal policy, informal carers in the
community provided most of the housing and support for people with intellectual disabilities (Power 2008). This role of the community has particularly expanded since the Post-World-War-II baby-coom, when many young parents then were reluctant to have their disabled children institutionalized. While all through modern history there have been parents who resisted the institutionalization of their disabled children, defying both public policy and cultural norms, this has never had such a significant implication as in the case of the postwar baby-boom generation, for three main reasons. First, the proportion of parents resisting institutionalization has grown due to cultural changes. Second, this generation was larger in size than any other that preceded it. Third, the life expectancy of people with intellectual disabilities has grown overwhelmingly from about 20 years in 1930 to 70 years in 1993 (Bigby 2004a), meaning that people with an intellectual disability born after World-War-II were not expected then to still live today.

The discourse of community-care entails an underlying assumption, or aspiration, that relatives and friends would actively and voluntarily provide support for people with intellectual disabilities to live in the community, and that others in the community would at least accept them as part of their community by not actively excluding them, and by paying taxes which in part help fund disability services. Much geographic research has challenged these assumptions by studying community opposition to establishment of care facilities, mainly for people with mental illness (Dear 1977; Dear et al. 1980; Gleeson 1986; Joseph and Hall 1981; Taylor et al. 1979; Wolpert et al. 1975). Such studies show that communities will not always accept people with disabilities. They were also pivotal in linking these processes of exclusion with socio-spatial theories of place, for example, through use of the NIMBY (Not in My Backyard) concept.

Therefore, the role of community is more complex than that which is inferred by narratives of direct community opposition to care facilities. Very fine lines separate a supportive social network that enables choice, a controlling social network that oppresses individual choice, and the lack of any social network that marginalizes people with disabilities, making it impossible for them to actually exercise choice. As argued by Hall (2005), ‘far from being absolute positions, social inclusion and exclusion are fragmentary and
relational, ‘entangled’ within each other in particular ways and in particular contexts’ (p. 108). Hall’s assertion contributes to an understanding of inclusion and exclusion which goes beyond questions of economic engagement and beyond a dichotomized terminology of power relations.

First, the actual existence of effective ‘support networks’ and the availability of informal support are often questioned (Bigby 1997; Mansell and Beadle-Brown 2004). Furthermore, when informal support networks do exist, their role in facilitating inclusions is complex. Gleeson and Kearns (2001), for example, discuss the public debates surrounding deinstitutionalization and community care in Victoria. The authors argue that while the parents of people with intellectual disabilities are central actors in carrying out any policy concerning disability housing and care, their voices are often marginalized and considered oppressive once they argue for the continuing existence of institutional facilities. Gleeson and Kearns, leaning on ideas that were first introduced by feminist scholars such as Giligan (1982) and Tronto (1993), argue that while traditional notions of justice suggests impartiality, care is essentially biased because it is founded on feelings of affection and partiality. Community-care as an idea claims to offer a more humane form of care than that which was offered by institutions, because it is founded on feelings of affection within the community rather than formal client-provider relationships. At the same time, Gleeson and Kearns note that by taking a seemingly objective position that institutional-care is inhumane, community-care in fact move away from the sphere of care and subjectivity to the sphere of justice and impartiality.

In this thesis, particularly in Chapter Six, I show how the individual choices of people with intellectual disabilities are both enabled and constrained by a variety of communities of different types and different geographies with which they interact. Moreover, I show how these interactions are mediated by place and its complex relationship with community. I discuss the role of the state in mediating such interactions.
2.4.3 Choice and institutional change: applying the market model to the state

From an institutional perspective, providing people with intellectual disabilities more choice about housing and support means handing over to them some power and control from those who have previously controlled such decisions. This calls for significant restructuring of the way state bureaucracy addresses the provision of disability services. Indeed, the literature shows that disability services are being restructured in recent decades in three general directions which are often explained and justified by a rhetoric of choice: first, decentralization of the service system as a whole towards a quasi-market model; Second, a move towards smaller models of housing; Third, development of funding mechanisms that are not attached to services (housing and support) but rather to users as individuals. However, these practices do not necessarily mean a transfer of real power from support agencies to people with disabilities, but rather only imply new forms of control, in many cases just as restricting in terms of choice.

Decentralization of disability housing and support services is evident in various welfare systems around the world. This process is manifested in two ways: governments contracting out many of the support and housing services to NGOs and privately owned agencies; and, separation of housing and support services, to be provided independently by different providers. These practices are believed to promote a model of service delivery that enables something similar to consumer choice for people with intellectual disabilities, and something similar to free-market competition among service providers in order to increase the variety and quality of services. Contracting out of services by government to non-profit and private organizations, while strongly related to budgetary considerations and cut-backs in welfare funding, has often been justified within a discourse of choice, as a necessary restructuring process to undermine the monopoly held by the state over service provision (Wolch 1989: 199).

The decentralization of the service system is also apparent in the move towards models of housing which are smaller in size and number of residents – from state-run institutions to group homes since the 1960s.
(deinstitutionalization), and a more current move from group homes to independent living models. Institutions could be seen as a highly centralized model of service provision, in the sense that a large number of clients are concentrated in one place, and in the sense that all aspects of their lives are dealt within the institution (Goffman 1961/1978). Group homes have been a first step towards decentralization of the service system, as they are smaller, more dispersed and, unlike institutions, do not provide a full range of services within them – in particular, day programs are provided in a different place and often by a different organization. However, in the current group-home model, both housing and basic supports are still provided by the same agency. Some scholars argue that if housing were to be provided by one agency – either a disability services agency, a public/social housing agency or in the private market – and support staff were provided by a separate agency, then individuals would have more flexible options and would be able to exercise consumer choice. Moreover, the organizations providing housing would have specialist professional skills to purchase and provide housing in more efficient ways than disability service agencies (Bleasdale 2006; McNamara 2001).

The separation of housing and support can be understood as part of a broader process of change within the welfare state. Two models of housing provision by the welfare state have been known since the First World War. The mass model was dominant after the war, when many states provided housing for a wide range of social groups as a form of welfare provision. Gradually, most of these states have moved to a residual model of housing provision, under which state provision of housing is limited to those who are least well off, as a last resort option. Harloe (1995) explains this process, suggesting that in a capitalist society, housing is more difficult to decommodify than other welfare services such as health and education, therefore decentralization has been more dominant in the provision of housing than in other domains of the welfare state (p. 3). This explanation may also help understand the separation of housing and support in disability services towards a market-oriented provision of housing and welfare-oriented provision of supports.

However, even if we are to assume that contracting out services and separation of housing from support would indeed create more options for
people to choose from – a brave assumption on its own, as this thesis will repeatedly show - it is clear that people with intellectual disabilities do not easily fit in the role of choice-making consumers in this market-like system, because of their impairments, because they have not had much experience in this role in the past and because of their sense of powerlessness (McGlaughlin, 2004). Therefore, one of the major mechanisms adopted by service agencies as well as various governments as a means to support people with intellectual disabilities to make choices in this new service system was Person-Centred Planning, as discussed in the previous section.

Mansell and Beadle-Brown (2004), discussing services for people with intellectual disabilities in the UK, argue that despite such changes towards individualization of services, rather than devolving real power to clients, agencies maintain control over their resources through new mechanisms and structures such as the ‘introduction of waiting lists, the use of standardized procedures for assessment (prix fixe rather than á la carte), the bureaucratization of management processes and the reservation of funding decisions to higher-level managers removed from direct contact with service users.’ (p. 5). This new set of institutional structures and mechanisms are presented within a framework of individualized planning, and yet in effect they actually constrain individual choice rather than promote it. Similarly, Clarke (2006: 429) discusses direct payments in disability services (as well as child care and aged care) in the UK, and notes that users often perceive these bureaucratic constraints as ‘significant elements that make ‘choice’ a problematic, rather than a desirable, option (p. 429).

Separation of housing and support may also mean separate waiting lists – one for housing and one for support – that would only make it more difficult for many individuals to access any of those. Thus, the reconfiguration of welfare services is often criticized as a form of fragmentation rather than decentralization. Clarke and Newman (1997), however, suggest that the notion of dispersal is more appropriate than that of fragmentation:

Like other post-Fordist concepts such as ‘flexibility’, we find fragmentation a little imprecise [...] Fragmentation unites a number of processes (decentralization, delegation, devolution,
sub-contracting, and more) in an overly general category. As a result, it is difficult to see anything but fragmentation (just as the world is now full of flexibilities). […] We think it may be more useful to describe these movements as *dispersal* rather than fragmentation. The concept of dispersal signals such processes as the effect of strategic calculation rather than inevitable occurrences. […] The state delegates – through a variety of means - its authority to subaltern organizations that thus are empowered to act on its behalf. (Clarke and Newman 1997: 25)

Clarke and Newman use the notion of dispersal to highlight the state’s role as a central authority despite decentralizing processes. These processes of decentralization are often described in terms of an adaptation of the free-market model to the welfare state. For example, in their paper on the choice agenda in social housing in the UK, Fitzpatrick and Pawson (2007) argue that with a fixed housing stock, a choice-based system may only improve outcomes by reducing ‘unsuitable’ allocations. Applying the language of the market, they argue that a choice-based allocation system in social housing has its own ‘currencies’ – particularly need and ability to wait. Need is a major currency because it defines an individual’s eligibility for a service as well as their priority in the waiting list. Ability to wait is another currency that ‘buys’ choice, as it enables an individual to refuse unwanted offers and wait for another offer that better suits their preferences (p. 177). However, the power to determine the value of such currencies in the social housing market is still an administrative power. For example, in a system where individuals are penalized for refusing an offer, ‘ability to wait’ loses its value as a currency. In this sense, institutional control is maintained by the state rather than handed over to individuals. Moreover, those who are in greatest need are often further disadvantaged by this emphasis on choice.

From a geographic perspective, the institutional reconfiguration towards dispersal and individualization (or decentralization, a quasi-market model of operation) has a number of implications. Wolch (1990), as discussed above, emphasizes the consequent uneven development of the voluntary
sector in the UK and the US. Indeed, the focus on a ‘consumer’ diverts attention and resources from spatial planning and may thus lead to uneven development. Geographic and regional planning research makes a distinction between place-centred governance and people-centred governance. A place-based approach targets locations and provides assistance mainly in the form of infrastructure and community facilities. People-centred actions by government, on the other hand, are targeted at individuals, with no consideration of their location. People-centred governance focuses on issues of education, taxation and financial assistance for individuals to purchase or rent housing wherever they choose. ‘A strong people-based policy is premised on the belief that there is no friction in the adjustment process and that people can and will move jobs and residential locations to achieve their personal or family objectives’ (Stimson et al. 2003: 145).

A person-centred approach is more closely in tune with the assumptions and values of economic rationalism and neoliberalism. For people with intellectual disabilities it means increasing reliance on individualized rent assistance to live in the private housing market. A place-centred approach, on the other hand, means that the government builds and purchases housing and support services for people with intellectual disabilities, based on an assessment of their dispersion in space and of the differences in opportunity between places.

In theory, a person-centred approach offers more choice because people are free to use their individualized funding to purchase housing and support services of their choice, while a place-centred approach means that they have to use the facility that was built for them. However, in practice, if there is not enough private-market affordable housing suitable for the housing needs of people with intellectual disabilities, and if they do not have sufficient credit to purchase supports, individualized funding might decrease rather than increase choice. Moreover, variance between places undermines equality in outcomes with regard to choice – some places would allow more opportunities than others, and when individuals move there in search of opportunities, there are often implications for both the places of destination and the places and people who stayed behind.
To conclude, the notions of fragmentation, decentralization, dispersal, individualization and quasi-market models are helpful in explaining large-scale changes in the structure of the state and in the geography of disability housing. However, they are perhaps too broad and inaccurate to address the particularities of this geography. Indeed, disability housing has dispersed, but in very specific ways. This decentralizing movement is not just random dispersal, but is rather governed by certain patterns which have not yet been defined in the literature save for the very few studies mentioned above. While these studies were mostly conducted in the US and the UK, my current research is an opportunity to examine similar trends in a different context – housing for people with intellectual disabilities in Australia. It examines the specific implications of such dispersal in terms of the location of houses, their model and the way access to such houses is controlled by the state. Such an analysis enriches the theoretical understanding of the relationship between the institutional restructuring of the state and the geographies of disability. Moreover, it provides a conceptualization of housing choice, in which the role of place is not overlooked as in a purely people-centred planning approach.

2.5 Choice beyond neoliberalism

This chapter has presented three main themes which may help explain the challenges entailed in trying to achieve individual choice in housing for people with intellectual disabilities, and the kind of geography that may be created while attempting to do so. One thread runs through all of these themes: an individual’s choices are often in conflict with the choices of other individuals, organizations or communities. Therefore, increasing choice for one often means decreasing choice for another. In this sense, if governments interpret choice as a strategy to move away from taking sides in conflicts of interests, to minimize intervention and take a seemingly neutral position of mediation, in effect this strategy is more likely to reinforce the disadvantage experienced by people with intellectual disabilities, and particularly the most vulnerable among them. Indeed, the theoretical framework presented here suggests that an
agenda of choice plays a significant role in the withdrawal of the state from some of its welfare responsibilities towards redistribution of resources and institutionalizing conflict between different stakeholders and groups in the community. In this sense, the choice agenda in disability services can be seen as just one face of broader changes occurring in governance often referred to under the umbrella term of neoliberalism.

Nevertheless, considering the very limited control that people with intellectual disabilities have over their lives, I believe that in this context the choice agenda should not be abandoned altogether, but rather reframed and reclaimed in order to be more effective and just. This means abandoning the neoliberal interpretation of choice, rather than the aspiration for choice itself. The framework presented in this chapter has aimed to do just that, by re-theorizing choice as a structural feature of the state (the choice agenda) as well as an act of an individual. Rather than assuming a free, rational, self-determining individual (consumer), this theoretical framework implies an individual whose actions are always driven by a plurality of tensions and power relations. This idea is seemingly contradictory to the very essence of choice - people do not really choose individually, but act within certain relational webs. Nevertheless, I contend that even if individual action is only an outcome of external powers, it is also utterly unique in that respect. In this sense, it does reflect a unique individuality.

The application of these abstract notions of individuality and structure are applied in the design of this research, leading it in two main paths: first, an analysis of narratives of individuals with an intellectual disability, depicting their housing experiences and their own agency as choice-making individuals; second, a more structural analysis of the disability sector in the State of Victoria and the social and spatial contexts in which the choice agenda is being implemented. The following chapter further explains this methodological approach.
Chapter Three
Uncovering hidden landscapes of housing: the research design

Since deinstitutionalization and later, in some cities, the dismantling of inner-city ‘service dependent ghettos’, housing for people with intellectual disabilities is no longer a visibly distinct landscape as it used to be. Group-homes are now dispersed in various suburbs and very few visual signs can tell one from an ordinary suburban dwelling. The homes of people living in private rental are even harder to detect. Moreover, much of the information about the location of housing for people with intellectual disabilities is kept confidential by the service providers for safety and privacy reasons, so no maps are available. This is a challenging position from which to begin an empirical geographic enquiry. At the same time, these constraints also entail an opportunity for qualitative research which does not rely solely on concrete facts and numbers (although these play a significant part in it too), but mainly on discourse and interpretation. The gain is a richer understanding of the complexities driving the formation of this landscape, and of the experiences of those living in it.

However, issues of interpretation and representation in qualitative research make both the establishment and the assessment of rigor and validity a challenging endeavor. Mansvelt and Berg (2005) therefore suggest that writers of qualitative studies ‘explicitly state the criteria with which a reader may assess the ‘trustworthiness’ of a given piece of research’ (p. 259). This entails acknowledging in a transparent way the choices made by the researcher in the creation, conduct, interpretation and writing of the research (p. 260). The aim of the following chapter is to provide such an account.
3.1 Case study approach

The nature of communities, availability of resources and institutional structures of the state and welfare organizations – three major factors highlighted in the previous chapter as constituting the context for the choice agenda in disability housing - significantly differ from place to place. Therefore, in order to test how an agenda of choice influences the housing landscape, there is a need for a close familiarity with the way these different factors come to play in a specific place. This is where case study research may be an appropriate approach. On the one hand, case study research is limited in its scope as it is very difficult to make generalizations from case studies. Jensen and Rodgers (2001) regard the limitation of generalization as a matter of ‘external validity’. On the other hand, as argued by Geertz (1973), a highly contextualized ‘thick description’ may serve to examine broad theoretical assertions and systems of concepts by engaging them with densely complex specifics. This allows scholarly discussion to rid itself of theoretical concepts which are not found useful, and to adopt new ones which are (p. 28). While case study research is not always ethnographic in the sense envisaged by Geertz, it does essentially aim towards a thick description and may contribute to theory in a similar fashion.

Moreover, the accumulation of scholarly knowledge through a variety of cases studied by researchers in various places, overcomes the limitations of external validity which are inherent in any single case study (Jensen and Rodgers 2001). Therefore, my hope is that this study of one case will add to the literature presented in the previous chapter and will contribute another point of view and specific lessons to the debates elaborated there. The theoretical framework offered in the previous chapter (the three dimensions of choice) and the methodological framework explained in the following section may also be adapted to inform future case-study investigations of housing choice for people with intellectual disabilities.

The contribution of case study research is not only theoretical. In contemporary social research, the researcher does not only assume the role of a detached observer trying to learn from the case study. The researcher inevitably holds and develops some positions regarding certain things that he
or she thinks need to be changed or protected in a particular context. Choosing a case study, in this sense, is also about choosing a specific site in which the researcher would want to have some influence in a more practical sense. In my case, I had no a-priori particular sentiments towards the disability sector in Victoria, with which I had no involvement before taking on this research. My reasons for choosing Victoria as the site of my investigation and not another state were mainly practical, as I was based at the University of Melbourne. This does not mean, however, that I came to this project without holding any initial positions. Having been involved in community organizations in Israel, and having read some academic literature on disability, I did come with rather solid opinions and agendas of my own – not so much around what is good for people with disabilities in Victoria, as much as what is a good society in general. Only through the process of conducting the research, getting to know the people, the places and the problems at first hand, have I developed a desire to influence change in the particular context of Victoria, to which the detailed experiential knowledge I have gained through a single case-study may hopefully prove to be useful.

3.2 Multi-scale analysis: location, model and access

Although the decision to conduct the empirical enquiry in Victoria was driven by practical motivations, it was still necessary to make a methodological decision regarding the scale of the sites investigated. A focus on any single geographic scale could provide important insights on the relationship between an agenda of choice and the geography of housing. Studying one or more cities as case studies, for example, could tell much about urban contexts for choice. This would possibly open up theoretical discussions about the way cities differ in access to housing, and a more practice-oriented discussion on how policy and practice could target different cities in different ways so as to maximize outcomes. However, from very early stages of the research design, it became clear to me that access to housing in Victoria is governed and determined at many different geographic scales, not only the urban one, and that a focus on any single scale would be too limited and even misleading. For
example, administrative geographical divisions in Victorian disability services are mostly regional and not urban. An exclusive analytical focus on the urban scale would therefore fail to address these processes properly. Similarly, an analytical approach which compares regions, but overlooks smaller scales, would fail to address disparities and variations which occur within regions which are often just as significant as those that occur between them.

Methodologies which address processes occurring in more than one geographic scale are common in geographic research. Most notable is the large body of geographic literature on globalization which looks at the complexity of its workings in the global, national, regional and local scales (Marston 2000: 222). Many contemporary human geographers reject the perception of scale as an ontological a-priori existing entity, and refer to it as a social construction, a conditional outcome of tensions between structural forces and human agency (p. 220). This theory of scale contributes to analysis of power-relations between various actors in political and economic arenas in two ways that are relevant for this study: first, it helps avoid binary categories such as ‘global-local’ by offering a more careful and detailed analysis of the complexities of scale and the ‘in-between’ scales (Jonas 2006: 402); Second, it helps examine how discourses, political interactions and coalitions change when they are framed in relation to different geographic scales (p. 401). In disability literature, for example, Wilton and Kitchin (2003) have looked at the politics of scale in disability advocacy, and the strategies employed by advocacy organizations to operate effectively in local, regional and national political arenas.

Scalar analysis is particularly essential in studies of housing. The feelings of being at home in one’s dwelling are mediated by processes occurring in different scales such as the neighbourhood, the city, the state and the global world. Fincher and Gooder (2007) point to the importance of understanding housing in a multi-scaled way that considers differences between neighbourhoods as well as streets and particular housing blocks. Critics of multi-scale analysis argue that power-relations are often illustrated in such studies as vertical hierarchies rather than a struggle taking place in multiple sites that are connected to each other in various ways (Marston et al. 2005). Indeed, the abstractness of scale makes it easy to fall into such
misconceptions and other ungrounded generalizations. Therefore, multi-scale analysis should be very clear as to what it is that scalar categories contain, in terms of material resources, political and economic interactions, legislative contexts and other elements which could be relevant to the way scales are socially constructed (Jonas 2006: 401).

These debates on the use of scale in geographic enquiries, and an understanding that the notion of choice may have different meanings and implications in different geographic scales, have informed some of the major decisions concerning the design of this study. I have defined three dimensions of the housing landscape - location, model and access – which together provide a comprehensive multi-scaled perspective on the disability housing landscape. These three dimensions relate to three different kinds of questions that could be asked about housing for people with intellectual disabilities: where, what and, for whom?

No geography of housing can be depicted without accounting for the location of houses. Understanding where houses are located and why may help examine disparities between places, their causes and their implications. Different geographic scales can be used as perspectives from which to examine such disparities: cities, regions, suburbs and even streets. In this study I have managed to find some quantitative data on the location of housing in different regions, mainly from the Community Visitors' annual report (Office of the Public Advocate 2006; See Glossary). In addition, qualitative data obtained from interviews was used to analyse the location of housing in smaller scales, mainly by suburbs. Moreover, qualitative data was used to examine how such scales were constructed in the first place, following the literature on the social construction of scale.

Beyond location, the geography of housing takes place at another important scale: the home. An investigation focusing on the domestic scale is essential to understand the everyday experiences of people with intellectual disabilities. Moreover, as discussed in the previous chapter, in the literature on housing for people with disabilities, in policy and in public discourse, the most controversial debates are focused on this scale, on what kind of domestic design should be adopted as a model to accommodate people with intellectual disabilities. Therefore, the empirical investigation conducted
looked at how these debates inform the production of particular kinds of homes for people with intellectual disabilities.

However, an investigation of location and model, despite attending to a variety of geographic scales, would still not capture the full complexity of this housing landscape. It would provide a geography of houses – of the physical shape of dwellings and their distribution in space - but not a geography of homes which must take account of the people living in those houses as well. It would not be sufficient to maintain that particular houses in particular places accommodate people with intellectual disabilities. People with intellectual disabilities are a diverse group, with differences among them which are often just as significant as the similarities. Therefore, in order to explore a geography of homes, one must account for those differences.

Taking account of difference calls for more than just charting more nuanced geographies. It is also about interlinking power, identity and place as a ‘located politics of difference’ (Jacobs and Fincher 1998: 2). In this case, such a task entails not only mapping where and how different sub-groups of people with intellectual disabilities are accommodated, but also trying to understand how such groupings are underpinned by the ways access to housing is policed, and by the experiences of living in particular forms of housing. Methodologically, this has meant a double focus in the empirical investigation: one on people’s lived experiences in their current and previous homes, to learn how these experiences both shape and are shaped by particular identities; another, studying the management process by which access to housing is controlled, and the kind of identities that are constructed through them.

Thus, location, model and access have been defined as the three dimensions in which to explore the relationship between an agenda of choice – and its three dimensions discussed in the previous chapter - and the geography of housing for people with intellectual disabilities.
3.3 Collecting information about choice

In order to study how the choice agenda affects location, model and access to housing in Victoria, other significant methodological decisions that had to be made were what kind of information to collect and how. Qualitative case study research may rely on a variety of sources of data, such as focus groups and participatory observations. The most common source in qualitative research, however, is the semi-structured in-depth interview in which interviewer and interviewees ‘co-create meaning by reconstructing perceptions of events and experiences’ related to the research question (Dicicco-Bloom and Crabtree 2006: 315). In this act of co-creation, interviewees share rich descriptions of events and experiences, which are later interpreted by the investigator. I have chosen semi-structured interviews as the main source of information for this research, for one critical reason. The act of making housing choices (and, more so, the act of not having housing choice) does not necessarily happen as a single event in a particular time and place, but is often an on-going process occurring in various settings, involving many small decisions, conversations and private thoughts. An on-going participatory observation within the homes of people with intellectual disabilities may have been very helpful as a means of witnessing some of those moments where choice (or lack of it) occurs. Nevertheless, mainly for practical reasons, I have chosen another method – that of listening to those who make or are expected to make such choices, and work with their descriptions. Defining who those people might be was based on criteria of relevance, diversity and location.

Relevance: The participants targeted had a meaningful role in housing for people with intellectual disabilities, and were involved directly or indirectly in housing decisions concerning individuals and in broader debates around housing choice in the sector. Therefore, among professionals in the disability sector, people in decision-making positions who have more influence on policy and on the choices available to individuals were targeted. Particularly when studying a political project such as the choice agenda, which it is closely related to what Clarke and Newman (1997) term the managerial state, it is
useful to examine the role of managers, ‘as both the objects of change strategies and as the subjects through whose agency change is delivered’ (p. 84).

**Diversity:** To achieve triangulation (Stake 2008: 133) - a variety of perspectives and interpretations to gain a richer and more reliable overview of the case study, the participants who were targeted represented a diversity of actors: service providers from different sectors (government, non-government and business), advocacy organizations and parents’ associations as well as people with intellectual disabilities themselves. I have made no attempt to define ‘intellectual disability’ from a medical perspective. Rather, intellectual disability is understood in this research as a socially constructed identity, and therefore people who are identified by others or by themselves as ‘people with intellectual disability’ were invited to participate. Reaching a diversity of people with intellectual disabilities was another target however this was achieved only partially. Following the three dimensions of the housing landscape defined above, I hoped to find people living in housing of different models, in different locations, and with other differences among them which may affect their access to housing, such as gender, age, ethnicity and types and degrees of disability. However, due to various constraints in the recruitment process such diversity among participants with an intellectual disability was only partially achieved. This matter will be reflected upon further on in this chapter. At the same time, as elaborated below, most participants I was able to recruit were people considered as having a relatively ‘mild’ level of intellectual disability. In a sense, acknowledging that this is a bias means acknowledging a medical definition of intellectual disability. Therefore, although my thesis is in many ways critical of the medical approach to disability, it is not entirely liberated from it.

**Location:** In addition to quantitative data that was collected about the location of housing for people with intellectual disabilities in Victoria, participants were targeted in particular locations to gather qualitative information on the locational dimension of the housing landscape. The main criterion by which locations were targeted was the availability of housing for people with
intellectual disabilities in a place. Four main locations were targeted for recruitment of participants, two where most housing for people with intellectual disabilities is located, and two with the least.

Data on the location of housing was available only at a regional scale, and only for numbers of group homes (officially termed in Victoria Community Residential Units – CRUs). Calculating which of the regions had the largest and smallest numbers of houses for people with intellectual disabilities was based on data available from the Community Visitors annual reports (Office of the Public Advocate 2006). I have also used the State Government Department of Human Services’ data on population size in each of its administrative regions (Department of Human Services 2005b; see Figure 5 at section 5.2.1 for map of DHS regions). Both the total number of supported houses in each region and the proportion of houses in relation to the region’s population were taken into consideration. In relative terms, a highly populated place may have a relatively low rate of facilities per population despite a large number of group homes (Community Residential Units – CRUs) in total figures. This might mean that most facilities are full and not really available for people to choose from. However, a large number of CRUs in a place still implies a greater diversity of services than a place with a similar rate but fewer CRUs in total figures. Therefore, both the total and the relative numbers of facilities were considered criteria for selection. As Table 1 below shows, in total numbers there is a clear distinction between urban and rural regions, with the latter having far fewer facilities. For this reason I have selected two rural and two urban regions as sites for data collection. This table also suggests that most CRUs are located in the Grampians and Eastern Region of Melbourne Metropolitan, and the least of them located in the Southern Metropolitan and Gippsland regions in both total and relative terms. Therefore, these regions were targeted as the main sites from which to recruit participants.
Table 1: Location of group homes by regions

<table>
<thead>
<tr>
<th></th>
<th>Metropolitan</th>
<th>Rural</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>East Region</td>
<td>South Region</td>
</tr>
<tr>
<td>Population (in thousands)</td>
<td>972</td>
<td>1200</td>
</tr>
<tr>
<td>Total number of group homes</td>
<td>244</td>
<td>154</td>
</tr>
<tr>
<td>Proportion: residents per group homes (in thousands)</td>
<td>3.98</td>
<td>7.79</td>
</tr>
</tbody>
</table>

Sources: Department of Human Services, 2005a; Office of the Public Advocate, 2006

Following this set of selection criteria, I interviewed participants from the disability service sectors (Mostly Government and not-for-profit NGOs, and several private businesses providing housing) as well as people with intellectual disabilities in each region targeted. In the Grampians region, however, I was not successful in recruiting any participant with an intellectual disability. Two of the participants recruited in Melbourne, grew up in different places in the Grampians region and were able to comment on that, but this information was not sufficient for a more systematic comparison of accounts by people with intellectual disabilities in different rural regions. Therefore, I conducted more interviews than planned in the Gippsland region (nine instead of four), and used other sources of data (interviews with professionals as well as quantitative data) to reflect on differences between rural regions.

Another significant bias is that all the participants with an intellectual disability recruited for this study may be referred to as having a low or medium level of impairment. While not intentional, this bias occurred because access to people with more severe impairments, using the recruitment methods...
described below, was more limited. This significantly limits the scope of the study, because previous research has suggested that the choice agenda may be a source of disadvantage for people with more severe intellectual disabilities (Bigby and Ozanne 2001). However, the implications of the choice agenda for people with severe intellectual disabilities have been addressed in this study through the use of other sources of information – mainly interviews with service providers and policy makers, as well as analysis of quantitative data – to balance this bias.

In addition, while collecting data following the criteria described above, I have also gained access to several organizations and key actors working in other regions that were not specifically targeted. Most commonly, participants I have interviewed mentioned them as ‘people you should also talk to’. Since access to senior management in the Department of Human Services and in Support Agencies is often limited, it would have been a missed opportunity not to take advantage of these available contacts. Therefore, in addition to the information gained in a more structured way about each of the four regions that were targeted, much information was also gained in a more scattered and casual way about other regions. This information proved highly valuable in analysis, as it enriched the diversity of participants. Some of the most illuminating stories, comparisons and examples involved information collected in this fashion. In many ways, this could be termed a limited form of ‘opportunistic sampling’ (Bradshaw and Stratford 2005: 72) – in which the researcher ‘flexibly follows new leads during fieldwork and takes advantage of the unexpected’ – to complement the more systematic recruitment criteria, and to achieve a deeper and broader insight into the realities of the case study.

The selection criteria were thus not used as overly strict rules, as much as a set of guiding principles by which to achieve a greater diversity of participants. An understanding that this is by no means a representative sample of the full diversity of people in the sector is crucial. Nevertheless, I believe this sample is inclusive and diverse enough to avoid a biased one-sided perspective on disability housing in Victoria, and to fulfil the aim of the empirical enquiry which is to examine the theoretical insights on housing choice in highly contextualized specifics, from a variety of perspectives. This
diversity is evident in tables 2, 3 and 4 below, presenting the distribution of interviewees by location, sector, gender and age.

**Table 2: Interviews by location and sector**

<table>
<thead>
<tr>
<th></th>
<th>Eastern Metro</th>
<th>Southern Metro</th>
<th>Grampians</th>
<th>Gippsland</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professionals, Government</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Professionals, Non-Government (Including parents’ associations)</td>
<td>6</td>
<td>3</td>
<td>2</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Professionals, Private sector</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>People with intellectual disabilities</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>9</td>
<td>3 (all in Melbourne Metropolitan area)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>49</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Table 3: Interviews by gender and sector**

<table>
<thead>
<tr>
<th></th>
<th>Female</th>
<th>Male</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professionals, Government</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>Professionals, Non-Government</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>Professionals, Private sector</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>People with intellectual disabilities</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>49</strong></td>
<td></td>
</tr>
</tbody>
</table>
### Table 4: Participants with a disability by age and gender

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-29</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>30-39</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>40-49</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>50-59</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>60-69</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>16</td>
<td></td>
</tr>
</tbody>
</table>

All interviews took place in a location chosen by the participant. Professional participants were usually interviewed at their office or a café nearby. One person with an intellectual disability chose to be interviewed at his home – a group home. Four other participants with an intellectual disability asked to be interviewed in the office of an advocacy organization in which they were members. The rest of the interviews with people with intellectual disabilities took place at their day program facility.

The interviews were semi-structured – I came with a prepared list of questions, but was very flexible to allow the conversation to drift sideways to issues raised by participants when these were not covered in my list. The extent to which such issues were raised by a participant determined the length of the interview. Most interviews with professionals lasted between 45-90 minutes. The longest interview, with one manager in a non-government support agency lasted almost three hours. Interviews with people with intellectual disabilities were much shorter, 25-40 minutes long.

### 3.4 Theory, description and interpretation

For ethnographers, theory provides a vocabulary with which to express what the ‘symbolic action’ they witness has to ‘say about itself’ (Geertz 1973: 27). However, unlike the symbolic actions studied by Geertz and other ethnographers or anthropologists, here I study the words of participants who
speak for themselves, which brings into question my role as an interpreter and the role of theory in such an interpretation.

The main problems with such interpretations are the power-relations between the researcher and the participants, and the bias which is inevitable in any form of interpretation. Rather than assume a seemingly objective position, Ley and Mountz (2001) suggest that the investigator acknowledge it through a ‘rigorous process of self-criticism to exorcise the demons of bias’ (p. 236). While these demons perhaps could not be fully exorcised, acknowledging them means that at least they are taken into account when considering the scope and the validity of the research outcomes.

In this study, I have engaged with three different forms of interpretation, each creating a different kind of bias: interpretation of opinions and positions which clash with my own; interpretation of people sharing my ‘theoretical vocabulary’; and, interpretation of accounts given by people with intellectual disabilities who are not always verbally articulate. The following sections account for each of those three forms of interpretation, explaining the biases, power-relations and methodological challenges involved and how I have attempted to address them. These accounts aim to answer Mullings’s call to identify in the dialogue between the investigator and the participant not only the biases created by difference, but also those spaces where trust can be established (Mullings 1999:349).

3.4.1 Interpretation of interpretation: interviews with professionals

Rita\(^1\) is a disability rights advocate. I assume she accepted my invitation to participate in this research because she saw it as yet another medium in which to voice the positions held by herself and her organization. This is both her job and her passion. Like several other professionals I interviewed, she is well familiar with much of the academic literature in the field of housing for people with intellectual disabilities, and speaks its ‘vocabulary’ fluently. There seems to be no need to translate her words to the theoretical language I am using – on the contrary, I have found that in some cases Rita expressed the

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\(^1\) The names of all participants have been replaced by pseudonyms for privacy protection
very points that I wanted to make much better than I would have. But the
question of interpretation remains just as challenging. Here, the language of
theory itself becomes a ‘thick description’, not just the tool of an observer but
also an actor in the play observed. When Rita refers to findings of a study she
has read, it suggests that this study has become part of the discourse
operating within the sector, and my interpretation should not just cite this
research again, but rather learn how actors use it in particular contexts. In this
sense, discourse analysis is not just about what is being said, but mainly by
whom, to whom, in what contexts and with what effects.

Following this understanding, most professional participants – mainly
management staff in the Department of Human Services (DHS), support
agencies and advocacy organizations - were asked about their role in the
provision of housing and support for people with intellectual disabilities, their
perception of this housing system and their relationships with other actors in
this sector. Some of the questions address the issue of choice directly (‘what
do you see as the main barriers to choice in housing for people with
intellectual disabilities?’; ‘how does your organization support people with
intellectual disabilities to make choices in housing?’). However, much of the
information about participants’ interpretations of choice was gained indirectly
from comments about their relationships with other stakeholders and about
the sector in general. Through various direct or indirect comments they have
made about choice, data was obtained about the meanings they ascribe to
this notion and practices they relate to it. These descriptions are the core of
the empirical enquiry conducted in this research. They helped formulate an in-
depth detailed picture of the housing system as a whole, the changes
occurring within it and various perspectives on how these relate to the choice
agenda.

3.4.2 Interpretation and representation of conflicting positions
Many professionals and organizations in the disability sector do not share
Rita’s positions, nor mine. When I came to interview Ella, an activist in a
parents’ association and the mother of a woman with a disability, she knew I
was most likely opposed to her views about congregate care which she sees
as a better and more realistic solution for the severe housing and support shortages in Victoria. She knew I was a PhD student, and might have guessed that my views in these debates have been predominantly shaped by reading academic literature, which most commonly – as she is well aware – strongly opposes congregate care. Nevertheless, she accepted my invitation to participate in a study about ‘choice in housing for people with intellectual disabilities in Victoria’. In my understanding, she may have assumed that a piece of research about ‘choice in housing’ would be more tolerant of a variety of opinions. Moreover, her consent was a sign of trust, an acknowledgement that while I would most likely disagree with her, I would represent her opinion fairly.

Nevertheless, ‘fair’ turned out to be a difficult notion when I started thinking of ways to interpret and represent her positions. On the one hand, I could have referred to her account using only direct quotes from the transcription of our interview, with minimal editing and paraphrasing to avoid misrepresentation. On the other hand, our interview lasted more than two hours, and it was not possible to quote all of it in the dissertation. Eventually, I ended up using very few parts of that interview in the final version of the dissertation (and even less will be used in any journal paper published), but these were presented in longer-than-usual direct quotes to minimize my intervention. Nevertheless, after representing her argument as accurately as I could, I have turned to present my interpretation of it, which in many ways challenges it. In the power-relations involving researcher and participant, I have clearly kept the advantage of having the last say for myself. This is only fair in the sense that Ella anticipated this in the first place, and accepted it as part of her own strategy to make her voice heard, believing perhaps that her truth is strong enough to withstand my interpretation. This accords with Rose’s (1997: 313) assertion that there is more than the question of difference in the relationship between the researcher and the reseached. Understanding can be achieved despite difference just as misunderstanding and bias could emerge despite sameness (Valentine 2003: 377).
3.4.3 Interpretation of an ‘other’ voice: finding, interviewing and interpreting people with intellectual disabilities

In the interview I conducted with Naomi, she showed several signs of distress. I assume this happened because she suspected that my questions about the group-home she had just left were part of a planning process to move her back there. She had a good reason to believe so – present with me in the room and taking a very active role in the interview was Hannah, a planner in the organization running that group home as well as other services Naomi receives. Hannah tried to reassure Naomi that there was no intention to move her back into that group-home, and I tried to explain the purpose of the research again. Naomi seemed to be relieved, and her participation enabled a very rich insight into a story which touched many of the central themes addressed in this study. Nevertheless, once in a while she would restate her suspicion (‘why are you asking this question?’). Moreover, her responses about that group home were contradictory – once she stated she loved the place, and then she stated she was unhappy there. This reflects, in my view, two things. First, simply a range of feelings, often contradictory, she has about that place. Second, her confusion about the aim of the interview leading to uncertainty around the narrative she wishes to portray. To me, as a researcher, this was a sensitive situation related to the validity of Naomi’s consent to participate in the study. Lloyd et al. (2006: 1398) suggest that consent should not be understood only as an a-priori event of signing a form or declaring verbal consent, but rather as a continuing process. As well as an explicit consent given prior to the interview, the researcher should be aware at all times during the interview of any verbal or non verbal signs which may imply discomfort or a desire to end the interview. However, with Naomi, ending the interview and leaving things as they were would not have resolved her fears about its purpose anyway. Continuing the interview while constantly reaffirming its aim was also not ideal. Eventually, I skipped some other questions I wanted to ask her about that group home, and moved on to the part about the place where she lives now, which she felt more comfortable to describe in positive terms.
I find that this interview reflected several of the methodological and ethical challenges for qualitative research involving participants with an intellectual disability. There are several strategies I could have used to counterbalance the power-relations that were at play. If no staff member had been in the room, perhaps Naomi would have interpreted the intention of the interview differently. If I met Naomi several more times, rather than a single interview, it could have been structured differently to allow Naomi more time and less pressure to reflect on her housing career and, essentially, her life story. However, I have chosen to make these compromises following several considerations. First, in the context of this study, reaching a diversity of participants was an important priority. I wanted to have at least 16 participants with intellectual disabilities to be able to address a variety of differences among them – location, age, gender and type of housing. Thus, I did not have enough time to conduct more than one interview with each participant. Second, the process of recruiting participants with an intellectual disability was subject to the very strict requirements of three different Human Research Ethics Committees (HREC) which entailed several constraints.

I required HREC clearances from the University of Melbourne, the Victorian Government’s Department of Human Services (DHS) and Scope Vic, one of the largest non-government support agencies in the state. The main challenge was the different requirements of each committee, particularly around the process of recruiting participants with an intellectual disability. In my original HREC application to Melbourne University I stated that I would not approach people with intellectual disabilities directly but rather through senior management staff in advocacy and support organizations. I would ask them to think of clients who might be willing to be interviewed and were able to give informed consent. They would approach those clients on my behalf, tell them about my research and ask them whether I could contact them myself. That would prevent me from intruding into people’s private lives without their consent, would provide more certainty that the individual was able to give informed consent, and also provide them two chances to consider their participation – once when approached by the staff and once when approached by me. This form of recruitment was approved by the HREC in Melbourne University and DHS, but rejected by the HREC in Scope.
From my interaction with the HREC of Melbourne University it appeared to me that one of the committee’s main concerns was to protect me, as a student, and the university as an institution, from potential litigation regarding the ethical conduct of my research. Therefore, their main concern was the process of obtaining formal letters of support from senior staff in advocacy and support agencies through which I recruited clients as participants. Such letters would serve as evidence to protect me and the university in case anyone suggested that the people I interviewed were not able to give informed consent, or that I had somehow intruded upon their privacy.

The research committee in Scope had a very different agenda. They were more concerned with the power-relations within their own organization. In a conversation I had with one of the committee’s members, he explained to me that my method of recruitment through senior staff in Scope was not considered by the committee ethical because it reinforces existing power relations in which staff members act as gate-keepers to the full participation of their clients in mainstream social life.

This realization, as well as my own concern that the organizations I approached would only refer me to ‘best practice cases’, led me to revise the recruitment method to compromise between the litigation concerns and the ethical and methodological concerns. In the new method, senior staff in any agency I approached would invite me to present my research in particular settings where their clients were present. That allowed me to have both the letter of support required from senior management, as well as direct contact with people with intellectual disabilities which was not mediated by gate-keepers.

This meant that I changed my recruitment process in the midst of the field work stage (which required applying for amendments in all three of my original HREC submissions). After having conducted four interviews using the first method whereby clients of support agencies were referred to me by staff, I started recruiting new participants using the second process, whereby I presented my research to potential participants directly. Nevertheless, in both methods, while I have always preferred to conduct the interview with the participant and myself alone in the room, in most cases a staff member
requested to be present in the interview, and I agreed. The main advantage was that staff members knew their clients well, and helped prompt life-stories with questions which I could not have considered. The main disadvantage was, again, the power-relations at play and the biases that needed to be addressed, as in Naomi’s example above.

Participants with intellectual disabilities were asked to tell about their history and present - how and why they moved from one home to another, as well as accounts of daily life in these homes. Their narratives were used to reflect on the variety of ways by which individuals make housing choices, and what this means for the choice agenda as a central feature of the service system. Their stories also served to personalize the ‘case study’, to take it beyond the abstractness of ‘scales and rubrics… a construct of criteria’ (Stake 2008: 135) towards experiential knowing which is more embraceable for both myself and the reader. The design of these interviews was inspired by some of the research based on oral history. Oral history aims to record the first-hand knowledge and experience of interviewees, and to study the ‘hidden histories and geographies, the place-based lives and memories of disadvantaged people, minority groups, and others whose views have been ignored or whose lives passed quietly, producing few, if any, written records’ (George and Stratford 2005:107). While I did not attempt to provide such detailed accounts as those presented in oral history research, as the focus is quite different, the questions were designed to prompt a narrative that spans different periods in the participant’s life time, often in a rather chronological order, for a similar purpose: to ‘track and understand changes across spatial scales as well as temporal ones’ (p.107). However, the past in such narratives is always mediated by time and by memory. (p. 108). Indeed, several participants have found it difficult to recall places in their past, and the chronological order of their narratives did not seem coherent. This reaffirms Hall and Kearns’s (2001) assertion that data obtained by interview may fail to represent the geographic lives of people with intellectual disabilities (p. 243). But even when participants do not have an intellectual disability, discourse analysis means that a researcher cannot treat their accounts as factual, but as subjective narratives that reflect particular points of view and interests. This does not mean that narrative is in any way weaker than any other form of evidence. On
the contrary, an appreciation of biases, diverse perspectives and interests is precisely what a qualitative researcher would be looking for!

3.4.4 Quantitative data: facts and discourse

Quantitative data was necessary to establish an understanding of some aspects of the housing landscape, and to counter or support the discourses played out by various actors. Such data was obtained about the numbers of housing facilities in different locations in Victoria, about distribution of services and funding by the Government, and about the waiting lists for accommodation. The main sources of such data were the Department of Human Services in Victoria (Department of Human Services 2002; Department of Human Services 2005a; Department of Human Services 2005b; Department of Human Services 2005c; Department of Human Services 2006c; Department of Human Services 2008a), the Australian Bureau of Statistics and other sources such as the Community Visitors - a branch of the Victorian Government Office of the Public Advocate - (Office of the Public Advocate 2006) and the Australian Institute of Health and Welfare (AIHW 1998; AIHW 2002; AIHW 2005; AIHW 2006).

Quantitative data was treated in two ways which are seemingly contradictory - as facts and as yet another form of discourse. On the one hand, I treated the numbers provided by these sources as facts, as these are the only sources of quantitative information which were available. On the other hand, the manipulation and presentation of these numbers, in a way that often excludes certain categories, was analysed as a form of discourse used by particular actors for particular purposes (for example, the misrepresentation of care provided by parents in the data discussed in Chapter Six).

3.5 Analysis and presentation

Bringing together into analysis the accounts of people with intellectual disabilities, management staff in support agencies, state government officials, disability rights advocates and activists in parents’ associations, aimed at
responding to the ‘necessity of an ethnographic approach to understand the experiences of people with disabilities by connecting the personal and the socio-political context’ (Hall and Kearns 2001: 243). Such an analysis attempts to identify the roles and power-relations played by various actors in shaping the housing landscape in terms of location, model and access for people with intellectual disabilities. It seeks to understand how these roles and power-relations are affected by different interpretations of the notion of choice, in the narratives and meanings they construct, the problems they define and language they use. This kind of analytic approach would perhaps be considered by Waitt (2005: 176) as typical of the Foucauldian strand of discourse analysis in geography, in which meanings, subjectivities, and places are all studied as elements of power-relations.

Discourse analysis is founded on an understanding that language – in various forms, including spoken and written – is not only used to describe social practices but is itself a significant social practice. Discourse analysis addresses spoken and written accounts as the act of ‘making meanings’, which are intrinsic to processes of social reproduction and social change (Hastings 1999: 7). From a post-structuralist Foucauldian perspective, language is a central way by which power relations are realised, as well as a major practice which constitutes, alters or reproduces power relations (p. 10). Meanings created by discourse are powerful, since once they are established they are ‘difficult to shift and often rest unexamined’ (Fincher 2007: 635). Approaching discourse analysis from a perspective of power-relations, means studying the act of creating meaning through discourse, and the role of various institutional processes whereby such meanings are given legitimacy, spread and translated into other forms of social practice (p. 632).

A useful categorization of discourse analysis strategies is offered by Batten (1999). Batten describes the construction of a particular housing discourse in Australia, termed by the author ‘the mismatch argument’ – a notion that there is a mismatch between the size of households and the availability of the housing stock. Batten suggests three ways to critically examine such a discursive orthodoxy: empirically, conceptually and discursively. The empirical critique provides evidence to challenge the ‘facts’ on which a particular discursive orthodoxy is founded. The conceptual critique
challenges the truth of the orthodoxy from a broader theoretical or normative perspective. A discursive critique, as opposed to both empirical and conceptual approaches, does not question the ‘truth’ of discourse as much as its implications as a social practice. Thus, it examines how such an orthodoxy has emerged historically as a dominant discourse, how this discourse ‘works’ and its influence (p. 139-140).

Unlike the ‘mismatch argument’ discussed by Batten, the choice agenda is not an argument about an existing reality as much as a vision for a future one. Hence, there is no point in challenging the choice agenda by claiming that it is factually wrong. Therefore, my analysis is mainly based on conceptual and discursive critiques. It looks at the way the choice agenda has developed historically as a dominant theme in discourses of disability, examines its underlying theoretical and normative foundations, and empirically investigates its rise and its implication as a discourse in the particular context of the State of Victoria.

I examine the choice agenda not only as a discursive or rhetorical practice, but also as a set of other social and political practices, namely, distribution of material resources, construction and reconstruction of particular housing forms in particular locations, and relocation of people with intellectual disabilities. Discursive practices - the rhetoric of choice - give these material practices a meaning and their legitimacy. However, none of the material practices described in this thesis is exclusively tied with the choice agenda. Each may be explained as driven by other agendas, discourses and ideologies, such as community inclusion, neoliberalism, normalization and others. Moreover, it is very difficult to distinguish methodologically between discursive and material practices when material practices, too, are made evident to the researcher through discourse (by hearing and reading about them). Thus, the role of the empirical investigation is not to distinguish between the choice agenda as a set of discursive practices and the choice agenda as a set of material practices. Rather, it is an attempt to describe the choice agenda as a set of both discursive and material practices, and to examine its relationships with other competing agendas, discourses and ideologies in a particular context.
A major challenge in the practice of discourse analysis is defining the empirical data that will be analysed. As explained above, I chose semi-structured interviews as the main source of data. However, it was also essential to establish criteria by which to select from the hundreds of pages of transcribed interviews those pieces of text that would be edited into the final dissertation. The criteria I used were, first, relevance to the theoretical themes identified in the previous chapter; second, richness of the data; and, third, maintenance of a balanced representation of the various participants.

In the first stage of analysis, I read each of the transcriptions and coded their texts in full using Nvivo software. I did not establish any a-priori codes, but rather allowed the codes to emerge from my reading of the texts, with the theoretical framework in mind. For each paragraph I read, I often used more than one code. Most codes were titles of particular processes and key words that have often been mentioned by interviewees (such as: ‘vacancy coordination’, ‘internal moves’, ‘up-skilling’, ‘individualized funding’, ‘compatibility’, ‘challenging behaviours’, ‘level of support needs’, ‘urgency’). Some codes related to particular housing models (‘Group homes’, ‘institutions’, ‘independent living’, ‘public housing’). Some related to particular geographic scales (‘domestic scale’, ‘regional scale’). Some were more thematic and already involved a deeper level of interpretation that came to my mind while reading the text (‘relationship between DHS and NGOs’, ‘path dependency’, ‘cultural change’, ‘structural change’). I ended up with more than 50 codes in total, and had to code the whole material twice, because after completing it once I had to return and reconsider whether codes that were only established when working on later interviews, might also be appropriate in earlier interviews. This process of coding was not a fully inductive process of ‘grounded theory’ (Charmaz 2008: 217; Cope 2005: 224) but it was also not entirely deductive. My coding was certainly influenced by the theoretical themes that I already had in mind, but still allowed consideration of ‘empirical themes’ that emerged from the data, more than would have been possible if I had only used codes established a-priori. For example, had I not coded ‘urgency’, a key word that was evident in the interviews whose connection with the theoretical themes was not immediately obvious, this significant
feature of the disability sector in Victoria and its complex relations with the choice agenda might have been lost in analysis and editing.

In the second stage of analysis, I started working in a way that corresponds more systematically with the theoretical and methodological framework of this research, and addressed the three main themes defined in this chapter: location, model and access. For each of those themes I worked with two separate documents: one to which I imported any transcribed text with codes that seemed most relevant. I left out text that was repetitive or not rich enough for interpretation in the sense that I could identify particular discourses operating within it. The remaining transcriptions were sorted and edited in a way that crystallizes their essence as forms of discourse, adding my interpretations, and making sure that a diversity of voices was represented in a balanced way. However, some interviews were not directly quoted in the final text to avoid repetitions. In the second document I worked the other way around, starting from my interpretation with no use of actual transcriptions – only my impressions from the field work in general, and their connections with the theoretical framework and the structure explained above. Later, I merged the two separate documents, and the result of this process is the empirical chapters that follow.

Another decision that had to be made in the writing stage was the terminology that would be used. I have chosen to use the notions of ‘people with intellectual disabilities’ or ‘person with an intellectual disability’ as this is the common terminology in most contemporary literature written in this field in Australia. In other English speaking countries such as the UK and the US, however, other terms which are commonly used are ‘people with developmental disabilities’ or ‘people with learning disabilities’. The notion of ‘people with disabilities’, rather than ‘disabled people’, places the emphasis on the person prior to the disability. However, some scholars argue that this notion also naturalizes ‘disability’, whereas the notion of ‘disabled people’ politicizes it by emphasizing the act of ‘disabling’ (Morris 1993: x). The term ‘intellectual disability’ is particularly problematic because of ‘a deep sense of unease about what it is to be “intelligent”, how we are judged by schools, employers and society on our level of intelligence and, importantly, how we than judge others’ (Hall and Kearns 2001: 241). This sense of unease is
underpinned by a history of terminologies which today seem completely inappropriate, but were once dominant. In the early 20th century the formal terms used were ‘idiots’, ‘imbeciles’, ‘moral imbeciles’ and ‘feeble-minded persons’. The notion of ‘retardation’ has been commonly used until very recently, particularly in the US, as evident in some of the Journals that are referenced in this thesis (Mental Retardation, The American Journal of Mental Retardation and Mental Retardation and Developmental Disabilities Research Reviews).

3.6 Towards a subjective-inclusive tense

The chapter started with a proposition that housing for people with intellectual disabilities is not a visibly distinct landscape in the city or the region. Indeed, in many ways, it is not even a ‘landscape’ in the typical sense of the word. However, the following chapters do attempt to uncover some of its spatialities – providing not only factual information on location and designs of houses – but also first hand accounts on the way these are seen in the eyes of a variety of people who experience these places in different ways. This leads to an analysis of the power-relations which construct this housing landscape, and in which these various perspectives are embedded. Therefore, although this chapter has placed a relatively strong emphasis on my positioning as a researcher, the overall aim of the ethical and methodological choices described above is not just to present my own subjective opinions, but also to enable analysis which includes a variety of perspectives, to acknowledge those biases that are inevitable in interpreting and representing these perspectives, and to overcome other biases which are not inevitable.
Chapter Four
Individualizing the disability sector in Victoria: background

A dominant discourse of choice characterizes current disability policy and practice in Victoria, making it a useful case through which to examine the three dimensions of the choice agenda. Victoria is a State in Australia (see Figure 1 below) with approximately 70 percent of its 5 million population located in the Melbourne metropolitan area.

Figure 1: Australian States and Territories
Around 40,000 people in Victoria have an intellectual disability, with approximately 30 percent of them eligible for government funded services by law (Bigby and Ozanne 2001). Eligibility is based on an assessment of need, an issue that will be further discussed in Chapter Eight. Less than 5,000 people with intellectual disabilities live in Government funded housing in Victoria, which is provided by the State Government’s Department of Human Services (DHS) and by non-government agencies it contracts. Around 8,000 other people receive different forms of State funded supports in their homes (see Figure 2 below). Most Victorians with intellectual disabilities live with their parents and are being cared for by them. The distribution of primary informal carers by age and gender is illustrated in the graph below (Figure 3) taken from an Australian Bureau of Statistics survey. This data refers to people with all sorts of disabilities, and thus does not accurately reflect the distribution among people with intellectual disabilities.

**Figure 2: Government-funded housing and support services by number of users, 2005, Victoria**

**Source:** AIHW, 2006
4.1 Disability policy reforms and social-democratic managerialism in Victoria

The *International Year of Disabled People* in 1981 is considered by Ashman (1989: 75) a major milestone in the history of people with disabilities in Victoria, the point when the international disability rights movement made its first significant impacts on Victorian disability policy. The events of this year encouraged a greater sensitivity and awareness to issues raised by people with disabilities and their advocates. A newly elected Labor Commonwealth Government in 1983 established the Disability Advisory Council of Australia (DACA) to provide direct advice to the Government in the area of disability, with open public consultations which attracted over 5,000 people as participants and 1700 submissions.

In Victoria, perhaps the most significant policy change following these events was the launch of the deinstitutionalization movement. The movement, however, was gradual and slow: In 1989, more than two thirds of disability services were still being provided through 11 institutions housing 2600 tenants. Today, some institutions - such as Colanda near Colac and Sandhurst near Bendigo (see Figure 4 below) - are still operating. The closure of the largest institution in the state, Kew Residential Services (KRS) in inner
Deinstitutionalization was implemented through the foundation of a shared supported accommodation system of 914 State funded group homes (officially termed CRUs – Community Residential Units) dispersed across the State (Victorian Auditor-General 2008:10).

Deinstitutionalization was accompanied by integrationist education programs aiming to include more students with a disability in regular schools, rather than special-needs schools which were not only segregated but also unavailable in small rural towns (Ashman 1989: 76). Concurrently, physical infrastructure in cities was modified to meet accessibility standards for people with mobility restrictions or sensual impairments (p. 74).

The Disability Services Act 1986 and the Disability Discrimination Act 1992 provided a legislative framework for these reforms. A significant aspect of the 1986 Act is the recognition of ‘advocacy services’ – that is, disability rights organizations - as programs to be funded by federal and state governments, by that affirming the Government’s cooperation with the disability rights movement. The Act also meant a gradual and partial transfer of responsibility for disability services away from health departments – which could be seen as an attempt to step away from the medical model of disability towards a social model.

For Gleeson (1999: 157), this series of legislative and programmatic initiatives was a result of the hybrid strategy of disability movements, pursuing both improved civil rights and social structural changes, mainly through initiatives in state policy regimes. These reforms integrated well within a broader political movement - the emergence of social democratic managerialism, which had set off gradually in Victoria since the mid 1960s, under pressure of community activists, developers and planners to force a more open political debate about public bureaucratic functions (Gleeson and Low 2000: 76).
4.2 Neoliberalism and the rise of a choice agenda

The movement from social democratic managerialism towards corporate liberalism meant a greater emphasis on creating the conditions that were perceived as attractive to investment and economic growth, namely low taxes, deregulation and subsides to business. Consequently, reductions in public expenditure on welfare became a major political agenda (pp.: 72-73). As stated by Gleeson (1999: 143), the emergence of neoliberalism in Australia during the 1990s, and the cost cutting agendas of federal and state governments incised a blow to the Australian disability rights movement and resulted in a retraction from its achievements.

Local governments in Australia play a relatively minor role in the provision of housing and support for people with intellectual disabilities, and the provision of welfare in general, compared for example with the UK and the US (Worthington and Dollery 2000: 2-3). The 1991 Commonwealth-State and Territories Disability Agreement (CSTDA) assigned the Commonwealth responsible for employment services and the States and Territories responsible for accommodation and other support services. Individuals with a
disability have been affected directly by the reduction in Federal coordination and funding of disability programs. The immediate eligibility of all people with disabilities to pension payments from the Federal Government was cancelled, and people with disabilities considered capable of working were required to take rehabilitation, training and labor market programs as a pre-condition for eligibility for an only partial pension as a supplement to earning from labor (McIntosh and Phillips 2002). The CSTDA also signified a decrease in the status of organizations controlled by people with disabilities and the degree of their participation in national politics (Cooper 1999: 221-222). An overall decline in funding for disability advocacy was a major reason for the crisis of the Australian disability rights movement, which reached its climax in 1995 with the collapse of a major advocacy organization - Disabled People International (Australia). Yet, Cooper maintained that despite the lack of funding and the apparent fragmentation of the disability movement in Australia, this movement has still been alive, active and diverse.

In Victoria, this neoliberal political climate was reinforced by the actions of a reformist conservative State Government led by Premier Jeff Kennett between 1992-1999. The Kennett Administration adopted the principles of deinstitutionalization - which were first introduced by the previous Labor Government - and further enhanced it as a means to achieve community inclusion for people with disabilities and mental illness, as well as decreased public expenditure associated with the operation of large scale facilities (Meadows and Singh 2003). Apart from deinstitutionalization, the Kennett Administration reforms included the amalgamation of various non-government support agencies.

In 1999, the Kennett Administration was replaced by a newly elected Labor State Government, led by Premier Stephen Bracks, which has sought its own reforms in disability policy. In 2002, the Bracks Administration introduced the ten-years 2002-2012 State Disability Plan, which may be seen as the first major expression of a choice agenda in Victoria’s disability policy. The plan highlights individualized services and more choice for people with disabilities as major principles along with community inclusion. The rhetoric of choice characterizing the state plan, consequent policy documents and the language of professionals in the disability sector in general, is discussed and
elaborated in the empirical chapters that follow. In many ways the plan is not an action-plan as much as a vision, which can only be implemented if followed by more concrete and detailed mid-level policies (Bigby 2007: 71). However, some changes are already in effect. Growth funding was diverted from Shared Supported Accommodation towards individualized funding schemes such as Home First and Support and Choice which are not attached to a specific place of residence. Such schemes enable people with disabilities to receive support services even if living in private rental or their own home, rather than in government funded group homes.

The 2002-2012 Disability State Plan has been followed by a number of other programs introduced to test new and more individualized models of housing and support for people with disabilities. The Accommodation Innovations Grants scheme and the establishment of the Disability Housing Trust, are both major initiatives towards this aim. The individualization of the system is also implemented through State-funded programs of person-centred planning and through legislation of the Disability Act 2006 that includes a right for a General Service Plan for people with intellectual disabilities in which their life-goals and required supports are identified. Such plans may serve to prove an individual’s eligibility for services, but do not ensure provision.

The implementation of the visions of choice and inclusion is undermined by severe shortages in housing and supports for people with intellectual disabilities in Victoria. International comparative research suggests that in 2002 Australia fell 22.3 percent behind the UK, and 63.4 percent behind the US, in terms of Government funded support for community care or home care services for people with intellectual disabilities (Stancliffe 2002). In Victoria, the shortage in support and housing is evident in the waiting lists for shared accommodation and in-home and community support – the Disability Support Register (DSR) - that in June 2008 reached 1,358 people listed as having immediate need for shared supported accommodation, and 1,282 people in immediate need for in-home supports (Department of Human Services 2008d). It is estimated that by 2016 the demand for government funded support and housing will increase by over 50 percent (Victorian Auditor-General 2008: 51) due to increasing numbers of people cared for by elderly parents.
This shortage is reinforced by the shrinking of affordable housing markets in Victoria. While in March 2007 16.8 percent of new lettings were considered by the State Government’s Office of Housing as affordable (rent price within 30 percent of household’s income), by March 2008 this rate had fallen to 8.9 percent. Median rent prices for a one-bedroom unit in Melbourne was estimated in March 2008 at $235 per week and at $120 per week in regional Victoria (Department of Human Services 2008b). This is far from affordable for most people with intellectual disability who are reliant on their pensions as their only source of income and on rent assistance to finance their housing. The disability pension basic rate in 2008 for adults over 21 is similar to that of the age pension, with a fortnightly payment of $546.80 for a single or $456.80 each for a couple. In addition, people with disabilities who do not live in government funded housing, nursing homes or hostels may apply for rent assistance of up to $107.20 per fortnight (which is the maximum assistance for a person paying fortnightly rent of $238.33 and above). People with disabilities who are older than 21 and living with their parents may also be eligible for rent assistance. (Centrelink 2008:23). These figures suggest that a person with an intellectual disability living in a one-bedroom unit in Melbourne is likely to pay 72 percent of their very limited income on rent. A study conducted by Berry and Hall (2001) has found that despite the rent-assistance program, low-income households have long been unable to rent average value houses of any size in almost any suburb of metropolitan Melbourne, forcing people to search for low-rent dwellings in a time when these have been rapidly disappearing from the market.

These circumstances make timing difficult for the implementation of a choice agenda, as Tim, a senior officer in the Department of Human Services admits:

The irony is that disability services are really approaching individualized housing in probably the worst time in history. (Tim, Department of Human Services)
It may be questioned whether this ‘wrong timing’ is coincidental, or whether the choice agenda in disability housing is just another reflection of a wider neoliberal political agenda which can also be held responsible for the lack of affordable housing and the lack of planning for people cared for by their elderly parents. Nevertheless, the resulting shortages make spatial planning and allocation priorities even more significant than in times in which housing units are more readily available.
Chapter Five

Location and the choice agenda: patterns of dispersal

This chapter is first among four which examine the geography of housing for people with intellectual disabilities in Victoria. In order to understand choice in housing for people with intellectual disabilities, it first needs to be established what kind of housing is available for them and where. This chapter addresses the question of ‘where?’ Here I analyse the location of housing for people with intellectual disabilities in Victoria and the processes which determine it. I refer to the geographic distribution of the housing stock which is – at least in potential – available for people with intellectual disabilities to choose from.

This chapter allows an understanding of the extent to which an agenda of choice is enabled or constrained by location, and the extent to which it may affect it. In theory, a more dispersed geography would increase housing choice by creating a more diverse range of options to choose from in terms of location. However, the main argument that is put forward is that the spatial decentralization or dispersal of housing for people with intellectual disabilities began before the emergence of a choice agenda in policy rhetoric and discourse. Moreover, as argued by Clarke and Newman (1997: 25), dispersal is not simply a random or free movement from the centre outwards. Nor is it simply the outcome of diverse individual location choices. Rather, in the case described in this chapter, the dispersal of housing for people with intellectual disabilities in Victoria is a movement that follows very specific and rigid patterns and, in fact, many of these patterns entail significant barriers to individual choice.

Two theoretical perspectives are employed in this chapter to analyze the factors affecting location in housing for people with intellectual disabilities. First, Section 5.2 presents an institutional perspective that focuses on the state and its geography. This form of analysis follows Mountz’s (2003: 628) call for geographic research that explores ways by which the state shapes
local and regional communities, but also examines how the state itself is shaped by such geographies at multiple scales. Second, Section 5.3 presents a spatial-economic perspective focused on locational advantage and disadvantage as a means to understand both the causes and implications of particular location patterns. Prior to this analysis, however, the following Section 5.1 examines the significance of existing literature on the location of housing for people with intellectual disabilities.

5.1 Location of housing for people with intellectual disabilities in the literature

A very limited number of studies examine location in the specific context of housing for people with intellectual disabilities. All of the studies I am aware of were conducted in North America (Dear and Wolch 1987; Joseph and Hall 1981; Metzel 2005; Radford 1985). Two of these studies are reviewed below in order to illustrate the contribution of this particular form of analysis focused on location.

Dear and Wolch (1987) discuss the location of services for people with disabilities, mainly mental illness, in two North American cities: San Jose, California (USA) and Hamilton in Ontario (Canada). Their analysis clearly illustrates the meaning, the causes and the implications of decentralization. The authors describe a process involving three main stages: first, the institutions as highly-centralized locations of service provision; next, services located mostly in inner-city ‘service-dependent ghettos’ in both cities; and, later on, a more dispersed geography of care facilities in various locations of the city. During the early stages of deinstitutionalization in both cities, most new care facilities and services congregated in cheaper inner-city districts, becoming a hub of mutually-supporting services. However, gradually since the 1980s, political action by coalitions of local businesses, as well as a process of gentrification and rise in rental prices in inner city districts, has led to the dispersal of services into the suburbs. The ghetto was dismantled: ‘[it] seems highly ironic that the service-dependent ghetto should have grown ‘organically’ as an unexpected outcome of deinstitutionalization; and that now, when we
are recognizing the need to adopt a deliberate policy attitude toward the ghetto, it is under-going another market-induced change that could lead to its attrition and demise’ (p. 26).

In a later research project in another North American city, Metzel (2005) studied the patterns of location in housing for people with intellectual disabilities in Baltimore, Maryland, providing another illustration of decentralization. She shows that all location decisions of housing services were based on criteria deriving from the residents’ roles as service-dependent, especially transportation-dependent, clients. By reinforcing dependency, Metzel claims, place ‘failed people with intellectual disabilities’ (p. 102). Metzel finds that during the 1970s the most central location factor was proximity to workshops in the inner city. Residents who were relatively mobile were relocated first and were expected to travel independently from their new group-homes to the workshops. Later on, when people who could not travel as independently moved out of institutions, they were housed in a more dispersed fashion in more distant suburbs, and specialist transportation services were launched to enable their journeys to workshops. Most new group homes were located in the same general area of the previous home of their residents. Personal preferences of staff members were considered too and a major preference was for middle-to-upper income neighbourhoods (p. 100).

While Dear and Wolch highlight external social and economic processes occurring in the city as a whole (gentrification and exclusionary political action) leading to the dismantling of the ‘service dependent ghetto’, Metzel emphasizes internal structural changes within the service system leading to the formation of a more dispersed geography of housing for people with intellectual disabilities. It is clear, however, that in both cases, both processes occurred simultaneously, reinforcing one another. Both studies also address the question of locational disadvantage, as a question of concentration of poverty, on the one hand, and access to services, on the other. Dear and Wolch, in particular, are critical of the way a focus on the concentration of poverty as a form of locational disadvantage, has diverted attention from the advantage of access to services in the inner city and the advantage entailed in proximity between services. Similarly, the analysis
presented in this chapter examines the location of housing as an outcome of institutional changes within state bureaucracy and the disability sector as well as broader social and economic changes in the city, and discusses the implications of location in terms of advantage and disadvantage, related to concentrations of poverty as well as access to services.

5.2 Institutional change and path dependency in the location of housing

There is an important connection between the administrative geography of the disability sector, and the location of housing for people with intellectual disabilities. The processes determining location of housing differ from place to place due to particular organizational arrangements of the sector, the most significant of which is the regional administrative divisions in the Department of Human Services (DHS) of the Victorian State Government. These spatial constructs enable a very particular and limited kind of housing choice for people with intellectual disabilities in Victoria.

5.2.1 The making of regions: social construction of scale and the state

As discussed in Section 2.3, Mountz (2003) discusses various ways by which the geography of state-bureaucracy mediates the agency of state officials. In this section, I follow Mountz’s approach, studying the geography of the state in the context of the Victorian disability sector. In particular, I look at a specific spatial construct that characterizes this geography: DHS regions. Over time, each of these regions has followed a different path of development, leading to distinctive regional institutional cultures and distinctive relationships among state officials, and consequently to the formation of distinctive regional housing landscapes.
The eight DHS regions in Victoria (Figure 5) have been defined through an internal administrative process within the department. The geographic data available on these regions reflects the logic underlying their construction: a distinction between metropolitan and rural regions; an aspiration to a relatively similar size of population in all metropolitan regions and in all rural regions; a relatively similar geographic size for all metropolitan regions and for all rural regions; and, overall a relatively small number of regions across the state. One may find some loose connections between DHS regions and distinct regional identities deriving from historical, political, cultural and economic differences. However, despite these connections, as a whole the regions are rather arbitrary administrative constructs which would not have otherwise been considered distinct ‘regions’.

This administrative geography has filtered from DHS to the non-government support agencies it contracts. Many support agencies are organized in institutional structures that adhere to DHS’s regional lines, with a
separate branch for each region. Even organizations that were not initially
aligned on geographic lines, consider restructuring in accordance with DHS
regions, as can be learned from the account of Natalie, a manager in a
support agency. Natalie’s agency is currently structured with two main
branches - disability services and aged care services – both of which are
operating across more than one region:

We may reorganize the configuration of our team, down the track,
more on geographical lines rather than demographic lines. Now
we’ve got our disability services running across regions, and our
aged care services running across regions…if we’re going to work
more geographically we will be combining services for people with
disabilities and services for older people who have not required
disability support in the conventional sense. It’s combining not the
services but combining the management of the services under the
same management structure. And at this point disability services are
much clearer on supporting people with disabilities in the community
than the aged care. Our aged care services are very very good,
excellent case managers, excellent carers, however, not as
developed in thinking about bringing the developmental model into
aged care. When they’re thinking of individual planning they’re not
thinking as clearly as disability staff, about links to the community,
keeping relationships going, that kind of thing. (Natalie)

As in Mountz’s (2003) Canadian example, this too is an illustration of how the
geography of state bureaucracy (and mainly DHS regional divisions) mediates
their agency. According to Natalie, the geographic reconfiguration will mean
combining disability and aged-care services under the same regional
management. It would be more efficient in terms of coordinating the
relationship with the regional offices of DHS. However, it may be challenging
in terms of different organizational cultures in the disability and aged-care
sectors, particularly with regard to individualized planning and community
inclusion.

Not all organizations adhere to the DHS regional configuration. One
agency I visited is not organized along DHS regional lines, in order to increase
economic efficiency, as explained by Thomas, a senior manager:
We’re three regions across the state… Our structure is very simple and flat, just three regional managers. It’s not top heavy, as you would say. (Thomas)

Also for organizations which have no direct relationships with DHS, these regional boundaries are not very significant, as can be learned from the following account given by Paul, a manager in a housing association:

I: do you find any advantages or disadvantages of working in different regions?
P: It's a bit hard for us to comment on that. Because we work with NGOs [and not with DHS] we don’t see a regional thing very much...
It’s not regional, it’s always different organizations. (Paul)

From the housing association’s point of view, since their dealings with DHS are limited, they attribute very little importance to the Department’s geographic regions. This points to the fact that regions in the Victorian disability sector are first and foremost a DHS administrative construct which has infiltrated to other organizations working closely with it and has become a powerful institutional structure embedded in a particular geography of its own.

In the following sections I argue that the administrative regionalization of disability housing generates an up-scaling of local processes: processes which occur in certain places affect entire regions. Three major implications are discussed: systematic mismatching between the location of informal support networks and the location of vacancies in housing due to a regional process of allocation; disparities between centre and periphery within each of the regions; and, disparities between different regions related to the histories of state-run institutions in Victoria. This uneven development significantly constrains housing choice for many, and will not be easily altered by the choice agenda due to persistent forms of path-dependency.
5.2.2 Regional shuffles: systematic dislocation

The eight DHS regions in Victoria, particularly the rural ones, are huge in geographic size – up to 58,895 square kilometers. Because placements are allocated on a regional basis - each region has its own waiting list – a successful applicant is likely to be offered a placement very far away from their preferred location. This often means separation from their local support-network and family, as explained by Jane, a DHS officer in one of its metropolitan regions:

We always want families and individuals to make choices, but the reality is that our region is so big that we can’t guarantee that … And that’s probably one of the big hurdles that we’re battling, that families are making that choice and say ‘I want to stay in this particular area, and I want my son or daughter to stay at the day program where he or she goes’, when the vacancy we have that is most suited is in (the other end of the region). (Jane - DHS)

As Jane’s account suggests, location is a major factor in the housing choices of people with intellectual disabilities and their families. However, location is often compromised due to the size of the regions, on the one hand, and the scarcity of housing available, on the other. The huge geographic size and low-density of metropolitan Melbourne reinforces this problem, as the distances between the location of housing and the location of family can be far more significant then they would have been in a denser metropolitan area. In rural regions, such geographic distances are even more difficult to overcome, as explained by Alice, a DHS officer in one of the rural regions:

A: Most people have a preference of where they want to be located. Sometimes there might be a house way down south, and the person in the east might be in a rather urgent need but doesn’t want to shift, so it’s a matter of waiting until something comes up [in the location they prefer]. That’s very rare. People who are so desperate get to the stage that they’ll take anything.
I: So they really don’t have a choice of location.
A: They have a choice, but it means time. Sitting there and waiting. Could be a couple of years. We have a person who – because of his
really high support needs – just been offered a place in the last month or so, there was nowhere else suitable for him and he didn’t want to leave the area, and he’s waited. And I think – much to his mental deterioration – he didn’t want to move (Alice)

Alice suggests an individual does have a choice to wait for another placement in a more suitable location. However, often applicants are penalized for turning down an offer, as this suggests that their needs are not urgent enough – the main criterion for eligibility in the CRU system (as elaborated in Chapter Eight).

If a person is placed in a distant location – responding only to the short term urgent need for accommodation, any accommodation anywhere - in the long run that individual is prevented from moving into a more suitable placement. At the same time this takes away the opportunity for a suitable placement from another ‘local’ person who might need exactly this placement now or might need it in the future. That person too, may eventually be offered a distant placement – this is a self-reinforcing process which leads eventually to a system which is full of unsuitable placements in terms of location. In this sense, the lack of placements in one location affects the entire region.

5.2.3 Regional centre and periphery: housing in remote locations

Each of the regions has its own centre and periphery, with significant disparities in the availability of housing in each. In metropolitan regions, location of housing tends to move away from the city centre where housing is more costly, whereas in rural regions housing is more often located in the major regional towns. In both cases, however, these patterns create a mismatch between the location of families and the location of housing for people with intellectual disabilities.

The existence of a regional periphery, remote locations where housing and support services are scarce, raises significant barriers to housing choice. Access to support is hindered by geographic distance for individuals living in remote locations, as explained by Thomas, manager in a support agency:
W: When you get to the outer line areas obviously your capacity to staff becomes more difficult. It comes down to the availability of people, and a support worker isn’t going to drive his car half an hour to do a one hour shift. So it’s hard.
I: So you have clients who actually can’t get support because of their distance?
W: Yes. Absolutely.
I: Do you know of clients that have moved to other locations?
W: Yes. People with higher more demanding needs need to think about where they are located now. (Thomas)

Separation of housing and support is one of the main policy strategies to provide more choice for individuals (Bleasdale 2006; McNamara 2001). Thomas’s account suggests, however, that even though support and housing are provided by different agencies, they are often still attached by geography, particularly in remote locations. The fact that people change the location of their homes to receive support also suggests that support is scarcer than housing. It means that under individualized funding individuals need to be mobile – to move to places where opportunities for housing and support exist. This often entails giving up the informal support network in the local community where one lives, for the sake of formal support available in another location.

For support staff, providing individualized services for people living in the outskirts of the metropolitan area or in other remote locations, means deteriorating employment conditions - limited hours of work in casual conditions and low wages, and no pay for traveling time and costs as they move from providing a few hours of support for an individual living in one town, and then a few hours for someone in another town. Declining working conditions means declining overall quality of services (Gleeson and Kearns 2001: 68). Such working conditions are perhaps the most obvious connection between neoliberalism, and its industrial relations model, and the choice agenda in disability policy. Nevertheless, managers in support agencies I have interviewed in rural towns, maintained that it is still easy for them to find and employ staff, because there are not many other competing employment
opportunities. This finding is different in some ways than those published almost a decade earlier by Alford who found that rural health care services in Victoria have often been more short of experienced management staff to write successful applications for contracts than their urban counterparts (Alford 2000).

A similar geographic attachment between housing and support is also apparent in the fact that day programs cannot be too far away from their clients’ accommodation. This too is most significant in remote locations in the peripheries of DHS regions, as explained by Jane, a DHS officer in a metropolitan region:

Because we don't have staffing during the day in most of the houses that we fund, and because the majority of people we serve require staffing during the day, that means a person needs to have a day program regardless of their age and regardless of what they want to do… So when people move, one of the biggest problems is trying to identify the day-program they want to go to and try to access that. And a day program may not have a vacancy where you want to go to, and that can be difficult. We get through it… And in the majority of cases, when a vacancy occurs in a house, it’s more likely that there’s also a vacancy in a day program, because if a person passes away, or moves a location – so that means a vacancy in the day program. So they often go hand in hand. (Jane)

Jane’s example, with Thomas’s before her, suggests that due to the geographical attachment, housing and support are not always truly separated – particularly in remote areas. The vacancy in accommodation and the vacancy in the day program are in fact attached, and in this sense they are not individualized. Whilst Jane maintains that in her region vacancies are eventually filled despite this difficulty, some evidence suggests that in other regions this is not always the case, as Peter, a manager in a support agency, claims:
That’s one of the reasons we have vacancies sometimes. If their day service or employment is over there, why on earth would you put someone here? (Peter)

The remote locations of many housing services are not coincidental, since often these are the places where vacant and affordable properties are readily available. This is particularly true in Metropolitan regions:

One of our houses – built by the department – is likely to fall down, but the only property that is quickly available is – well, let’s face it... - in Reservoir [a low income suburb at the northern fringe of the metropolitan area], which is not that convenient, so we have to see what are their day activities and how do we get them there, where their families lives and how do we maintain their connection with their family, and also what public transport access they have (Peter)

There were a couple (of vacant properties) in Reservoir, but in Reservoir there was already a high ratio (of existing CRUs) so we tried to avoid it, we didn’t want to add to that. That’s always cheap and easy and there’s lots of land. (Chris, DHS officer, about his search for a property on which to build a new CRU)

In contrast, in remote rural locations, there is often not sufficient population to make a local service viable. In rural regions the distances between remote towns and major regional towns are more critical, and the population in remote towns is far smaller than the population in the metropolitan fringe. Alice, a DHS officer in a rural region explains the implications for people with intellectual disabilities:

There could be people, right up on the border, who have no hope to get to a day centre because it’s too costly and travel time is too long. If you’re on the highway it’s a lot easier – all the major towns are along the highway. (Alice)
The lack of services in remote towns often means that people with intellectual disabilities have to move to more central regional towns. But in some cases, even major regional towns are not sufficiently large to make certain services viable. For example, Supported Residential Services (SRS) – privately owned congregate residential facilities providing services to people with intellectual disabilities who require very limited forms of support – are barely viable in rural regions because there is not enough population to sustain a client base (Green 2001). In such places, disability services are often provided as part of aged-care services. I have visited one of the few rural SRSs providing accommodation for people with intellectual disabilities. Most clients in this SRS – a large facility housing 49 clients – are aged care clients, and only two have an intellectual disability and they are significantly younger. Faye, manager and owner of this facility explains why it is not viable to have a separate facility for people with intellectual disabilities:

The town is too small to have a separate disability service, so we thought about joining with some other SRSs in other towns around the region. (Faye)

Such economies of scale are very obvious in the private market, as in the case of SRSs, where a service which is unviable economically has no chance to survive. However, also in the public sector it is clear that DHS’s locational decisions are very often driven by considerations of economic efficiency, and there is an expectation from individuals living in remote towns to move to a new more central location, rather than direct investment to infrastructure in remote towns. Emma, a DHS officer in a relatively large and central rural town, describes the implications of such a policy:

I think for some services there is more choice in Melbourne, in regard to accommodation. I know there are Acquired Brain Injury units in Melbourne, they don’t have it here… Sometimes we do not have a solution so people end up living on the street. Often when that happens they go somewhere else, to Melbourne. (Emma)
Emma’s account suggests that the disparities between rural and metropolitan regions in terms of availability of housing and support, means that people with an intellectual disability who are more mobile – in the sense that they can move to the city – are more likely to find accommodation. However, in many ways DHS regional divisions make it harder for individuals to move from one place to another, because moving to a new region means not only moving to a new community where one is unfamiliar, but also moving into a new bureaucratic system where one is unfamiliar, as evident in the following account.

Aaron is a person with an intellectual disability, in his late forties, lives in a small rural town with his father and his sister, who also has a disability, in the same house in which they grew up. Seven years ago he first left his father’s house when a local organization assisted him in finding a job in Melbourne. Aaron’s move to Melbourne was very difficult, and for reasons he could not explain he and one of his friends found themselves homeless, spending the nights in their cars in the parking lot of a McDonalds restaurant, and working during the day in a factory, for several months:

I: What about your family, were your sister or dad involved in all of this, when you were living in the car?
A: Yes, my dad actually came down and helped me.
I: What did he think at the time when you were living in your car?
A: (Long silence) (Aaron)

Eventually, Aaron was assisted in finding accommodation:

In the last two weeks of the 6 months that I lived in my car, they found out that I was staying in my car, they tried to find somewhere better to stay… Eventually, after 6-8 months I rented a caravan in a caravan park. (Aaron)

Aaron took the place in the caravan park in one of Melbourne’s suburbs because it was better than living in his car, cheaper than renting a unit and because it was close to his work place. Indeed, caravan parks have become
since the 1980s a significant source of affordable housing in Australia (Reed and Greenhalgh 2004).

A: It was ok but it wasn’t a nice caravan park. Like, if I tell you the name of the park you’d already know.
I: what’s bad about it?
A: pretty much dick-heads on drugs and alcohol thinking that they’re better than anyone else. Which is what you usually get anyway. (Aaron)

Aaron considered moving out of the caravan park, but could not find any alternative. He was also misled by some people who told him he might move in to live with them:

I was going to move in with a friend, someone I know … I was all set to move in with those people, but they have moved and they haven’t got in contact and I couldn’t get in contact with them. (Aaron)

In 2004 Aaron took a holiday in his home town, and when he came back to Melbourne he was told by his supervisors that he was no longer employed in that job. Aaron was furious, and is still very emotional when speaking of this. He moved back to his father’s place, and he has been staying there since. He is still unemployed. However, now his father is very ill, and Aaron’s future is uncertain. He does not have any specific preferences about where and how he would like to live:

I: Where would you prefer to live, if you had the choice, Melbourne or (your home town)?
A: A choice?
I: Yes, Melbourne, (your hometown) or anywhere else. If you could find a job, where will you want to live?
A: Anywhere.
I: You don’t mind where?
A: I’m an adaptable person.
I: So what is important for you?
Aaron seems to consider the notion of choice irrelevant to his situation, as he does not have any particular preferences and wishes. This understanding undermines the assumption embedded in the choice agenda that people are able to ‘choose with their feet’, by moving to places with more appropriate opportunities for them (Jordan 2006). Indeed, Aaron’s story illustrates the way lack of services, housing and, in this case, employment in rural towns often means a need for relocation for people with intellectual disabilities. However, such moves are not always driven by choice, and they often entail difficulties that people with intellectual disabilities are not in a position to deal with.

5.2.4 Legacies of institutionalization and deinstitutionalization

The long centuries of institutionalizing people with intellectual disabilities, and a few decades of deinstitutionalization, have left their marks on regions in different ways. The most obvious mark is the number of Community Residential Units (CRUs, also referred to as group-homes and shared supported accommodation) in different regions. Significantly more CRUs are located in regions where large institutions were previously located and then closed in the 1990s – Eastern Metropolitan Region (where Kew Residential Services was the largest institution), and the Grampians Region (where Pleasant Creek and Aradale were the largest institutions). In these regions, the closures of institutions were accompanied by the development of new group homes in the regions, to which the residents were relocated. Table 5 below shows the total and relative numbers of CRUs in each of the regions considering their population (based on the Community Visitors’ 2006 Annual Report (Office of the Public Advocate 2006)), illustrating this disparity. As evident, Eastern Metro and Grampians regions present the highest rates of CRUs compared to other regions:
Table 5: Numbers and rates of CRUs by regions

<table>
<thead>
<tr>
<th></th>
<th>Metropolitan Region</th>
<th>Rural Region</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>East Region</td>
<td>South Region</td>
</tr>
<tr>
<td>Population (in thousands)</td>
<td>972 1200</td>
<td>1400 350</td>
</tr>
<tr>
<td>Total number of CRUs</td>
<td>244 154</td>
<td>246 70</td>
</tr>
<tr>
<td>Proportion: residents per CRUs (in thousands)</td>
<td>3.98 7.79</td>
<td>5.69 5</td>
</tr>
<tr>
<td></td>
<td>North West Region</td>
<td>South West</td>
</tr>
<tr>
<td></td>
<td>Gippsland</td>
<td>Grampians</td>
</tr>
<tr>
<td></td>
<td>Hume</td>
<td>Loddon Mallee</td>
</tr>
<tr>
<td></td>
<td>250 298</td>
<td>211 49</td>
</tr>
</tbody>
</table>

Sources: Department of Human Services 2005a; Office of the Public Advocate 2006

Before the closures of the institutions in these regions, they may have had larger proportions of people with intellectual disabilities in their population, because people with disabilities from other regions were relocated into their institutions. Now, however, there is evidence to suggest that such regional demographic disparities are no longer as significant. In fact, the proportion of people with intellectual disabilities in the Eastern Region’s population is similar and perhaps even slightly lower than all other metropolitan regions (ABS 2001a).

The population of people with intellectual disabilities in those regions where institutions were located is different not in its size as much as its characteristics. People who have come out of institutions moved into CRUs under different conditions, within the framework of an institutional closure, and often as a group that moved together into a CRU that was built specifically for it. An account by Natalie, a manager in a non-government support agency, illustrates how this creates differences between regions:
N: The people that we’re supporting (in the Eastern Region) have all except one moved out of Kew Cottages. And there’s a group of women who’s known each other for years and years and years, and that sets a certain ambience.
I: They all moved together to the house?
N: They moved together, and then one died two years ago and some one else came in who wasn’t from that original group. But the others have known each other probably most of their lives.
I: And in (another region) was it different?
N: The people have come in more from home. A different process.
(Natalie)

Natalie’s account implies that in regions where large-scale state-run institutions have operated and have been closed down, there is not only a significantly larger number and proportion of group homes, but also a different kind of group homes (‘a certain ambience’) due to the different life experiences of their residents. Over time, this often creates a difficulty for new people who have never been institutionalized to move into these houses, as explained by Beth, a manager in a non-government support agency:

B: In 1984 they started moving people from institutions into the houses that we bought in the community. So there were different groups in different houses.
I: did the mismatches [between residents] start occurring already then?
B: more problems started to happen when people died and that created a vacancy. The external matches were more the problems.
(Beth)

To conclude, while regions were originally only administrative constructs, their existence has been institutionalized in the sense that they have become in many ways actual places, with particular housing landscapes and cultures. Their histories – predominantly the presence of state-run institutions in their past – have set paths of development that are not easily diverted by any new policy agenda.
5.3 Choice, redistribution and locations of advantage and disadvantage

Being a government funded system means that there’s always limited resources and always a balance between a little bit for everybody and a lot for a few, and that’s never going to change, there’s never going to be enough to go around it (Zora, Department of Human Services)

Increased choice in housing for people with intellectual disabilities implies redistributing additional resources to provide access to housing for a diverse population with various preferences. However, in Victoria, such redistribution has not occurred. Publications by the Victorian Government maintain that since 1998 there has been a steady rise in State funding for disability services: during 1999-2002 state and federal funding for disability services in Victoria have increased by 34 percent (Department of Human Services 2002). However, with growing demand for services on the one hand, and growth in expenditure for people with disabilities due to inflation (particularly in housing) on the other hand, it is more accurate to talk about an overall decline in resources available for people with disabilities in Victoria, rather than an increase. Therefore, the tension between distribution and rights is manifested in Victoria as a policy dilemma between ‘a little bit for everybody and a lot for a few’, as suggested above by Zora, a senior manager in DHS. Moreover, with limited resources, the sector turns to cost-saving strategies – particularly economies of scale in housing models, and location in low-income neighbourhoods where housing is cheaper. The latter strategy is discussed in this section (economies of scale strategies are discussed in Chapter Seven about housing models).

Disability housing in Victoria is often located in low-income neighbourhoods, often termed locations of disadvantage. Such disadvantage is apparent in the average income of local households, as well as their access
to services and quality of infrastructure. Housing in places of economic
disadvantage is often more affordable, and DHS and support agencies also
tend to locate their services, including accommodation, in such areas.
However, the relationship between locational disadvantage and the location of
housing differs from one housing model to another. The following sections
address these differences and conclude by examining their short and long
term implications.

5.3.1 Geographic distribution of various housing models by
locational disadvantage

Group homes
The data available is not sufficient to accurately depict the relationship
between locational disadvantage and location of group homes in Victoria. The
quantitative data on the location of group homes is by regions, so it is difficult
to tell where CRUs are located within the region. Even in a wealthier region,
group homes could be located in poorer suburbs or towns, and vise versa, so
the data on regional distribution is often misleading. Moreover, as stated in a
previous section, other factors - particularly the location of institutions in the
past - have had such an effect on the location of group homes today that it is
very difficult to quantitatively isolate the role of locational disadvantage as a
single factor.

Table 8 below shows the relationship between the number of CRUs in
a region, its population and its Socio-Economic Index for Areas (SEIFA) - an
index of relative locational advantage and disadvantage developed and
evaluated by the Australian Bureau of Statistics (ABS), which is based mainly
on the proportion of high and low income residents in a location, their level of
education and their occupations. Other factors such as living conditions,
family status and fluency in English are also taken into consideration. A low
score on the index points to a high level of disadvantage in an area. Scores
range between 800-1200 (Australian Bureau of Statistics 2001b). Locations in
this index are determined by postcodes but I have manipulated the data to a
regional scale by calculating an average score for all the postcodes in each
The table may help examine whether wealthier regions have a lower rate of CRUs:

**Table 6: Locational disadvantage and rate of CRUs by region**

<table>
<thead>
<tr>
<th>Metro</th>
<th>Rural</th>
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<tbody>
<tr>
<td>Eastern Region</td>
<td>Southern Region</td>
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<tr>
<td>North West Region</td>
<td>Gippsland</td>
</tr>
<tr>
<td>Barwon South West</td>
<td>Grampians</td>
</tr>
<tr>
<td>Loddon Mallee</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Population (in thousands)</th>
<th>Disadvantage Index</th>
<th>Total CRUs</th>
<th>CRUs per 1000 residents in the region</th>
</tr>
</thead>
<tbody>
<tr>
<td>972</td>
<td>1065.4</td>
<td>244</td>
<td>0.25</td>
</tr>
<tr>
<td>1200</td>
<td>1132.98</td>
<td>154</td>
<td>0.128</td>
</tr>
<tr>
<td>1400</td>
<td>994.9</td>
<td>246</td>
<td>0.17</td>
</tr>
<tr>
<td>240</td>
<td>1161.1</td>
<td>38</td>
<td>0.15</td>
</tr>
<tr>
<td>350</td>
<td>1024.1</td>
<td>70</td>
<td>0.2</td>
</tr>
<tr>
<td>211</td>
<td>1009</td>
<td>76</td>
<td>0.36</td>
</tr>
<tr>
<td>250</td>
<td>1000.7</td>
<td>70</td>
<td>0.28</td>
</tr>
<tr>
<td>298</td>
<td>998.73</td>
<td>49</td>
<td>0.16</td>
</tr>
</tbody>
</table>

Sources: Australian Bureau of Statistics, 2001b; Department of Human Services 2005a; Office of the Public Advocate 2006

Table 8 does show that, for example, there are more CRUs in the North-West Metropolitan region than in the Southern Metropolitan Region whose population is generally wealthier. On the other hand, the Eastern Region shows a relatively high rate of CRUs despite a high score on the SEIFA index. However, the high rate of CRUs there can be attributed to the region’s history of institutions, as explained earlier. In any case, a strong connection between locational advantage and disadvantage and location of group homes on a regional scale cannot be established with this data. In the rural regions such a relationship appears even weaker.

Nevertheless, there is some qualitative evidence to affirm a connection between locational disadvantage and rate of CRUs in Victoria. Several managers in DHS and support agencies I have interviewed maintained that due to funding limitations, as well as lack of available properties which are suitable for a CRU, it is much more difficult for them to establish group homes in suburbs which are wealthier and more expensive and therefore they are more often located in low-income suburbs within the regions. One significant
exception is the cluster of twenty group homes in Kew, a wealthy suburb in Melbourne, which will be further discussed in sections 5.3.2 and 6.5.

Private rental
In the private housing market, people with intellectual disabilities wishing to live independently are more likely to find private rental opportunities in low income locations. However, the current situation in Victoria is such that housing in the private market – even in its most affordable locations - is still not affordable for a person living off a disability pension. Ironically, the move towards individualized disability services and the policy encouraging a growth in independent living arrangements comes at a time when private rental is unprecedentedly expensive, not only in the city – including the poorest suburbs - but also in rural towns, as expressed by Emma, a DHS officer in a rural region:

The rent has gone up quite a bit here over the last 10 years, you’ll pay about $180 (per week) now for what used to be $100 ten years ago, a 2 bedroom house (Emma)

Private rental of such costs - which represent the lowest end of the housing market in Victoria, and have already increased since the interview took place - is likely to cost a person with an intellectual disability around 55 percent of their income (assuming that person receives a standard disability pension of $546 fortnightly with maximal rent assistance of $107.20). In Melbourne, if a person with an intellectual disability is lucky enough to find an affordable private rental unit in times when these are rapidly disappearing from the market, they are likely to spend around 70% of their pensions on rent (more detailed figures are presented in Chapter Four). This, again, is only true in the cases where they have not been denied even this opportunity because of various other forms of exclusion enacted against people with disabilities in the private rental market, as elaborated in Chapter Six.

Public housing
The inaccessibility of private rental often means that people with intellectual disabilities who wish to live independently are dependent on the availability of
public housing. The location of public housing in Melbourne has been
determined by historical factors including those related to the slum clearance
efforts of the Victorian Government after World War II. Many public housing
estates were built in suburban locations to accommodate low-income families.
During the 1960s, many public housing estates have been developed in inner-
city locations which were considered slums then, but today are among the
most sought-after locations in Melbourne.

On a regional scale, there are extreme disparities in the distribution of
public housing, and its availability. Table 9 below shows the distribution of
public housing by DHS regions (based on analysis of data published by the
Department of Human Services (2008c)), in relation to the relative economic
disadvantage of these regions, as calculated by SEIFA:

Table 7: Public housing and locational disadvantage by regions, Victoria

<table>
<thead>
<tr>
<th></th>
<th>Metro</th>
<th>Rural</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Eastern Region</td>
<td>Southern Region</td>
</tr>
<tr>
<td>Disadvantage Index (SEIFA)</td>
<td>1065.4</td>
<td>1132.98</td>
</tr>
<tr>
<td>Public housing units in region</td>
<td>6339</td>
<td>27,619</td>
</tr>
<tr>
<td>Public housing units per 1000 residents in the region</td>
<td>6.52</td>
<td>23.01</td>
</tr>
<tr>
<td>People on the waiting list for public housing</td>
<td>4,485</td>
<td>9,706</td>
</tr>
<tr>
<td>Rate – number of applicants per unit</td>
<td>0.70</td>
<td>0.35</td>
</tr>
</tbody>
</table>

Sources: Australian Bureau of Statistics, 2001b; Department of Human
Services, 2005a, 2008c; Office of the Public Advocate, 2006

The table suggests that The Eastern region, which is among the wealthiest
regions (high score on the SEIFA index), has the least number of public
housing units in its area compared to the size of its population. Indeed the rate
of applicants on the waiting list for public housing in the Eastern Region is
among the highest in the state: an average of 0.7 applicants per unit in the region – double the rate when compared to the Southern Metropolitan Region, another relatively wealthy region. Since private rental is also the most expensive in the Eastern region, it is probably the place where it is most difficult for people with intellectual disabilities living off their pensions to find a place to live independently (unless they receive financial support from their families).

The Southern Metropolitan Region appears to be far more advantageous in terms of availability of public housing. However, this advantage is balanced by a very low rate of CRUs in the region. Rural regions seem to enjoy a relatively higher rate of public housing available, yet due to the size of the regions, the location of public housing is likely to be more distant from the applicants’ original home towns.

Having said that, it should be stated that in many ways the regional comparisons made above are not very significant, because when the waiting lists are as long as they are – it does not really matter if there are 5,000 or 10,000 other applicants – in both cases there is no real access to public housing.

**Social housing**
Provision of affordable housing by non-government organizations - social housing - has become a major trend in various countries around the world. In 2003, around 7500 housing units in Victoria were owned or managed by local government or community housing organizations. Most of the housing stock held by housing associations was transferred to them from the Office of Housing, but such agencies are also engaged in acquiring and developing new housing units through partnerships with local government and support agencies (Jacobs et al. 2004). In some cases, poorer areas are further disadvantaged by this practice of partnerships, because of the requirement for some local input to the investment, as explained by Sam, a senior officer in one of DHS’s rural regions:
Affordable housing associations [...] would like to have some local input on the assets purchased, I suppose. Some families are able to contribute to the capital, so I think that we regionally have to build our knowledge and databases of families that may be able to contribute to the capital build, with the view that affordable housing associations may come up with an option suitable for them. But there are people out there without any capital, and our role is to try to make sure that people with individual packages and dollars are getting options provided. And I don’t think we’ve been very good in this to date. (Sam)

This type of locational decision is not based on an assessment of the particular preferences of specific individuals, or specific communities, but is more ‘opportunistic’ in its nature. Where an opportunity exists – such as a potential property that could be built and a potential partnership of agencies – this opportunity is seized by the partnership and a new housing facility is developed, as in the example below, a written account provided by Joyce, a manager of a non-government housing association:

A newer housing project was developed in partnership with (a support agency) in 2006. Of a total of eight self contained units, (the support agency) has nominated rights to five. Two are allocated to persons with a physical disability and the remaining three are allocated to persons with an intellectual disability. Considerations were not made for this group in terms of location and housing model – these were determined before the partnership was entered into. (Joyce)

Joyce’s account points to one of the problems with development based on partnerships in terms of choice. Often such developments are not planned to meet the needs or preferences of particular individuals, but rather respond to opportunities. Nevertheless, such developments do increase the range of options available. Two opposite locational factors operate in this form of
development by partnership. On the one hand, the limited capacity of disadvantaged communities to offer ‘local input’ in the development of housing for people with intellectual disabilities seems to keep such developments away from low income locations, particularly when they are isolated as in the case of some rural towns; on the other hand, the affordability of space in such locations seems to draw them in.

**Supported Residential Services (SRS)**

SRSs are privately owned congregated residential facilities providing services mostly to aged care clients, but also to some people with intellectual disabilities who are relatively independent but do require some forms of support such as assistance with taking medication. *Table 10* below shows that SRSs are located in more economically advantaged regions, and predominantly in urban regions. However, most of these facilities charge fees which exceed the disability pension (Green 2001) and are therefore not accessible for most people with intellectual disabilities anyway.

**Table 8: SRSs and locational disadvantage by regions**

<table>
<thead>
<tr>
<th>Metro</th>
<th>Rural</th>
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<tbody>
<tr>
<td>East Region</td>
<td>South Region</td>
</tr>
<tr>
<td>Population (thousands)</td>
<td>972</td>
</tr>
<tr>
<td>Disadvantage Index (SEIFA)</td>
<td>1065.4</td>
</tr>
<tr>
<td>SRS facilities</td>
<td>60</td>
</tr>
</tbody>
</table>

*Sources: Australian Bureau of Statistics, 2001b; Department of Human Services 2005a, 2008a*

5.3.2 Implications of housing in low income locations

Some participants raised concerns about the safety of people with intellectual disabilities in low-income locations:
If you look at where the properties are the cheapest, they’re in the lower socio-economic areas, which are environments we don’t want our clients going into because there’s crime, high unemployment and all the rest of it, and our clients will not fare well and may be taken advantage of, and that creates a whole host of other problems. It’s a vicious circle. I don’t think it’s going to be pretty and I don’t know how they’re going to fix it. (Matthew, DHS officer)

C: When facilities were redeveloped and they were looking for properties to build they were looking at areas they could afford, so we got a lot of places around (a low-income suburb) because at that time it was what we could afford.
I: So now your houses are still in low-income neighbourhoods?
C: Yes, they tend to be. We’ve got a property in (another low-income suburb) – we got the best location and it’s an improving area, but there still are a lot of issues with drugs and alcohol.
I: Do you find problems with that?
C: Yes. Wallets have been stolen, and one client was attacked by a person (Corinne, manager in a non-government support agency).

The risks described by Corinne and Matthew are not exclusive to low income neighbourhoods, yet various studies, such as Judd et al (2002) in Australia, do find a strong association between places of economic disadvantage and high crime rates. However, beyond the actual experience of crime, the very fear of crime may negatively impact opportunities for social interactions in a place (Palmer et al 2005: 396). For people with intellectual disabilities living in State-funded housing, opportunities for social interaction in their community are very much dependent on the extent to which their support workers and service administrators allow and support them to do so. When administrators express fear of crime in low income neighbourhoods (regardless of whether this fear is based on actual experience), they may also be more reluctant to support social inclusion for their clients in such places. In contrast, some service providers avoid locating houses in low-income or remote neighbourhoods where housing is cheaper, and maintain their services in
more expensive suburbs or towns. Such an approach means that eventually they can provide housing for fewer clients.

Whilst in the disability sector, most of the financial burden of providing housing in more expensive suburbs is absorbed by government or support agencies, in the private sector it directly affects the individual renting the house. Even housing associations often take more rent in more expensive suburbs, as explained by Harris, a manager in a housing association:

L: One model (of calculating the rent) is 25 percent of the income (of the renter). Another model that we use is that we look at what the market rent for a property is, and we charge accordingly. We can't charge more than 75 percent of the market rent. But if that's too much, we charge 65 percent of the market rent, or 55 percent. It depends where the property is, in different parts of Melbourne ,, So we charge according to the market rent, but on top of that, what we charge can't exceed 30 percent of the client's income. We charge as much as we can charge to get the maximum rent assistance from the government, but it will never exceed 30 percent.
I: how much is it in dollars?
L: it depends. We've got a single’s accommodation here in (the CBD), and that’s about $130 a week. And they get $60 a week from the government in rent assistance, and the rest is coming from their own income. For a lot of people the market rent is low so they’re paying 75 percent and that’s less than 25 percent of their income, it’s about 22 percent of their income. (Harris)

Housing associations often charge less from clients in locations where the median rents are lower, (22 percent of their income, as opposed to 30 percent of their income in more expensive locations). Therefore, it can be concluded that in the current policy context, in economic terms, people with intellectual disabilities could be better off in low-income neighbourhoods. However, in other terms – mainly security or sense of security – low-income locations may be a source of growing disadvantage for people with intellectual disabilities. Nevertheless, appropriate planning of services in low-income neighbourhoods may help overcome each of these challenges, as evident in Dear and Wolch’s
(1987) discussion on the advantages entailed in a network of services in close proximity, even within a low-income neighborhood.

The economic considerations affecting location of new State-funded housing developments for people with intellectual disabilities are mostly short-term and relate to the initial investment, as Paul, manager in a housing association, explains:

Property is much more expensive in the city than the country. That’s very much true. That’s a real problem, but in the end that’s only a problem at the capital grant stage. Only the first stage. Once you’ve got it, we charge income based rent, so it doesn’t matter so much after that. (Paul)

However, for people with intellectual disabilities there are long term implications associated with locations of disadvantage. People with intellectual disabilities already living in low-income locations are more constrained in their choice to move out. A very illustrative example for this can be learned by comparing the redevelopment process in two institutions in Victoria: in Kew Residential Services and in Colanda (see Figure 4). In Kew, an upper-class suburb in Melbourne, selling the land enabled much more capital investment in the redevelopment, which allowed building a cluster of CRUs within the new residential suburb developed on the site. The capital investment in the redevelopment would be completely covered by the income raised from selling properties in the new suburb, as explained by Shirley, a DHS senior officer:

I: How much does it cost, the whole redevelopment?
S: The capital money, each CRU costs about $900,000 – the land and the building and the rest of it. And the intention is that the capital fund will be returned from the sales of the site. And it now looks as if there will be additional funds, because the sales brought a lot of money, and a percentage of each block sold returns to government and over a certain sales price another percentage goes to government, and they sold all of the houses in stage one. And it was
sold without any advertising at all and for figures we were quite frankly astounded by. (Shirley)

In Colanda, this is unlikely to happen, as explained by Zora, another DHS senior officer:

(Colanda is) about 3 km out of the centre of Colac, so it used to be in the rural area, although it’s a disadvantage because it’s quite a long way from the centre of town, and shops and services. And there’s no public transport, and it’s stuck up the side-road. But it used to be a rural site, and it used to look out on rural land, and it used to be very picturesque. All of the land around it now from three sides is now industrial, and a new industrial estate has just been developed on one boundary and on the other boundary it’s also industrial. It’s on the road to a timber mill just up the road, so there’s a lot of noise pollution, and you can hear the processing noise, and the logging trucks stream up and down the road. So it’s not a suitable area for accommodation for anybody and it certainly wouldn’t be like in Kew, high value residential land – nobody will want to live there. (Zora)

While the explicit government policy is not supportive of clustering CRUs in small areas, in Kew the land value enabled such a development, and with the push of the parents’ associations it has been implemented. In the context of Colanda, as Zora maintains, a push towards a cluster is less likely to be accepted and implemented. Moreover, it is fair to conclude that the redevelopment in Kew has been hastened by the fact that the capital grant was more readily available, as well as by a possible push from private developers seeking to invest in the new suburb. In Colanda, in contrast, the redevelopment is delayed since the capital grant is not readily available and would be far more expensive for the Government. The comparison suggests that choice should be looked at not only in the immediate term (as this notion somewhat implies) but also in the long-term. In this sense, housing should also be seen as an investment to allow people with intellectual disabilities choice in the future as well as today. Cheaper housing may be seen as an opportunity in the short term, but would become more constraining in the long
term. Capital investment in more appropriate locations could allow mobility and more choice in the future. However, it is clear that as any other long term investment, it is very difficult to predict which investment would yield better choice for people with intellectual disabilities in the far future.

5.4 Uneven dispersal: conclusions

Dispersal of housing for people with intellectual disability in Victoria has begun since the early days of deinstitutionalization, prior to the emergence of a choice agenda in scholarly, professional and policy discourses. In this sense, the choice agenda may be seen as yet another step in the same path directed by the deinstitutionalization movement which started several decades earlier.

Some would consider geographic dispersal an essential precondition for housing choice, as if a more diverse range of locations in housing would allow more choices for individuals. Moreover, it may be argued that allowing people with intellectual disabilities real choice will inevitably lead to the formation of a dispersed housing landscape due to their diverse location preferences.

However, in Victoria, spatial dispersal occurred in very particular and uneven forms, creating very unpromising conditions for the implementation of the choice agenda. The uneven dispersal is evident in disparities between centre and periphery within each of the regions; disparities between low-income and high-income locations within each of the regions; and, disparities between different regions related to the histories of state-run institutions in Victoria. Such disparities suggest that the choices individuals make will be so heavily constrained by the geographic location of opportunity that asking them to choose without actively working to radically alter the housing landscape, will eventually change very little in outcomes.

Moreover, the choice agenda does not appear to address deeply embedded institutional and economic patterns which determine the location of housing. On the contrary, should they be given a ‘choice’, vulnerable individuals desperate for housing will move (if they can) to places where
housing opportunities exist, thus reinforcing the uneven development of the sector rather than resisting and changing it. Those who cannot move in search of opportunities will have no choice in housing whatsoever and for some – no housing at all.

To conclude, an agenda of choice cannot be effective without a commitment to provide a reasonable level of choice in location. However, the location patterns in the disability housing sector are deeply embedded in its institutional history and geography, and in the ongoing lack of resources. Disparities between places and shortages everywhere, in terms of access to housing and support, emphasize the need to balance the person-centred approaches, upheld by the choice agenda, with spatial planning. It cannot be assumed that people are always able to ‘choose with their feet’ and move in search of opportunity – a notion that Jordan (2006) relates to neoliberal philosophies. Spatial disparities – and, again, lack of services and housing everywhere – will not be fixed by individualizing access to funding but by creating housing and services where they are most needed, to cater specifically for people with disabilities.
Chapter Six
Inclusion, exclusion and location

This chapter continues the task that has been set up in the previous one (Chapter Five), of defining the factors and implications of location in housing for people with intellectual disabilities in Victoria. The previous chapter focused on two such factors: the institutional structures of state bureaucracy which lead to particular patterns of location of housing; and, a chronic shortage in resources for disability services as a persistent condition leading to establishment of housing in locations of disadvantage. The current chapter addresses a third factor affecting location choice in housing for people with intellectual disabilities: community inclusion and exclusion. This theme is addressed in a separate chapter – rather than a section in the previous chapter - because of its complexity and length, and because it relates to a unique body of literature and set of theoretical questions, as discussed in the following section.

Community plays a significant role in housing choice for people with intellectual disabilities. Disability housing – particularly shared supported accommodation and independent living – is embedded within an ethos of community, and is often termed ‘community care’. However, communities are not always inclusive and supporting, but often rather exclusive or oppressive in ways that hinder choice for people with intellectual disabilities (as discussed in Section 2.4.2). Furthermore, the community-care ethos entails a very particular kind of imagination of community. In this section, however, I show how location choice may be enabled or constrained by the involvement, or lack of involvement, of a variety of communities of different types and different geographies.
6.1 Inclusion and community in the geographies of people with intellectual disabilities

Exclusion and inclusion are useful concepts to discuss the integration of people with disabilities in the community. These notions address not only the wellbeing of one individual in a particular time and place. They help illustrate deeply embedded multi-dimensional social norms and material realities in which certain social groups are systematically rejected from participating in social life (Levitas et al 2007). However, for this very reason, when one delves into the subtleties of a specific context, the distinctions between inclusion and exclusion often seem blurred. In order to make best use of these concepts, what is necessary is an analytical distinction between various types of communities into which inclusion is imagined.

The notion of community appeals to liberal critics of the state who see it as an alternative to its ‘abstract formalism’. Critics of liberalism, however, flag community as an alternative to individualism (Darcy 1999: 15). Community-based provision of public services may also be seen by some as a means to reduce the state’s welfare responsibilities and costs. With such a wide appeal, it is no wonder that community-care has emerged as the major alternative to institutional care, and the central notion in current disability policy (Gleeson 1999: 153). However, for the very same reason, the philosophy of ‘community-care’ was always ambiguous about the nature of the ‘community’ it implies. Three interpretations of community are discussed below as an example for this ambiguity: community defined by municipal jurisdictions, community defined by voluntary-sector activity and community defined by informal affiliation and interdependence. Each interpretation emphasizes a different element of community, and has particular implications on the spatiality of the inclusion and exclusion of people with disabilities.

The interpretation of community as defined by municipal jurisdictions implies place-based communities. This interpretation is implemented through
transfer of responsibility to disability services from federal or state to local government. This has some significant implications for the inclusion of people with disabilities. It means that the ‘burden of care’ on the local community is strongly related to taxation levels. In Los Angeles, for example, ‘Fair Share’ urban planning policies were introduced in order to ensure that tax burdens associated with community-care are evenly distributed across municipalities (Dear and Wolch 1987). Dispersal of care facilities, in this case, was mainly an attempt to minimize inequities between municipal communities. However, at same time this was also described as a way to increase community inclusion for people with disabilities, with an assumption that communities would become more inclusive if the ‘burden of care’ is spread more evenly. In Victoria, however, community-care is mostly funded the State government and is not associated with increased local taxation. Hence, the community-care movement in Victoria does not rely on an interpretation of communities defined by municipal jurisdictions, as much as on two other elements: community-sector activity and informal affiliation.

Community-sector activity was originally envisioned as an opportunity to move away from centralized state control to more flexible locally-oriented forms of service delivery (Wolch 1990). It was place-based in the sense that some community organizations emerged from local initiatives and operated within a restricted local scale. However, as Wolch’s study found in the US and the UK, local voluntary sector activity is always influenced by broader structural and institutional forces, particularly within the state (p. 33). Moreover, many voluntary organizations operate on national and global scales. Therefore, community-care, in the sense that it relies more heavily on community-sector organizations, does not imply a reliance on actual place-based communities as much as a more ‘disembedded’ ethos of community.

The third interpretation of community, as a group of people who share a sense of belonging and affiliation, is perhaps the most elusive in terms of its spatial form. Facing this challenge, geographers have attempted to define the spatial dimensions of community exclusion and inclusion of people with disabilities. For example, since the early stages of deinstitutionalization, much geographic research in the US, Canada and Australia pointed to cases of local opposition to establishment of care facilities for people with disabilities –
mainly mental health but also intellectual disabilities (Dear et al. 1980; Joseph and Hall 1981; Wolpert et al. 1975). Dear et al (1980), examined community attitudes in metropolitan Toronto to local mental health facilities, and found that the most negative attitudes occur within a very limited area around a potential facility. Beyond these areas there is a general acceptance of mental health facilities. Further, the authors argue that expressions of group opposition to mental health care facilities are not necessarily representative of the wider community as much as a ‘vocal opposition from a minority (usually with extensive media coverage) [which] can often inflate a local difficulty out of all proportion’ (p. 352).

Thus, some researchers emphasize forms of community exclusion that are more subtle than explicit organized opposition to establishment of care facilities. Widespread lack of social networks among people with intellectual disabilities (Bigby 1997) is perhaps a form of exclusion far more important than scattered cases of direct community opposition. Hall’s (2004, 2005) work on the geographies of people with intellectual disabilities has further developed the understanding of more nuanced forms of inclusion and exclusion. Hall notes that people with intellectual disabilities often respond to various forms of discrimination, abuse and rejection by ‘self-excluding from certain public spaces and places and by actively making ‘safe spaces’ and networks where new forms of ‘normality’ and inclusion can be shaped’ (p. 304). The notions of ‘self-exclusion’ and ‘safe spaces’ offered by Hall, shed light on the nuances of exclusion and inclusion, attentive to both subtle and explicit practices enacted by a variety of actors in the community, including people with disabilities themselves.

In a similar fashion, Power’s (2008) study is also sensitive to subtle forms of exclusion and inclusion and their spatial expressions. Power reminds that informal care by families has always been the major source of care for people with intellectual disabilities, despite the disproportional attention given in the literature to formal care facilities (p. 834). This understanding even further complicates the meanings of community inclusion and exclusion— is a person living with and cared for by their parents in the community, necessarily experiencing community inclusion? Power’s study focuses on the carers’ perspective and suggests that they, too, experience various forms of
exclusion. Many carers in Power’s study have expressed a sense of isolation, of being tied to their homes and to very particular spatial boundaries and routines.

Hence, strategies of inclusion and exclusion are tied with particular interpretations which emphasize specific elements of the community, and have specific spatial dimensions. The themes and cases discussed in this Chapter, and the way they are organized, reflect the range of interpretations of the notion of community, and the range of types of communities, which give rise to different forms of exclusion and inclusion, in the context of an agenda to increase housing choice for people with intellectual disabilities.

6.2 Imagining community as a platform for individualized services: policy makers’ perceptions of community

Victorian disability policy, as articulated in the 2002 State Disability Plan, and as part of a wider political agenda of the State’s Labor Government, aspires to make use of the advantages provided by communities, as Tim, a DHS senior officer suggests:

There is a lot being done to make community participation in the regions real. It’s not just in disability, it’s the Department of Victorian Communities, their role primarily is to equip the broader community in relation to accepting and embracing people with disabilities as contributing citizens, but there’s still a long way to go with that. It varies from place to place, some rural communities are very good, the families of people with disabilities all look after each other and help out … and probably the smaller the community, the better. In the bigger metropolitan areas there is less sense of community, and there is where it needs to be developed … they have to put a lot of work into developing those circles of support. It’s around an individual, so it’s not the whole community, but there are a number of people within a community there prepared to take part in that.
person’s life. There’s along way to go, and it takes quite a bit of effort to get those people to be engaged. (Tim)

Tim suggests that ‘some rural communities are very good’, and that ‘the smaller the better’, by that pointing to the way the ideal of community is perceived by some policy makers and their expectations from it. It is perceived as a tight community, grounded in a particular place, which not only passively ‘includes’ people with intellectual disabilities, but actively supports them to be engaged. In this sense, it is not just the person with the disability who takes part in the community’s life, but also the community that takes a caring role in that person’s life. Indeed, some research conducted in Victoria suggests that people living in smaller rural towns are more likely to have an informal carer than their metropolitan counterparts (AIHW 2006: 47). However, it is difficult to tell whether this is so because of stronger community networks in rural towns or due to their lack in formal services.

Tim makes a distinction between ‘the whole community’ and ‘a number of people within a community’ which form a ‘circle of support’. I refer to these in this chapter as the primary and secondary circles of community – a primary circle is a network of people who are directly involved in the life of a person with an intellectual disability, providing different forms of informal support; the secondary circle is the rest of the community, people whose involvement with people with intellectual disability is infrequent and mostly indirect. As Tim suggests, most policy initiatives are focused on the primary circles of community, since these provide unpaid support to complement the limited formal support funded by DHS.

Similar to Tim, a very particular imagination of ‘community’ is evident in the account given by Kay, another senior manager in DHS. This account is particularly useful for discourse analysis and is presented at length because it is explicitly hypothetical, but at the same time very rich in detail, a description of her vision of community inclusion:

Let’s just take a small country town in a rural region, where there are, let’s just say, people with an intellectual disability. They have grown up in that town; the families of those people know each other relatively well because
they live in a small community. Their sons or daughters attended day services in that town, and a few of them get together and start talking about what their sons and daughters are going to do when they die, and they will need somewhere to live. It's much easier – I think, not always, but as a general rule - for us to work with small groups of people in smaller towns because there is a different sense of community and connection, and what might be possible. And the sort of thing that could emerge – and this is hypothetical but there is some truth in all of it – maybe that group of parents, one of them would say 'I want to leave my house when I die to my son or daughter, but I don’t mind if they share with a couple of other people’, and maybe they could share their packages of support, and down the track they're great mates and they choose to live together. So maybe that is easier than in a metropolitan region – let’s just take the inner city for example, where there are other questions around the massive size of demand, and it’s hard to facilitate some of those networks and get that thinking happen in a creative way … there’s something a bit more contained or a bit more manageable when you take a country town – particularly a smaller one where you can actually help to facilitate some of that work and people know each other so if someone has moved out and done something different then chances are that his friends and their family members know about it and want to do something similar. (Kay)

Like Tim, Kay sees small rural towns as a more appropriate model of community in which to implement an agenda of individualization and choice: on the one hand, there is a stronger ‘sense of community’ that might motivate and enable people to cooperate with each other in more creative ways; on the other hand, there is ‘something a bit more contained or a bit more manageable’ due to smaller size. In the following sections I examine how these imaginations and expectations expressed by policy makers translate into practice in different contexts of ‘community’, and how this affects the location of housing for people with intellectual disabilities.
6.3 Excluding communities: subtle NIMBYs

Much literature has been written about the notion of NIMBY, of communities rejecting people with disabilities by opposing the formation of residential care facilities (Dear 1977; Dear et al. 1980; Joseph and Hall 1981; Taylor et al. 1979; Wolpert et al. 1975). In Victoria, my findings suggest that overt community opposition to formal care facilities is not a significant factor directly affecting the location of housing for people with intellectual disabilities. However, more subtle forms of exclusion and rejection are very significant, and particularly affect people wishing to live independently. Also, the way community opposition is perceived and anticipated by decision makers does affect their locational decisions, in order to avoid such occurrences in the first place.

Chris, a DHS officer who was in charge of finding and purchasing properties for new CRUs provides an account of some of the ’avoidance strategies’ (Gleeson 1999: 158) used to avoid and manage conflicts with local communities:

> When I would go past a property and my staff member would say ‘yes, it’s a nice property’, and I would look at it and say ‘hang on, it’s only 10 years old. We can’t be demolishing this, because of the public outcry and the neighbours complaining about the government coming in and bulldozing a perfectly good property’. We wanted to avoid that. So that was another factor – a property that was vacant or with a house that was old and needed a lot of work so it wouldn’t be an issue for neighbours if we pulled it down. (Chris)

Chris’s account suggests that even before community opposition actually occurs, some locations are avoided as they are perceived problematic, not so much due to the nature of the local community as much as the nature of specific properties. However, generally, in most cases several strategies are put in place so as to create positive relationships with neighbours and avoid community resistance to the development of new CRUs, as explained by Chris:
C: there was a neighbourhood consultation – 2-3 neighbours each side of the house and the one across the road. We wouldn’t inform them before we bought, but before we started building, in the planning stage, the staff would go and consult with the neighbours, tell them who we are and what we’re doing. We would do that so that when the people moved in we had reasonable relationships with the neighbours.

I: were there any particular problems with neighbours?

C: look, initially, you would get a lot of complaints because before we had a chance to get out there they might have found out at the day of the auction that the government’s bought it, so local neighbours might think ‘we don’t want sex offenders living next to us’. They think that because it’s government it’s going to be terrible. But once we go and visit them saying ‘…they’ve got disabilities, they’ve got a right to live in the community like everyone else,’ then it’s fine, once that is related, once they knew who we were. There was only one property, one of the first ones that we’ve bought down in (name of place) … there were already issues with the neighbours around a previous plan, it was going to be like a tribunal justice facility, they just wanted the department to get out. So there were local meetings… municipal officers were talking to neighbours about what was happening. So it was all worked through … And that was probably the property that we had the worst to go through, but once we got in there it all turned around. (Chris)

Chris’s story suggests that housing for people with intellectual disabilities does not evoke as much resistance as housing for people in the criminal justice system. However, the fact that the houses are owned and operated by the state is often a cause for concern and resistance among neighbours, as it is not certain who would live in the house in the close and distant future. A very similar story was told by Corrine, regional manager in one of the metropolitan regions in a non-government support agency:

But there’s a property – DHS built a property for people coming out of the criminal justice system, and the local residents formed an action group, and they managed to stop that group from moving in.
And we came into the picture, we had a group of people [with intellectual disabilities]… they needed somewhere to live temporarily, so we got that opportunity. So what we had to do then – we had to do a letter drop in the local area, and I had to meet with the action group and talk to them about the clients that were coming in. And that was fine … The interesting thing is that the property where they built the house, there was a house there before with people with disabilities – even quite significant disabilities – but no one even noticed they were there. (Corrine)

Perhaps due to such strategies, or perhaps because people with intellectual disabilities are not conceived as a threat as much as other groups such as ex-prisoners, community resistance to the establishment of local facilities does not seem to play a very significant role in the process of locating CRUs in Victoria. Gleeson (1986) notes that in the early 1980s, when deinstitutionalization had just begun in Victoria, developments of mental health care facilities were met with intensive community opposition, supported by local municipalities which required non-residential planning permits. However, in 1984 the State Government intervened and amended some of its planning policies to ensure that group homes no longer require non-residential planning permits (unless they include more than six residents) (p. 32). This may also perhaps explain why local opposition is not a significant factor affecting the location of group homes for people with intellectual disabilities today.

However, individuals with an intellectual disability moving alone into private rental do not enjoy the same kind of support from government and other agencies, and are more vulnerable to being rejected by the community. In Victoria, the choice agenda upholds a move away from group housing in the disability sector, which is considered too inflexible (as elaborated further in Chapter Seven), towards increased use of housing in the private sector, which is considered providing more options to choose from, all within the community. However, this move may also reinforce the vulnerability of people with intellectual disabilities as isolated individuals, to various forms of exclusion in the private housing market.
One mechanism of exclusion, deeply embedded in the housing landscape, is the physical inaccessibility of most of the housing stock, which makes it unsuitable for people who have both physical disabilities and intellectual disabilities. This can be seen as another form of exclusion, perhaps more subtle than overt community opposition, yet far more effective. Many service providers have told me about clients with complex disabilities who already had funding available for supported independent living in the private rental market, and yet could not find accessible accommodation:

C: There’s one lady (in our day-program), she’s got high physical support needs, and to get into the private rental market there’s just nothing for her. And she doesn’t want to live in a group home. So what do you do about that? There’s a real gap.
I: What do you mean ‘there’s nothing’? Nothing affordable?
C: Being accessible for her with an accessible doorway and an accessible bathroom. For her to get a private rental, she needs to renovate a property. (Corinne, senior manager in a non-government support agency)

In Victoria, as in the rest of Australia, there is no legislation to ensure that residential housing is built according to accessibility standards for people with disabilities. Here, the choice of the community not to build accessible housing, which is legitimized by legislation, overruns the choices of people with disabilities to live in private rental.

Another mechanism of exclusion – subtle yet effective – is evident in the following account provided by Matthew, a DHS officer, suggesting that real estate agents and landlords may choose not to rent a property to a person with a disability without a history in the private rental market:

I’ve worked with a chap who has no rental history, and of course if you’re going around in the private rental market and you’ve got no record, no one wants to take you. Because I’m assuming the (real estate) agencies look and say ‘ok, this guy has no history. Why?’ … I know we traditionally try to play out the poverty, we try to say ‘look, we guarantee the bills will always be paid, and if there is any
damage it will also be paid as well, there’s no risk to your pocket.’ But for most of them the unknown is more daunting than the known. They would rather take someone else who might trash the place and move on. And you never get to find out who eventually got the place. You never know why they weren’t taken or why the other person was better. (Mathew)

The requirement of references for applicants can be seen as another subtle mechanism of exclusion in the private rental market. As a Department of Human Services worker, Mathew’s sense of powerlessness in light of such mechanisms of exclusion reflects a government’s policy of minimum intervention. The government encourages people with intellectual disabilities to live in the community, but does not pro-actively ensure the community accepts that individual, and does not arrange an alternative if the community does not accept them since access to public housing and disability housing is very limited and waiting lists are enormous. Research conducted in Australia has shown that indeed, even the very limited stock of affordable housing available, is occupied by higher income households (Yates and Wulff, 2005), perhaps due to similar mechanisms of exclusion. This suggests that it is the community members who have the right to choose not to accept tenants with a disability. In this sense, a focus on choice in the context of an excluding community may actually undermine real individual choice for people with an intellectual disability, as the community has more power to execute its choices than the individual with the disability. However, such subtle forms of exclusion do not appear to have much influence on the location of housing for people with intellectual disabilities, because they occur almost everywhere, as opposed to more overt forms of community opposition which have often been more localized.

While the discussions above concern a community’s exclusion of people with intellectual disabilities in general, it must be taken into account that people with intellectual disabilities are not one homogeneous group and a community may support one person with an intellectual disability to live within it, and reject another. For people considered as having challenging behaviours, for example, housing options are even more limited than for other
people with intellectual disabilities, as discussed in Chapter Seven. Communities are also much more willing to accept people with disabilities who have grown up in the place, ‘locals’, than people who come from other places. Sam, a senior manager in one of DHS rural regions explains:

> Usually we prefer to match local people. Locals tend to get a bit upset when someone from another city comes in and takes the vacancy. (Sam)

The ‘locals’ described by Sam, are families of people with intellectual disabilities waiting for a vacancy to become available in their town. In some ways, perhaps, this could be seen as a negative form of exclusive localism. However, at the same time, such practices may serve to counteract the systematic dislocation described earlier in Section 5.2.2.

### 6.4 Supporting communities: from community organization to support networks

Historically, community involvement in the disability sector was significantly affected by location (Wolch 1989), and significantly affected the location of housing for people with intellectual disabilities. In Victoria, parents of people with intellectual disabilities have often organized in formal and informal associations to provide alternative forms of support and housing for their sons and daughters outside the state-run welfare system. In locations where such associations were present, they have managed to draw funding from various sources, mainly the state, to develop local accommodation and support services.

In Victoria, while many of the non-government support agencies have evolved from community-based parents’ associations, as these associations grew bigger they have in some ways lost their initial connection to the ‘community’ from which they originally evolved, because they have started operating in larger geographic scales. Also, the original parents who have managed those associations were often replaced by professionals, in many
cases former DHS staff (several of the participants in this study were indeed former DHS staff who moved to the non-government sector). Moreover, Government control over these organizations has tightened over the years, turning such organizations into an apparatus of the state (referred to by Wolch as the ‘shadow state’ (Wolch 1989)) more than an apparatus of the ‘community’. In its extreme, this approach was manifested in the amalgamation of many of the non-government service by DHS in the early 1990s. In this sense, the Government’s tightening control over NGOs has been a move away from community based informal support.

The more recent policy claims and initiatives to move closer to community based informal support – as in the 2002-2012 Disability State Plan - could perhaps be seen as an attempt to undo this history. This attempt is evident in initiatives to encourage and create ‘circles of support’ for people with intellectual disabilities in the community. ‘Circles of support’, or ‘support networks’, is a dominant feature in the discourse of person-centred planning and the choice agenda. These notions refer to an informal organization of people – mainly relatives, friends and support workers of one person with an intellectual disability. That person and their support circle convene every couple of weeks or months to discuss his or her main goals and challenges for the near and far future and to plan the provision of both formal and informal supports necessary in order to meet these goals. Voluntary and informal support circles made up of close relatives and friends are believed to bring commitment, energy and knowledge to the planning process and more imagination and creativity than evident in more formal planning and provision of supports (Mansell and Beadle-Brown 2004: 2; Sanderson 2000: 4). A number of State-funded programs have been initiated in Victoria (mainly under the Accommodation Innovation Grant scheme) to develop and coordinate support circles for people with intellectual disabilities.

Yet, the current move towards community involvement is very limited in its scope. The State Government has made no move to loosen its control over the non-government support agencies. On the contrary, such control has actually increased over the last decades: control over allocation of vacancies was taken away from support agencies and is now fully controlled by DHS. Moreover, the Victorian Government uses the contracting of Non-Government
agencies as a means to reduce expenditure, resulting in funding disparities between government and non-government services which are greater than any other state in Australia (Bigby and Fyffe 2007:25). Circles of support, too, are being developed through top-down initiatives – as opposed to the grassroots movement from which most support agencies have grown historically – mainly as a means to provide unpaid support to compliment the funded support. Moreover, while Government aims to strengthen ‘circles of support’ through initiatives such as the Accommodation Innovation Grants, its location practices in Shared Supported Accommodation actually work to disable such networking, by placing individuals at some distance from their parents and original communities (as discussed in Section 5.2.2). While it would be wrong to blame the Government for the lack of a grassroots movement, it is clear that its actions aim towards community involvement which is not State-funded, and is not organized in a way that would enable groups to raise demands in an effective way as in the past.

The growing control of Government over the community sector has also been reflected in the location process of new housing developments. For more than a decade, support agencies have succumbed into a ‘tendering mentality’ in which they have no control over the location of housing, as they do not initiate the development of new housing but rather respond to tendering processes instigated by DHS. As argued by Wolch (1990), the factors which determine variance between places in terms of both the presence and the agency of non-government organizations are ‘extraordinarily complex’, and lead to uneven development of the voluntary sector (p. 149). In Victoria, too, my study suggests that community sector involvement in the provision of housing for people with intellectual disabilities is not equally significant across the state. Presence of non-government agencies is different in each of the regions, as evident in the table below:
Table 9: CRUs by regions

<table>
<thead>
<tr>
<th></th>
<th>Metro</th>
<th>Rural</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>East Region</td>
<td>South Region</td>
</tr>
<tr>
<td>Percent of CRUs run by non-government organizations</td>
<td>57 62 40 37 46 25 36 35</td>
<td></td>
</tr>
<tr>
<td>CRUs per 1000 residents in the region</td>
<td>0.25 0.128 0.17 0.15 0.2 0.36 0.28 0.16</td>
<td></td>
</tr>
</tbody>
</table>

Sources: Office of the Public Advocate, 2006

Table 7 above shows that most CRUs in the Southern Region are run by non-government agencies, more than in any other region. Yet, the number of CRUs available in the region is relatively low, considering the region’s population. This suggests a weak connection between the location of CRUs and community sector activity. Indeed, the previous chapter has shown other more significant factors determining the location of CRUs in a region – such as its history of state-run institutions. This implies that most non-government support agencies in Victoria do not operate in a way that effectively attracts funding and housing to specific locations, but rather respond to Government tenders.

However, some of the new independent living facilities currently developed by support agencies can be seen as a move back towards non-government-sector initiative for and control over the location of housing. This has been enabled by the availability of individualized funding, and is therefore closely related to the choice agenda. In this sense, community may have control over the location of housing through the initiatives of non-government support agencies. However, as discussed above, it is not clear that these agencies do in fact represent the community more than they represent the government. One exception that should be noted is an organization working within a particular ethnic community in Melbourne which is developing a new
housing facility in the suburb, in a place which is considered the geographic centre of this community. Despite the extremely high land values in this area, the agency managed to raise the funding necessary from the community so as to develop an independent living facility for more than ten people, in a location which will enable them to maintain their relationships with the local community more easily. This and other similar developments are elaborated in the next chapter concerning models of housing.

To conclude, community involvement in the disability sector in the form of formal non-government organizations and informal support networks - has little effect on the location of housing for people with intellectual disabilities. If NGOs do represent some form of community-based support for people with intellectual disabilities in Victoria, then they do not stand for a ‘local’ community in a place as much as for an ethos of community which is not related to any particular place. The move towards informal community-based ‘support networks’ is a move towards a more place-based community, however one that is much more limited in its political power to raise demands and draw funding. Rather, it is used as a means to compensate for lack of State funding. Nevertheless, the availability of new individualized funding schemes appears to allow more space for community-based initiatives, because it is more loosely controlled by the State-Government.

6.5 Perceived inclusion and the dispersal of housing

As explained above, in most cases community, as a proactive source of support, does not significantly affect the location of housing for people with intellectual disabilities. However, the capacity of a community to include people with intellectual disabilities within it, and - more so - the way this capacity is estimated by different actors, plays a significant role in shaping the housing landscape. The dispersal of group-homes across metropolitan suburbs in Victoria is motivated by a view held by many professionals in the disability service sector, that any community has only a limited capacity to include a very small number of people with intellectual disabilities in their community life. This adds to a wish to avoid the creation of a disability
services ghetto. Clusters would be particularly unfair where funding for services is allocated by local government, meaning that the burden of care, including the financial burden on local councils, would fall on one community and not be distributed evenly across the metropolitan area (Dear and Wolch 1987). In Victoria, however, funding for disability services comes from the State Government so there is no significant local tax-burden associated with cluster housing.

In most cases (with some exceptions, as explained below) DHS’s policy is to avoid clusters of more than 5-6 CRUs in one suburb, and to maintain that the CRUs in each suburb are in different streets, despite the lower costs and availability of properties in less affluent suburbs which may lead to the creation of clusters in such places. Opponents of this policy argue that having a cluster of houses will not change significantly the (lack of) capacity of the broader community to include people with intellectual disabilities in its community life. In this sense, it is preferred to have more people with intellectual disabilities in a smaller area to allow them to have a community of their own and to overcome some of the difficulties of integrating in the community. This view is advocated by some associations of parents of people with intellectual disabilities in Victoria.

Such conflicting views about the community’s capacity to include people with intellectual disabilities, were most strikingly manifested in the debate around the redevelopment of Kew Residential Services (KRS) in inner Eastern Melbourne – which has been the largest institution for people with intellectual disabilities in Victoria. Some of the parents of people who have been housed in KRS have successfully convinced the government – despite its policy to avoid clusters – to have 20 CRUs built in the new residential suburb developed on the site of the institution. These parents have argued that having a cluster would enable a community of people with intellectual disabilities – an ‘intentional community’ (Bostock et al 2004: 45) to exist within the broader community of the suburb. In this sense, some individuals they do not consider likely to be integrated in the mainstream community will at least be part of another kind of community. Robert and Thelma, leaders of a parents’ association who have been involved in the planning process explain their position in favor of a cluster:
R: In cluster housing, with a common area in the middle where they can move around – they wouldn’t be isolated in their own house. In Kew people could have moved around more freely, and it’s not like that in a CRU. In the community you need a staff member to go out with you.

T: And no matter how far we’ve come forward in the community, there are some behaviours that are very difficult to manage in a shopping centre or an urban street. I know that it is all terribly ideologically unsound for me to be speaking like this, but in a smaller community where there’s a greater degree of understanding and acceptance, there’s more potential for individuals to be themselves ... It’s going to be very interesting, it’s going to be an unusual community and I think that’s fantastic ... Multi-million dollar development, people coming in with a lot of money knowing there are 100 people with intellectual disabilities. That’s amazing. (Robert and Thelma)

For Thelma, ‘smaller community’ is a community of people with intellectual disabilities and their carers, and not the wider mixed community depicted by disability rights advocates and the normalization movement. Parents were also concerned that the whole redevelopment was driven by a desire of private entrepreneurs and Government to take advantage of the expensive location. Some parents also feared seeing their son or daughter exposed to the dangers of urban life, as evident in the following poem, ‘Elegy Written On a Hill in Kew, the Former Site of Kew Cottages’, by Robert F. Riddiford of the Kew Cottages Parents’ Association (Kew Cottages Parents' Association 2007: 48):

...Their site too good for such as them to hold,
     To richer citizens it will be sold.
These lesser ones to scattered sites must go,
     And where and why is not for them to know.
Now gone the aimless wandering of their feet,
     But safe were they from danger on the street...
In contrast, disability rights advocates who have not supported the development of a cluster, when realizing this was unavoidable, advocated to at least have the CRUs dispersed within the new suburb and avoid a ‘secluded village’, but have not been successful in achieving this aim. Rita, a disability rights advocate who was involved in the planning process explains her opposition to the clustering of houses:

There’s been a concern that there wouldn’t be a public mix of housing, but a secluded village at one end. And we were given guarantees that it wouldn’t happen. As it turned out, the disability houses will be clustered in one area with 16 units in one part of the land, and 4 in another. And the argument that has been put to us is that it has to be done that way because accessible houses could be built on the flat area, and therefore they will be built in one area. It’s a shame, because of the community inclusion principles behind the whole idea, but you can only expect the community to be inclusive to a certain extent, and I think that the expectations on the community to incorporate over 100 people with a disability, many of them clustered in one area – it’s not going to happen, really. (Rita)

Both sides - for and against dispersal - present convincing arguments. Advocates of dispersal, such as Rita above, emphasize inclusion within the broader community, while advocates of clusters, such as Robert and Thelma, emphasize inclusion within a smaller community of people with disabilities and their carers. However, it is important to recognize that all of these arguments are based on an assumption that exclusion from the general community is inevitable. In my view, neither dispersal nor clustering should be used as ‘avoidance strategies’ – rather, the roots of exclusion must be identified and challenged directly.

In the case of KRS’s redevelopment, it is difficult to determine whether the physical constraints of the site were indeed the real reason for the decision to have most houses clustered in one area within the site, or whether it was – as Rita suggests – an excuse that covers the real agenda which was
to please some of the stakeholders and reduce the media attention they have attracted.

Shirley, a DHS senior officer who was also involved in the planning process describes the negotiation and the decision making-process from the point of view of the government, which has mediated the negotiations and eventually made the final decisions:

S: The Government had a view that it would not be replacing the institution if they were all clustered in one group. Because of a media campaign … they set up a group of all the stakeholders together and working out what would be the principles that would drive the locations on-site … It made it very difficult for the developers to come up with something that actually meets these principles …one of the principles was that the residents blend with the neighbourhood, and our houses could only be single story houses because DHS was very clear about CRUs being only one story. And another principle was that the gardens would not be overlooked by anybody – that was a significant challenge in itself … The design is such that you can have a two-story house next to a one-story house and they would actually look very similar. And when you drive down Princess St., you wouldn’t know, you wouldn’t be able to pick up which are two stories and which are our houses.. (Shirley)

Shirley admits that many of the decisions were driven by the influence of a media campaign rather than the explicit policy, and her words (the government had a view) imply that those decisions have perhaps been made at a higher level of State government beyond DHS, serving broader political aims. Her account suggests that the design and planning efforts were aimed at achieving a ‘blend’ of CRUs with the other houses, yet this blend is mostly visual, for strangers’ eyes more than for the locals who would know who lives where, particularly if the CRUs are clustered in a smaller area within the suburb and have some typical signs such as the accessible bus parking in the front. Figure 6 below presents photos taken at the redevelopment site, suggesting how the new neighbourhood might eventually look.
One thing that disability rights advocates did successfully achieve was a commitment that no two CRUs would be built adjacent side-by-side or back-to-back. Robert and Thelma from the parents’ association explain why they have advocated in favour of such adjacent developments:

T: We were hoping that it might be a couple of houses on a slightly larger block of land with some sort of adjoining space and additional recreation facilities, because the blocks are actually tiny – you only have a tiny courtyard.
R: they couldn’t even accept our suggestion to have two CRUs standing back to back because that’s like an institution. (Robert and Thelma)

Rita, the disability rights advocate, explains her objection:

R: all that research that is showing that the more staff you have, even if the ratio is good, say it’s 1:5, but if you’ve got 15 people with 3 staff, the 3 staff will spend more time with each other. But if you have one staff member for 5 people, that staff member will spend a lot more time with those 5 people, because he hasn’t got 2 other staff to go chatting with. So that’s what happens when staff are next door to each other sharing a back fence with a gate that is always open. (Rita)

While the parents’ association’s argument is based on a perception of economies of scale, where land and staffing can be shared by more people with disabilities, Rita’s the professional staff members’ tendency to segregate themselves from people with disabilities.

Interestingly, some CRUs that were built off-site with the closure of the institution were indeed built side-by-side, unlike the planning decision made for the CRUs on-site. According to Chris, the DHS officer who purchased these properties, this was not planned but a response to existing opportunities:

There are two places where we got two CRUs side by side. In (one place) we found two blocks available, both were 750 square meters, we asked (a more senior DHS officer) ‘is this an issue?’ We were
more worried about the neighbours having two CRUs side by side. But (the senior officer) said ‘no, it’s actually good that those two groups could actually go and visit each other, we can put a gate in the fence between them’. There’s another two side by side in (another place) – it was a massive block of land – 4,000 square meters and we only needed 2,000. So we built them there, separate, and even now they’ve got a big block of land at the back where you could build two more – but they didn’t. But they were just available – I was never asked to find two blocks together – it was just an opportunity […] When we were looking for properties, we also asked the Region to advise us if there’s any other CRU in that street, so we wouldn’t have a high ratio close together. (Chris)

While advocacy organizations were successful in preventing the building of adjacent group homes on-sites, they have not been successful in preventing this from happening with some of the group homes built off-site. This is probably because their views were not considered in the planning process, as opposed to their inclusion in the planning process for the houses on-site.

Meanwhile, the redevelopment progresses and Walker Corporation, the private company contracted by the State Government to lead it, continues marketing the new houses on sale. Looking through the marketing material published online by the corporation (Walker Corporation 2009), I have not found any mention of the history of the site, or of the fact that the neighbourhood will include group homes for people with intellectual disabilities. Whether or not that should have been mentioned, is yet another question pointing to the delicate balance between recognition of difference and discrimination. A recent article in The Age newspaper describes the consequences of the strategy that was chosen, not to inform purchasers about their neighbours:

…most troubling for all involved are the complaints now being made by newcomers about the behaviour of KRS residents. No one involved will discuss the behaviour issue, on the record at least. It is just too sensitive […] A letter to Walker Corp from the new resident committee complains of KRS residents relieving themselves in
public, wandering the streets and into neighbours' homes with little or no supervision, screaming loudly late at night, throwing food and garbage and even scissors into a neighbour's property […] Some homebuyers have complained to The Age that they were never briefed about the reality of living next to intellectually disabled residents. Others say there was no mention of disabled neighbours at all (Millar 2008: 3).

The ‘newcomers’ mentioned by Millar expect their disabled neighbours, who have lived there long before, to modify their behaviour. Millar reports avoidance of explicit (‘on the record’) opposition to the presence of people with intellectual disabilities (mirroring the discussion in Section 6.3), although making these claims public in a national newspaper can hardly be considered implicit. In this sense, the claims made in Section 6.3 about the ‘subtle’ nature of community opposition – while relevant in the context of dispersed development of group homes, may not be applicable in the context of a large scale development such as that in Kew. But a closer look at Millar’s article suggests that such complaints are made public in the context of broader political and financial agendas: first, the political opposition wishing to criticize the State Government’s policies (the article covers a visit to the site by an opposition party leader); and, second, the private corporation’s pressure to increase the State Government’s share in the financial risks. Hence, what may initially seem as ‘local community opposition’ to presence of people with intellectual disabilities is not purely local.

In sum, the conceptual debates about the meaning of ‘inclusion’ and the means to achieve it, as discussed in this section, have very much shaped the planning process that led the redevelopment. In this sense, ‘community’ is significant not only as an active agent in the urban landscape, but also as an idea. Interpretations of this idea influence the location of housing for people with intellectual disabilities.
Figure 6: Kew Residential Services redevelopment.

Above: the old Kew Residential Services sign replaced by Walker Corporation’s sign. Some of the new houses are seen in the background.
Below: a closer look at the new houses. The group homes are one-storey only, but similarly designed.
Photos by Ilan Vizel, 16 March 2009
6.6 Confining communities

Communities may constrain location choice for people with intellectual disabilities, by denying them the option of living in a certain place and also, in some cases, by denying them the option to leave. In some communities, particularly rural communities where large institutions are located, these institutions are a major industry on which that community relies, in the sense that they are a major source of employment for the local community, as well as a purchaser of local services. Closing the institution and relocating the residents to other towns of their choice would stand in conflict with the institution’s support workers’ interest which is to be re-employed in the same town.

In Victoria, this has occurred in the closure of Pleasant Creek, a large institution that had been located in a rural town named Stawell until 1999:

In Stawell they had the steering committee when they were closing down Pleasant Creek. They went from huge opposition in the local council in the beginning – people getting up and yelling and screaming and all the rest of it, and those meetings went on for a couple of years to the point where it was a done deal and everybody was kind of used to the idea, and they did actually keep a lot of houses in the area, the wider area – Ararat, Stawell, Horsham, and a few more towns that are close to each other in that particular area.

(Rita, a disability rights advocate)

Rita’s account suggest that the community’s interest to maintain jobs was a major driver of the location process of the new CRUs developed, limiting their dispersal.

Currently, a redevelopment process is occurring in another large institution – Colanda - still operating in the rural town of Colac. The process is still in the planning stages and it is not yet clear what kind of redevelopment would take place, however it is already obvious that the local community will be very much involved in any decision made, as explained by Zora, a DHS senior officer:
The Colac community is very accepting for people with disabilities, and they’ve got a big disability industry so we wouldn’t expect any extra problems with perhaps people moving into the residential areas of Colac which was sometimes [the case] in Metropolitan Melbourne. But there will be a significant level of concern about impact on the economics, because most of the staff are from Colac – it’s a significant employer in the area – so that would be a concern. And on another level, people would be concerned if large numbers of Colanda residents moved to a different part of Victoria – all the local businesses would lose, all their consumer goods were all purchased in the Colac area. So that would be a concern for the community – we already know that … There have been community meetings or meetings with the shire to express concerns about the future of Colanda, and from time to time local council would say ‘we need Colanda to stay as it is for the benefit of the community’, but at the moment there’s no obvious concern. Everybody’s just waiting to see what will happen. In any change of the service we would be taking into consideration the impact on employment. When we had closed institutions in the past we re-employed the staff – in fact it usually expands … even though people have families all around the state the majority of family contacts is still within the Barwon region …so it would be reasonable to expect that if there are alternative services developed – a lot of them would still be in the area… For country institutions it’s different to redeveloping metropolitan institutions. Because Kew residents, and following them the staff, have moved to all areas in Metropolitan Melbourne. And for a lot of staff they were able to relocate to another workplace without having to move house. When you’re talking about rural areas, you really can’t relocate lots of services and expect staff to travel so far to work. (Zora)

The Government’s commitment towards its staff, the power of the support workers’ unions and the power of communities, in most cases undermine the power of people with intellectual disabilities to exercise choice with regard to relocation in institutional closures.
The fine line separating a supportive from an oppressive relationship between an individual and the community is evident in the following stories of Donna, Joe and William, three people with intellectual disabilities that I have interviewed. Donna considers the small community in the rural town where she grew up an oppressive place, and she moved to Melbourne in order to get away from it. For Joe, on the other hand, the Melbournian suburb in which he has lived all his life is both a place and a community to which he feels a strong sense of belonging. William, like Joe, has spent all his life in a Melbournian suburb and has a strong sense of belonging to that place, but has also experienced social isolation and at times even oppression in its community. These accounts bring to question the relationship between belonging, mobility and choice, as elaborated below.

Donna lived in an institution in a country region until she was 21. When the institution closed down, she moved into a CRU in the same town. She remembers having no choice about where she would go, or who she moved in with. Moreover, since the staff in that CRU were the same staff from the institution, moving into the CRU ‘didn’t make much of a difference’ to her. Donna did not feel the CRU was any more a home than the institution:

We didn’t even have a key to our house. (Donna)

Donna’s main difficulties were with the other residents who ‘didn’t do their job’ in the house, and with the staff. She also had no other family she knew of or friends that could have supported her. Donna remembers being told one day that she and her co-residents were already independent and should therefore move out to allow other people to move in. Donna felt she was forced to move out to live independently and was unhappy about it. However, at that time, she got into a relationship with another person and they moved together to Melbourne.

It was like moving out from jail to freedom. I felt so free. In (the rural town) everybody knew me, the staff from the institution talked down to me. In Melbourne it’s not like that. Nobody knows you, and people respect you. (Donna)
She now lives in private rental in an outer suburb with her partner because suburban life feels closer the country life style she is used to. Donna and her partner’s pensions are hardly sufficient to maintain the house and the living expenses but they ‘make it from day to day’.

Donna is involved in self-advocacy organizations, and finds that she learns a lot from this activity. She also went through brain surgery a few years ago and that brought some significant changes for her – she feels much clearer and more focused now, and her long-term memory is greatly improved. She does her own shopping and cooking, and her only support is from her partner. She is happy with the way things are now, and cannot think of anything she would like to change. Donna thinks that people with more severe disabilities could move out of CRUs with a lot more support, and that CRUs could sometimes be good, however they could also be a bad place to live in, particularly when the staff are coming from institutions with the same attitudes of staff in institutions.

Joe is 52 years old, and lives alone in the same house where he grew up with his parents, in a Melbournian suburb:

Mum passed on, and my dad’s not living there no more. Nursing home – that’s where he’s now. He’s pleased of myself that I’m staying here. He knows, I write to him. (Joe)

Joe is proud of ‘pleasing’ his father by living independently in their old house. These feelings reveal how the relationship between the two influences Joe’s housing experience and sense of choice. The father’s opinion is still a significant factor directing Joe’s life, however from a distance now, and without the father playing a functional role as a carer. His involvement does not seem to constrain Joe’s choices but rather to enable it by providing moral support.

With the parents no longer acting as carers, Joe’s major source of practical support in his daily life is his extended family, with his two brothers and their families now being the most significant people in his life. They no longer live in the same suburb, but often come and take him out to dinner.
They also talk on the phone regularly. The family helps Joe maintain the house and live there by bringing food, even though Joe also cooks for himself. In addition, he receives some formal support from the local council – a person coming every week to help him clean the house.

However, maintaining the house is expensive, and a plan was devised by Joe, his brothers and Hannah – a planner in a person-centred planning program - to subdivide it into three units, two of which will be sold, and the third will be Joe’s.

I: Who’s idea was that – your brothers’?
J: Yes … They asked me if I want to move somewhere close to them. If I did that, it would be hard for me to be here (in the day program) again. (Joe)

Joe’s account suggests he has made a choice between two options – moving closer to his brothers or staying closer to the day program. He chose the latter. Apart from being close to the day program (to which Joe goes by bus), staying in the suburb will also help him maintain his social networks in the area, having lived there all his life:

I: are you happy to stay in the house in Altona forever?
J: yes, because it’s closer. I like that way a lot … I know neighbours, the owners of shops, everybody. They trust me. (Joe)

Joe’s sense that he knows ‘everybody’ and that people trust him reflects a deep sense of connection to the place and its people – the local community. Some of the structural changes in the disability sector, on the one hand, and Joe’s characteristic as an individual with a low level of support needs and with a strong social network, on the other, enabled him to maintain his life at the home where he grew up even after his father’s move into a nursing home. The policy move towards independent living models, and the introduction of individual funding and person-centred mechanisms in many ways make it possible for some people to have more and better options of housing than they would have had prior to those changes. Joe belongs to this group of
people thanks to his relatively low level of support needs. Also, having a closely-knit and supportive family helps Joe be part of this group. Finally, being a homeowner is another advantage which allows Joe to live independently without excessive rental costs. Joe’s story supports the case that the choice agenda should not be abandoned altogether, but rather reframed in a way that would enlarge the group of people who benefit from its advantages, to make it more inclusive.

William is 65 years old, and is involved in the same person-centred planning program as Joe. He grew up in an inner-city suburb in Melbourne and had moved only once with his parents and his grandmother to an adjacent suburb. His father and mother both died over 12 years ago, and William continued living in the same house on his own. His closest living relative now is his cousin Molly who lives just across the corner and acts as his guardian and administrator. Apart from Molly, William does not have many people involved in his life that are not paid staff.

William has no contacts with his current neighbours, and the only relationship he recalls is with one neighbour he did know in the past that gave him ‘a lot of trouble’:

Didn’t seem to like me for some reason – I don’t know why. I didn’t do anything to him. I had a bit of a fight with him. (William)

Despite this sense of isolation, and sometimes even rejection in his neighbourhood, William feels a very strong sense of attachment to it. William knows his way around the neighbourhood, remembers some of its history and feels a sense of belonging to it:

W: I know where there used to be a Pizza, a long long time ago, it’s a McDonalds now. They pulled that down. It used to be years and years and years a Pizza, and they haven’t got it anymore – it belongs to McDonalds now … I like the area …We have some trouble with the high-rise flats. That’s blocking the reception (of Channel Nine in his TV)… Why do they build these high-rise flats anyway? It gives you problems. Gives you trouble.
Referring to the changes that have occurred in the neighbourhood reflects William’s attachment to it. Even when referring to those aspects which he sees as problematic, he reveals his sense of belonging (‘we have some trouble’). As much as he hates seeing the neighbourhood change, William is also very assertive about maintaining everything in his own house just where it is. A worker from the local council who regularly cleans house, usually comes only when William is away because he gets too upset seeing her handling his personal stuff. However, the house needs a lot of expensive maintenance and Hannah, the planner working with William, and his cousin Molly considered subdividing it so as to gain another source of income and save the costs of maintenance. William, however, would have chosen to avoid such redevelopments, as can be learned from the following conversation involving William, Hannah and myself:

H: remember when we had someone come out doing an assessment of your house?
W: yes.
H: why did we have that?
W: I don’t know.
H: was the floor moving?
W: yes.
I: so that’s a lot of money fixing all this.
H: yes, $60,000, because you have to start from the bottom-up.
I: do you have enough savings to cover that?
W: I don’t know.
H: no, you don’t. but we’ve spoken about whether – William’s block is a really big block of land and we were thinking whether we could build two units on that, William is still deciding whether he would like that to happen or not.
I: what do you think about this at the moment?
W: I don’t want this to happen.
I: why not?
W: I just don’t like it.
I: What don’t you like about it?
W: That stuff about pulling the house down.
H: Lots of memories in there.
W: It might be pulled down.
I: So at the moment you wouldn’t want that to happen?
W: No, I want to keep it. (William)

This conversation raises some of the difficulties involved with the notion of ‘choice’ with regard to people with intellectual disabilities. It appears that William is not fully aware of his financial situation and the costs involved in maintaining the house, even though he has been involved all along in the process of planning. It is therefore difficult to consider his wish not to redevelop the house an informed choice. For Hannah, as a planner, and for Molly, as a guardian, this entails a difficult dilemma. On the one hand, they would not want to act against William’s will. On the other hand, they are concerned with his well-being and need to be realistic about the compromises that need to be made in order to allow William a life as close as possible to the one he chooses. This means, in their view, staying in the same house, but redeveloping it. The planning process is thus an attempt to inform William of this need, and to convince him to make a different choice. Anyway, it is reasonable to assume that the redevelopment will take place with or without Williams consent. In this context it could be questioned to what extent the notion of ‘choice’ is relevant to this discussion.

This context is further complicated by the triangular relationship involving William, Molly as a guardian and Hannah as a planner. In some cases it is not clear to any of them whose choices are being made. Doreen, Hannah’s manager, illustrated this difficulty in another interview conducted with both, discussing William’s wish to stop going to his day program on Tuesdays:

He was telling us that Molly wouldn’t let him have it (a regular day off from the day program), but when Molly talked to him he said that I am making him take time off… the reason why it fell down is because people didn’t communicate it to Molly, so she felt that we
were trying to do the wrong thing our way, and as a result William does not have a day off. (Doreen)

Doreen sees the difficulty in reaching consensus among all parties involved in the decision making as a communication problem. While it is often implied that people with intellectual disabilities are constrained in their choices because of their parents/guardians, the account above, and William’s story in general, reflects a far more complicated picture of the power-relations in which such choices are made, and indeed - more often than not – constrained.

Analysis of the accounts above provided by Joe, William and Donna sheds light on the relationship between mobility and choice. Some of the participants in this study have experienced a life full of moves from one place to another. Others, such as Joe and William, have experienced a very stable housing career in one place. Neither of these two very different kinds of narratives implies more or less choice in housing. As argued by Ahmed et al. (2003: 5), ‘both staying put and moving can take place out of necessity or force as well as ‘choice’, and thus depend on specific enabling or disabling relations of power’.

Such relations of power are mediated by place and community in a variety of ways. For Donna, a small rural community in an isolated place felt like ‘jail’, to the extent that she decided to move away to the city. For Joe, staying in place was a way to maintain his connection with a suburban community even if that means being slightly distant from his family. For William, the place itself is the source of a sense of belonging and attachment, in some ways more so than the community of people in it. Such an analysis implies that under a policy which enables people with intellectual disabilities to make residential choices, such choices will be very much influenced by their relationship with the local community. While the previous sections show that communities may be inclusive, excluding, caring and confining in a variety of ways, Donna, Joe and William’s stories come as a reminder that individuals too experience and react to inclusion, exclusion, confinement and care in different ways.
6.7 The choice agenda and community care: conclusions

Communities allow or constrain choice - in this particular context, choice of location in housing - through various forms of exclusion, confinement, inclusion and active support. Thus, the implementation of the choice agenda is reliant on the existence of inclusive communities that would actively support people with intellectual disabilities to live among them, without confining them to particular places. In this sense, the choice agenda is by no means contradictory to the ‘community-care’ ethos.

However, the choice agenda increases people with intellectual disabilities’ vulnerability to more subtle forms of exclusion. As discussed in Section 6.3, independent living, the model of housing and support most actively promoted by proponents of choice, exposes people with intellectual disabilities to various forms of exclusion which are often more subtle than direct community opposition to the establishment of care facilities. In this sense, it is not only that choice is constrained by community exclusion; the argument that is put forward here is that choice, as a central logic in the provision of disability services and housing, in some ways increases vulnerability of people with intellectual disabilities to community exclusion.

Moreover, the choice agenda changes the way communities are organized. Individualized funding – while its explicit aim is to provide more choice for individuals with disabilities - also allows community organizations more initiative and control over the kind of housing it creates and its location, whereas previously such decisions were more tightly controlled by the State Government (as analysis in Section 6.4 suggests). Consequently, people with intellectual disabilities become more reliant on decisions that are made by specific community organizations about how and where they develop housing for them.

Person-Centred Planning programs, another major feature of the choice agenda, also affect the way communities are organized. Such programs promote a very particular kind of community involvement in the lives
and geographies of people with intellectual disabilities: one that provides unpaid informal support rather than formal community-organizations.

This chapter and the previous one both examined the relationship between the choice agenda and the geography of housing for people with intellectual disabilities with a particular focus on location (where is housing available for them). The following chapter continues to examine this relationship, but is focused on a different aspect of this landscape – the distribution of disability housing models (what kind of housing is available for people with intellectual disabilities).
Chapter Seven

A housing model for choice

The graph below (figure 7) suggests that between 1997 and 2005 a meaningful change occurred in the Victorian disability housing landscape - the distribution of housing and support models which form this landscape was significantly altered. Particularly noticeable is the growing dominance of individualized (‘in-home’) models of housing and support. This change, in many ways, is an outcome of the choice agenda.

![Graph showing government-funded housing and support services by number of users, 1997-2005.](image)

**Figure 7: Government-funded housing and support services by number of users, 1997-2005**

**Sources:** AIHW 1998; 2002; 2006

The ‘Total accommodation supports’ column in the graph suggests almost a doubling of the number of services within less than a decade. Most of this growth was in relatively low-cost ‘in-home’ supports. The growth in group-homes is closely tied with the closure of institutions. However, the graph does
not tell a full and accurate story. The columns standing for different types of housing and support tell very little about the quality - in the broad sense of the word - of these models, making it difficult to compare one to the other in terms of the kinds of supports that are provided and their costs. Also, little can be learned from this graph about the reasons and implications of the changes it depicts. The aim of the current chapter is thus to provide a qualitative analysis that presents the complex relationship between the choice agenda and the use of particular housing models in the disability sector in Victoria.

The argument developed in this chapter is that the distribution of housing models in the Victorian disability sector derives from three interrelated processes: a political process of conflict and negotiation between various groups voicing their opinions about the most appropriate housing model for people with intellectual disabilities; an economic process through which the development of new housing models is mediated by fiscal constraints; and, an institutional process by which the development of housing models is mediated by the bureaucratic channels through which they are administered.

The choice agenda, I argue, plays a significant role in each of the three processes. First, as a political group, proponents of the choice agenda are hardly a unified alliance. They bring into the debate two major arguments which are in some ways contradictory. On the one hand, some argue that smaller housing models would allow more choice making opportunities for people with intellectual disabilities in their daily lives. On the other hand, others argue that a diversity of housing models would allow people with intellectual disabilities more housing choice. These two arguments play a significant role in the discourse through which development of housing is negotiated. Second, from an economic perspective, due to financial constraints the aspiration for smaller housing models clashes with the logic of economies of scale, leading to the development of particular models of housing as a result. Third, from an institutional perspective, the introduction of individualized funding schemes as a structural change to increase consumer choice, has further reduced the State’s ability to control the size and quality of non-government developments of new housing models. Consequently – considering the political, economic and institutional complexities - the implications of the choice agenda on the distribution of housing models in
Victoria has led to a number of unexpected outcomes which are not visible in the graph above, such as the introduction of some new models of congregated facilities.

The chapter is structured as follows. Section 7.1 presents a brief background review of studies that attend to issues of housing models for people with intellectual disabilities. Section 7.2 discusses the relationship between the choice agenda and the planning of particular housing models as a question of redistribution. Section 7.3 addresses the same question from an institutional perspective that focuses on the bureaucratic constructs that are applied as a means to allow people with intellectual disabilities a choice of their preferred housing model. Section 7.4 presents an analysis of the discourse through which various groups voice their opinions about the appropriate housing model for people with intellectual disabilities, and the role of the choice agenda in this discourse. Section 7.5 summarizes this discussion, developing it further into a question of ‘realism’ and ‘idealism’ in the disability housing model debate.

**7.1 The disability housing model debate**

This chapter makes a shift in the subject of its empirical investigation, from a focus on the *location* of housing (as in Chapter Five and Chapter Six) to a focus on *models* of housing and support. It joins a long-lived emotional and important debate among disability scholars about the housing models that should be funded by the state. This debate has been a central feature of deinstitutionalization. By applying the analytical perspectives taken in the previous chapters - examining housing models as a question of political conflict, of institutional processes and of redistribution - this chapter offers a unique perspective from which to approach this debate.

Much of the literature written about housing models for people with intellectual disabilities has been written by social work scholars interested in quality of life measurements. Various studies conducted in the UK (Emerson 2004a; Emerson et al. 2000; Wood 2004), for example, argue for the
superiority of group-homes over large-scale institutions in terms of quality of services and quality of life of their residents. In Australia, Stancliffe’s (1997; 2000; 2001) studies show that living environments that are smaller, in general, allow more choice making opportunities. Other studies, however, have also started to emerge, pointing to the fact that group-homes have failed to provide a better chance of integration for people with disabilities in the community and have often failed to provide a significantly better quality of life (Cummins and Lau 2003; Cummins and Lau 2004). Nevertheless, these studies, too, remain within the analytical framework of quality of life.

A number of geographic studies offer a different analytical perspective. Dear and Wolch (1987) argue that the shift from institutions towards dispersed group-homes has left many people with disabilities homeless or imprisoned, and the majority of people with disabilities cared for by their parents. Such an analysis goes beyond a comparison of one type of housing versus another, to a wider perspective on what happens during the transition process when moving from a reliance on one model (institutions) to another (group homes) on a national scale. An understanding of the transition process is particularly essential considering the fact that it is still underway, over twenty years later.

Gleeson and Kearns (2001) approach the housing model debate from a different perspective, focusing on its moral aspects. They argue that this debate has taken the form of a moral discourse, with the voices of many groups that criticised deinstitutionalization – particularly the families of residents - being marginalized as immoral (p. 62). Gleeson and Kearns conclude with a call for a greater diversity of housing models which would cater for a diversity of preferences and opinions. Following a similar approach, Bostock et al. suggest that the range of housing options for people with disabilities should be as varied as possible, and that people with disabilities should have as much choice as possible in deciding which opportunity best suits their own personal needs and desires (Bostock et al. 2004). Similar arguments are raised in other studies (Australian Housing and Urban Research Institute 2002; Cummins and Lau 2003; Cummins and Lau 2004).

Such contradictory approaches to choice were clearly reflected in a debate between Cummins and Lau (2004) and Emerson (2004b) in the Journal of Intellectual and Developmental Disability. While Cummins and Lau
critiqued Emerson’s use of objective Quality of Life criteria, Emerson responded with a critique of their libertarian approach to social policy ‘in which the freedom to choose is given precedence over all other considerations’ such as the ‘duty of care’ and fiscal responsibility (p. 208). Emerson raises the question of whether the state should allow people to use public money to choose an option that appears to be less beneficial to their overall welfare: ‘[in] England, for example, we simply do not allow people with intellectual disabilities to choose to live in large-scale state-operated institutions’ (p. 209). However, interestingly, Emerson too uses the notion of choice as a major quality of life criterion by which to determine which option is more beneficial.

In this chapter I follow the analytical perspectives offered by Dear and Wolch (1987) and Gleeson and Kearns (2001), and examine the relationship between the choice agenda and the distribution of housing models in Victoria as a transitional process from institutional, distributive and political perspectives. However, my analysis challenges the conclusion about a need for a diversity of housing models – not suggesting that this conclusion is wrong, but rather showing the implications of this approach when applied as it is in the particular context of the disability sector in Victoria.

7.2 Economies of scale and individualization

Certainly I think the reason for not building CRUs (group homes) is an economic one. And the reason that’s given in policy is individualization. Do I think it’s a conspiracy that’s happened? No, I don’t. Policy is developed in such an ad-hoc way that I don’t think it’s possible. (Patrick, manager of a non-government support agency)

Planning what housing models should be funded by the state for people with intellectual disabilities, may be considered a question of redistribution. Decision makers face a dilemma between providing smaller and more expensive housing models that would increase choice, but to a more limited population of users, and providing models which may be considered more restrictive, but will cater for a larger population through economies of scale. The implementation of the first option in a context of limited resources entails
a risk of widening the gaps between existing categories of ‘haves’ and ‘have nots’: those who are already clients of State-funded services and those who are not yet receiving any service. The distribution of housing and support models in Victoria, is analysed in this section in light of such widening gaps between clients and citizens.

Clarke (2006), referring to public services in the UK, considers the shift in policy rhetoric from ‘welfare clients’ to ‘citizens-consumers’ as part of a broader cultural shift towards a consumer-society. More specifically, Clarke addresses the ‘problematic intersection of resources, rights and rationing’ (p. 435. Emphasis in origin). The notion of ‘citizen’ implies a set of rights but also a set of responsibilities. By emphasizing these responsibilities, the policy shift toward ‘citizen-consumers’ has been partly an attempt to reduce ‘dependency’ and claims made by individuals and groups over public resources. Clarke maintains that in effect this attempt has done little to reduce demand for public services in general or the need to manage and prioritize conflict claims over limited resources. The analysis presented in this section points to additional implications of the shift from ‘welfare-clients’ to ‘consumer-citizens’ policy emphasis in terms of creating new divides between those who are more or less likely to gain recognition as clients or citizens.

Grouping a number of people with intellectual disabilities in a single dwelling saves not only the costs of housing, but also the costs of ongoing support services which, as explained below, are even more significant in the long term. In institutions, such groupings have often included dozens and even hundreds of people living under the same roof. During deinstitutionalization, following the critique on institutions as dehumanizing places of residence, group homes have emerged as an increasingly dominant alternative. While institutions represented the logic of economies of scale in its extreme, group-homes are a compromise in their scale: still a congregated setting yet far smaller. Generally, it could be seen as a more expensive solution, yet this was not always so. In England and Wales, the down-scaling of institutions into smaller dispersed residential units has meant additional costs per unit, due to increased need for staffing, while in the US it has often meant a reduction in costs per unit (Felce et al. 2008: 87) as well as additional
costs ‘saved’ by the fact that many ex-residents of institutions were simply not provided alternative accommodation (Dear and Wolch 1987).

In Victoria, most new group homes have been built to accommodate residents moving out of institutions. Not all institutional residents, however, moved into a group home. Three participants I have interviewed, for example, moved out of institutions and were provided with alternative accommodation in group homes, but only for a short term of several years after which they have had to find other forms of accommodation. Moreover, thousands of other people who have never lived in any kind of State funded accommodation have been living with their parents far into adulthood. In some ways, deinstitutionalization has further reduced their access to housing and support because extensive resources have been spent on closures of institutions, leaving very little for development of new services for people living with their families. For example, in Kew Residential Services, selling much of the land provided income that covered the costs of building new group homes. However, the ongoing additional costs to support clients in these new houses were above $10 million per year according to one senior manager in DHS I spoke with. In the closures of other institutions in Victoria, selling off the land could not even cover the initial investment, meaning an even greater strain on funding. In this sense, deinstitutionalization in Victoria has meant not only ‘more resources for fewer people’ but also more resources for those who have already been receiving government funded accommodation, and fewer resources for the majority of people with intellectual disabilities living with and cared for by families. Zora, a senior DHS officer, suggests the Department is well aware of this critique:

There are a lot of people waiting for accommodation and support and so it’s not uncommon to get people who are on waiting list to say ‘why are you spending money on people who have something instead of on us who have nothing?’. That was a critique about the Kew redevelopment, about the people in Kew having something and yet there are people waiting for accommodation, and we shouldn’t be funding people at Kew (to move out). So that’s always the tension. (Zora)
Zora’s account shows the conflicting pressures under which disability policy is being defined, and the gaps between the ‘haves’ and ‘have nots’. In this case, the haves are those already provided with Government funded services, to whom the Government is responsible as clients, and the have nots are those not yet receiving any services, to whom the Government is responsible as citizens. The Government’s decisions - investing funding in deinstitutionalization when most people with disabilities have no access to any form of State-funded housing - may appear to favour its registered clients over others who are only citizens.

While group homes are still highly sought after by families caring for a person with an intellectual disability – as evident from figures of over 1,358 people in June 2008 on the Disability Support Register (Department of Human Services 2008d) – in the disability sector they have become known as very problematic, mainly due to their inflexibility and conflicts between residents sharing a house. On the one hand, new group homes are still being built for DHS’s clients who are moving out of institutions, as in the closure of Kew Residential Services. Also, vacancies in existing CRUs are still being allocated to eligible applicants – many of whom come from their parents’ homes. On the other hand, DHS officials I have interviewed emphasize their efforts to move away from the traditional group home towards more individualized housing models.

In a few cases, DHS has modified group-homes so as to separate residents who are considered incompatible due to on-going conflict. The modification of stock is most often done by dividing houses or adding a relocatable unit at the back. However, participants in this study have raised two main problems with this practice of dividing houses into separate units: first, maintaining the same level of staffing is often difficult when units are separated; second, the extent of modification is limited due to the physical design of the houses and the space available, as explained by Tim, a senior DHS officer:

I: Are you going to modify existing CRUs?
R: Probably not, simply because of the logistics and technical issues around converting houses’ structures to something that is a bit more independent. That probably wouldn’t work. Even in a fairly large block of land you’re probably limited how far you can push things. So the idea is that additional new buildings will be done in a certain way, rather than modifying existing properties... once we consolidate individualized support and packages and make that a little more streamlined system, I suspect that the next step from that will be to look at how we can individualize support in CRUs to a greater extent. It can’t be completely individualized because of the economies of scale, but a greater emphasis could be put on supporting people to meet their individual needs within a group. (Tim)

Tim suggests that the emphasis put in policy on individualized support is seen as a first stage before tackling the problems in CRUs directly. In some cases houses are redeveloped into separate units as a reaction to very specific cases of incompatibilities and conflicts between residents that could not be solved otherwise, and in some cases houses that are in desperate need of redevelopment anyway, due to their poor physical conditions, are modified to be more ‘individualized’. Since 2004 DHS has replaced 51 houses with new ones, and significantly refurbished nine existing houses (Victorian Auditor-General 2008: 3). However, because of the need for increased staff and the physical limitations, DHS does not see the modification of the existing stock of CRUs as a priority.

In fiscal terms, maintaining the group home model has also been found financially inefficient in Victoria because some people living in group homes do not require as much support as is provided in them. Therefore, despite the economies of scale involved with grouping 4-6 people together in a house, it became clear to policy makers that it is possible to support some individuals more cheaply outside the group home model. Thus, it is my interpretation that the introduction of individualized funding is currently being used by DHS as a strategy to reduce its long-term funding commitments. The vast majority of individual packages allocated are smaller than $10,000 per year for one individual and only one percent of all individualized support packages
provided by DHS exceed $55,000 (Victorian Auditor-General 2008:1), whereas supporting an individual living in a group home costs the department over $70,000 per year. This is not because living alone is always cheaper than living in a group – it is only so for individuals who require less intensive support (Felce et al. 2008). Such packages are thus meant to prevent new people with low and moderate levels of support needs from entering shared-supported-accommodation in the first place, as well as to enable people already living in group homes to move out to live independently. For the latter group, a particular funding scheme has been introduced, often termed ‘exit targets’, as explained by Alice, a DHS senior officer in one of Victoria’s rural regions:

> What we try to also do is reconfigure people in the houses to make sure that people who don’t need the high support houses are moved out of them into something else - because we’re not building any more houses [CRUs], so we need to make sure that the houses accommodate people who are meant to be accommodated in such.

(Alice)

The ‘exit targets’ policy does not imply a complete withdrawal from the group home model, as the placements which are created by people moving out are often – though not always – filled by a new person moving in. What this policy implies is a redefinition of this housing model, by limiting its growth and by linking it with a particular group of clients with higher levels of support needs. This process has been identified by Bigby and Fyffe (2007), who argue that it excludes people with higher levels of support needs from being able to enjoy the benefits of a policy to increase choice, and also calls for reforms in the CRU model itself – in funding, management, organizational skills and transitional arrangements – which have not yet been addressed in policy (p. 22).
7.3 Flexibility to congregate

The institutional changes in the disability sector related to the choice agenda can be broadly described as a movement towards decentralization, to allow greater flexibility in service provision. The introduction of individualized support packages, attached to individuals rather than services, is a significant aspect of these changes. However, individualized funding is allocated in very limited amounts in Victoria. In this context, the flexibility that individualized funding allows has in fact enabled the development of new congregated facilities – much larger than group homes - for people with higher levels of support needs. This occurs despite an explicit State policy to prefer smaller housing models.

Development of new housing models: individualized yet congregated

Because individualized support packages are too small to enable most people with intellectual disabilities to live independently, people often need to share their funding packages with others, by sharing their accommodation. This need to share is reinforced by the lack of affordable housing. The practice of sharing creates new forms of group-housing which are distinct from the traditional group home model in some ways – particularly in the way they are funded and controlled by the Government – but are similar in other ways, as explained below.

These new individualized models of housing conform to a very dominant feature of the choice agenda in disability housing, a notion that a variety of different housing models would allow more choice than having one single dominant model such as the group homes in Victoria. This policy rationale is depicted visually in Figure 8 below. Several support agencies in Victoria work to develop new housing models on their own. A manager in one organization operating in Melbourne described their plan to build a new development of four adjacent houses, for people with lower levels of support
needs who have already been granted individual funding packages from DHS. Choosing to live in the new facility would allow them to share their funding in a way that benefits all, as provision of support becomes more efficient and housing is cheaper. However, the price that is paid is the loss of privacy in a congregated facility of 20 residents. To resolve this tension, the agency has developed an architectural design that allows the residents more privacy and more control and choice of who they interact with in their own rooms which also include a private bathroom.

Critics of the practice of introducing ‘new models’ to enhance choice, highlight the increased number of residents in such new models, which is an almost inevitable outcome of the lack of resources under which they are developed:
Under the guise of flexible models – I know an organization that has built an aged-care facility for people with intellectual disabilities who are older, and that’s 25-30 beds. So how is that individualized? It’s building a mini-institution… and that’s being funded and built under flexible models. The only flexible models built that I’m aware of have been larger places than five beds (Patrick, Non-Government support agency)

Patrick looks at the number of beds in a housing facility as the most appropriate measurement to define its quality. The more beds, the more the facility is like an ‘institution’ and less like a home. However, with existing resources, the dilemma faced by developers of new models is that between providing housing for as many people as possible and providing high-quality smaller-scale individualized housing, as explained by Michael, manager in the non-government agency leading the development described above:

I’m pretty sympathetic to a range of different views. I know that whatever we do is not the perfect solution, I’m not saying that, whatever we do is a compromise between different tensions… But there’s also the other argument saying why don’t you just build 2-3 one bedroom units on the site and work with 2-3 people, and do it properly from the ground-up with a person-centred planning process and build what they want, and then go find money to do it with other people. (Michael)

Michael, as well as others who support the development of facilities larger than 5-6 bedrooms, use the notion of choice to justify this practice, arguing that these would only be one option among others for people to choose from. A similar claim is raised by Anthony, senior manager in another support agency operating in one of Victoria’s large regional towns developing a similar facility with units for people with individualized packages:

We’re closing one of our CRUs which is 35 years old, and been expanded a couple of times to accommodate more people, and this is just not functional in the household level. And one of our aims is to provide more opportunities of accommodation for people with
Anthony, like Michael, describes the new facility as just another option among others for people with intellectual disabilities. While the Melbournian development is targeted at people with individualized funding only, in the other development there will be a mix of people with individualized funding as well as a group of people moving in from an existing CRU. Their new house will be divided into two separate units, with a staff room between them, as explained by Anthony:

(The plan) initially started with seven two-bedroom units, with a sleepover for staff attached to one of them, due to the people with medical needs, particularly in the night time. But what we’ve actually done is we’ve changed it slightly to incorporate the sleepover to rejoin two of the units. … The main reason that we’ve done that is because people’s needs, be it medical or other, change over time. So you have to have the flexibility for staff to be able to access both units if needed. Should there be no need, those doors (to the staff room) could be closed (Anthony)

While the notion of ‘flexibility’ is commonly used to describe the residents’ experience, Anthony refers to flexibility in terms of staffing models. The original plan to have all units detached was altered because of considerations of economies of scale – one staff member will have direct access to two units instead of one. The revised plan is attached below (Figure 9). Three units (units 3, 4 and 5) are connected to each other forming the long building in the centre of the image. Units 4 and 5 are separated by the staff’s office and sleepover room. Each unit has its own entry. The larger building in the centre is surrounded by four detached two-bedroom units for people with individual support packages – units 1 and 2 at the bottom and units 6 and 7 at the top of the image.

It appears that up to fourteen people will be able to live in this facility, which is located in a developing suburb in a major regional town in Victoria.
The agency invested 1.6 million dollars on the development which is built on Crown land. For eight people with individualized funding packages, this will be an opportunity to share the household expenses with one other person in affordable purpose-built housing. For the support agency, it will be much easier to coordinate staffing for these people, as they live closer. For six other people, already living in a CRU this will be an improvement in the way their
Figure 9: Plan for new housing development
Source: provided by participant with permission to publish
household is designed, with more privacy and better and more modern facilities. However, it will still be very much like a CRU:

I: how would the two units with the overnight staff room attached be different from a CRU?
A: In some ways it would be similar. It would be different in the sense that they would operate as independent units, so they would pay their own bills and these kinds of things. We’re trying to do more of an active support model there, where the staff prompt people to do things rather than actually do it for them. Theoretically, this is also tried in CRUs, but in practice it doesn’t quite happen that way.
I: and the staff are going to come from the CRU?
A: A combination. In the transition there would be staff from the CRU. (Anthony)

Again, critics would argue that such new developments lead to the clustering of people with intellectual disabilities in enclaves which make it harder for them to integrate in the surrounding community. While the Government’s explicit policy is to avoid developments larger than 6 bedrooms, its individualized funding schemes encourage support agencies to develop estates with more than twice as many bedrooms. By distributing Individualized funding which is too small for most people to live on their own in private rental, the Government pushes support agencies to developments which are based on economies of scale, and provides them with the ‘flexibility’ to do so. In this sense, the flexibility of individualized funding is not so much for people with intellectual disabilities as much as for the Government itself, to bypass its own policies. Advocates of such developments would argue that they create new affordable housing in a time when there is a severe shortage of it, and that these units are just one option among others.

In my view, developments of new congregated housing do answer a very pressing shortage in housing. However, in terms of choice, they do not really provide just another ‘option’ - that could only be true in a system where there is more supply of housing than demand and where decision making power is truly held by the person with the disability. Only then can one make a real choice between independent living, a group home or congregate care. In
an under-resourced system where there is simply not enough accommodation and support for all who need it, any kind of housing that is being built is not ‘just another option’, because people have no alternative.

7.4 Housing models and the discourse of community

The notion of ‘community’ has been central in the thinking and discussion about deinstitutionalization. Alternative models to institutions – the group home and supported independent living – are often termed ‘community care’, as their explicit aim is to ‘promote the integration of dependent peoples into the broader community’ (Gleeson 1999: 153). This expectation, in many ways has not been fulfilled. Nevertheless, while community has perhaps not met the expectations implied in the ethos of ‘community care’, it did play other significant roles in housing and supporting people with intellectual disabilities. First, long before and long after the notion of ‘community care’ was introduced as a formal policy and a housing model, informal carers in the community provided most of the housing and support for people with intellectual disabilities. Second, various sectors in the community have taken different positions in the debates around the most appropriate housing model. Beyond the community’s role in allowing or denying the establishment of housing in particular locations (as discussed in Chapter Six), communities have also been consistently involved in choosing which kind of facilities should be developed. This section examines the effect these roles have had on shaping the existing distribution of models in the housing landscape.

7.4.1 Parent carers: the other model of community care

The roots of many of the most crucial issues related to the housing landscape today can be traced back to the post-World War II baby-boom, and the reluctance of many young parents then to have their children institutionalized.
While all through modern history there have been parents who resisted the institutionalization of their disabled children, defying both public policy and cultural norms, this has never had such a significant implication as in the case of the postwar baby-boomers generation, for three main reasons. First, the proportion of parents resisting institutionalization has grown due to cultural changes. Second, this generation was larger in size than any other that preceded it. Third, the life expectancy of people with intellectual disabilities has grown overwhelmingly from about 20 years in 1930 to 70 years in 1993 (Bigby 2004a), meaning that people born after the war with an intellectual disability were not expected then to still live today.

Thus, in many ways, living with parents has been the dominant model of housing for people with an intellectual disability in the late 20th century, and not the institution, group home, independent living or any other government funded housing model. The label of ‘community care’ refers to the independent living and group home models, in a way that understates the care provided by parents.

For many parents, their distrust of the government (which, for some, once sought to institutionalize their children) has often led them to make no demands on the system and to avoid any contact with it. My conversation with Gina, an elderly woman living with her daughter who has an intellectual disability, reveals such sentiments:

I: what kind of services do you wish you’d had…?
G: I don’t know, really, because we haven’t even applied.
I: you don’t want anything to do with the Department [DHS]?
G: no! (Gina)

Gina’s approach may help understand why not all parents have approached DHS to apply for services. At the same time, since the 1980s, governments in various countries have started to perceive informal support provided by families (to people with disabilities as well as to elderly people) as a practice that should be encouraged as a means to reduce welfare demands. Investing small amounts to support informal carers – with tax benefits or allowances – was seen as a cost-effective strategy to ensure extensive supports from
families (Twigg and Atkin 1994: 6). If translated to fiscal terms, the value of informal support for people with intellectual disabilities in Victoria and the value of the housing provided by parents may mean several billions of dollars worth of saving of public expenditure every year. This implies a perception of carers as ‘resources’, an approach that often overlooks distinctions between different forms of care and different kinds of relationships between those who provide care and those who are cared-for (p.12). The people I have interviewed in Victoria, have not directly referred to the care provided by parents as ‘resources’, and have not translated the value of such care to dollars. While the perception of ‘carers as resources’ is a ‘predominant reality of social care’ (p.12) in post-industrial societies, in the Victorian disability services sector this perception is silenced in discourse.

At the same time, when the parents’ role as carers for people with intellectual disabilities was highlighted in public discourse, it was often in a negative way, being critiqued by deinstitutionalization campaigners for not allowing their son or daughter to move into independent living or group homes and for supporting institutionalization (Gleeson and Kearns 2001). Ella, mother of a woman with an intellectual disability, expresses how she, and perhaps many other parents, feel in light of such critique:

If families are so terrible at the way they care for their sons and daughters, how come we’ve still got them? Why haven’t they taken my daughter a long time ago and put her into an accommodation service? Because my care is appalling, I don’t give her choices, I don’t let her go out and do the things she wants to do. What a wicked woman I am! (Ella)

Being critiqued for not providing good enough care, but not being provided any alternative by the Government, leaves the carers in a very difficult position, reflected in Ella’s sarcasm. This situation is becoming even more complicated due to demographic changes. In the last few years many ageing parents have become too frail to continue caring for their son or daughter at home, and many other parents have died. This leads to a twist in the role of the community in housing and supporting people with intellectual disabilities -
and a rather sudden twist due to the lack of planning. Currently in Australia, one in six people with intellectual disabilities waiting for supported accommodation is being cared for by relatives aged 75 years and over. People with intellectual disabilities in the same age group who do receive government funded services, also experience inappropriate housing. People aged between 50 and 60 years, more than any other age group, appear to have ‘poorly serviced accommodation needs’ (Standing Committee on Community Affairs 2007). More than five thousand people with disabilities in Australia (1364 in Victoria) aged 50-65, and a thousand people (220 in Victoria) aged less than 50, 15 percent of them with intellectual disabilities, live in aged care facilities with people much older than themselves and in congregated facilities (Department of Health and Ageing 2006; Winkler et al. 2006).

7.4.2 Ambiguity towards the group home model

Different sectors in the community have conflicting positions regarding the group home model. Notable sides in this debate, which can be seen as representing various faces of the ‘community’, are people with intellectual disabilities themselves, their parents (with a distinction often made between elderly and younger parents), non-government support agencies and disability rights advocacy groups. Conflicting positions within these groups in the community allow the State Government to maintain its own policy ambiguity.

People with intellectual disabilities have different views on the group home model. Among the 16 people who were interviewed for this study, all of the people living independently (11) stated that they would not want to live in a CRU. Four of them have lived in one at some point in their life, so they are well aware of the implications. Two of five participants who were living in CRUs at the time of the interview have stated a general preference to move to more individualized forms of housing, but considered life in a CRU a reasonable compromise they are willing to make. The other three have expressed a sense of satisfaction with living in a CRU. This may imply a low level of expectations, as was found among participants in a study conducted by Laws and Radford (1998), reflecting a ‘resignation to the inevitable’ (p. 99).
Another interpretation would be that for some people a group home could be an appropriate and desired life-style.

The approach which acknowledges that group-homes are a compromise was evident in Julie’s interview. Julie was born in a small rural town in Victoria, and is now 37 years old. As a child she lived in a boarding school in Melbourne, but in 1988 she went back to her hometown, to live with her mother and step-father. She stayed with them for ten years, until she was 27, and never considered moving out: ‘never wanted to move out. I never could, couldn’t manage. Wanted to stay with my mum’.

When she was 27, her mother’s relationship with her step-father broke-down, and Julie had stayed for a while with her mother. Soon enough, however, she had to move out to a CRU. It was not her choice but ‘it’s just the way it was. Mum just couldn’t handle me, she couldn’t lift me.’ The move into the CRU was hard for Julie, and she felt unhappy. She was still living there at the time of the interview, and was still having a hard time, not so much with the staff as with the other residents: ‘they are not communicating properly. I’m not getting along with them.’ One of the residents, however, has become her best friend.

The CRU is divided into two separate sections, and she lives in the section which has a bigger toilet and shower, more accessible for a wheel-chair user. Her best friend, however, is in the other section of the house. Julie says she never tried to ask for them to be together: ‘it’s just the way it is’. This kind of response was repeated several times in Julie’s interview, revealing a sense of acceptance of a variety of constraints which prevent her from having things her own way.

I asked Julie where she would most like to live if she had the choice and she said: ‘I would like to live in my own house, but will have to have someone to assist me in showering, dressing and all of that kind of stuff’. Therefore, an option she considers realistic is to live in a CRU, but with people other than her current fellow residents. She would also like to live closer to her mother.

Roy, unlike Julie, expressed a sense of contentment with the CRU in which he lives with 5 other men. Now Roy is in his 60s. He moved to Victoria from New South Wales with his parents long ago, and cannot remember
exactly when. When his parents died he moved to live with his ‘aunties and uncles’. He then moved to another CRU which he says was ‘awful’ because it was too hot in summers. Then he moved to his current home, which he thinks is much better. Roy was happy about moving in with some new flat mates because he likes meeting new people and he liked them. He says that he is very happy in his home and that he would like to stay there forever:

I: Is there anything that you would like to change in your home?
R: No. I’m happy. I like listening to music. Country and all that kind of music. (Roy)

Apart from hearing music in his room, he likes watching TV in the living room. Roy is rather isolated geographically from his family in New South Wales. The CRU is located in an outer suburb at the fringe of the Melbourne metropolitan area, and Roy knows no one there apart from the people living with him, people in the day program he goes to and staff. He says he had never talked with any of the neighbours because he thinks they are all Italian and do not speak English. Despite such social isolation – or perhaps because of it – Roy is happy to live in a CRU because he is aware that it is hard to access any housing, and because he is happy with his daily routines there, with the other residents and with the staff.

It should be noted that due to the way participants have been recruited in this study, these accounts by no means represent the population of people with intellectual disabilities at its full diversity. Nevertheless, these accounts show that some people with intellectual disabilities do have clear positions about the kind of housing they would like to live in, and about group-homes in particular. These views of people with disabilities affect disability policy, but in very limited ways for two main reasons. First, people with intellectual disabilities are divided in their positions about the group-home model, so therefore do not represent a ‘united front’ in policy debates. In some ways, the choice agenda responds to this diversity of positions, suggesting that different models should exist to meet different demands. Second, some people with intellectual disabilities are given an opportunity to express such preferences, as individuals, within the framework of person-centred planning. Others
express their preferences – or, more accurately, their dissatisfaction with the current situation – by exhibiting ‘challenging behaviours’ in group settings. But many other people with intellectual disabilities often do not express their positions, in some cases because they were never asked, in some cases because they do not know how, in other cases (as those presented above) due to a ‘realistic’ approach, knowing that they have very little chance of fulfilling their choices anyway. This accords with McGlaughlin et al’s findings, that people with intellectual disabilities often have the capacity to make informed choices, but this capacity is undermined by a sense of powerlessness (McGlaughlin, 2004).

Parents of people with intellectual disabilities are also divided in their positions concerning the group home model. Many parents apply for a placement in a group home for their son or daughter, an environment they perceive as relatively stable and safe, when compared to the alternatives. This demand for group-homes is apparent in the long waiting lists for shared supported accommodation in Victoria. However, such demand comes exactly at the time when the Government is reconsidering the group home model. Government officials I have spoken with often tried to de-emphasize the demand for group homes. For example Kay, a DHS senior officer, maintains that the waiting lists do not represent the real preferences of the applicants:

There are a lot of people waiting for support, but a lot of the support that people are waiting for … is the traditional support. In other words, they might be reported as urgently requiring accommodation in a 5-bedroom CRU. Now, when you're having the conversation with that person or the person who has put their name on the list, there may be a whole other range of possibilities that that person may want to explore. They may not want to live with 4 other people. So there are the figures, and then there are the real stories that sit behind about what people really want (Kay)

An analysis of Kay’s account points to the way DHS often uses the notion of choice as a strategy in its negotiation with families. The line between the choices of the parents and the choices of the person with the disability is very
ambiguous. This ambiguity allows the Government to maintain its own ambiguity regarding the group home model and to defend its enormous waiting lists. Indeed, not all parents wish for their son or daughter to be in a group home. Some elderly parents and more dominantly younger parents are opposed to this idea, often for very different reasons. Kay emphasizes the differences between young and elderly parents:

Particularly for younger families - families who have a child with a disability or a young person with a disability – some of the aspirations they have for their sons or daughters are ‘I don’t want them to go to live with 4 people they can’t choose. I want them to be able to live in the house that I might leave to them when I die, or I want them to live with one of their friends from school.’ So we’ve got a generation of new families who are looking for something different, we’ve got some older families where there are elderly parents and their primary concern is ‘what is going to happen when we die and our sons or daughters are left behind? Who is going to be there for them?’. And it’s completely understandable. For them the certainty of the CRU type model is something that they are comfortable with. (Kay)

Kay speaks about having to work with two different groups of carers – younger and older, with very different expectations and demands, as discussed above. The conflicting positions among the community are not only between young and elderly parents, but also between those who already receive government funded services and those who receive none - those who wish more CRUs were built to increase their chance to access one, and those who have no other alternative but a CRU which they see as a mini-institution or just an unsafe environment for a person with intellectual disability.

Interviews with people in the ‘community sector’ also reflect an ambiguity around the group home model. For disability rights advocacy organizations, the conflicting perspectives of the group homes among people with intellectual disabilities and their families pose a very difficult dilemma of which side they represent in this debate. For non-government support agencies, the
dilemma is even more complicated, because they are funded by the government to provide group-homes. This puts them in a position of having to defend their own practice, and at the same time being critical of it and advocating for change. Tania, for example, a senior manager in a non-government support agency operating in Melbourne, expresses this peculiar position:

> Group homes are mini-institutions and I hate to say that but I'm sure the ones that we provide are too – they have everything – they have group routines, people don’t have choice who to live with, and we can make it as good as we can, but ultimately they’re living where they were placed, generally due to no other options. (Tania)

Tania, as several other participants, uses the notion of ‘mini-institution’ to refer to group homes. Since group-homes have been introduced from the very start as an alternative to institutions, referring to them as ‘mini-institutions’ in many ways undermines their legitimacy, in a similar fashion to the discourse that characterized the deinstitutionalization movement. Like Tania, managers in other agencies have also expressed their dissatisfaction with the group home model, as in the following account provided by Natalie, manager of a support agency in Melbourne:

> I: do you have people in your group homes in the process of moving to live independently?
> N: yes, we do. Our manager would like to move them all out. It doesn’t mean that the house will close, because other people will come in. (Natalie)

The ambiguity around the group homes is also reflected in their designation as ‘transitional’. There are two aspects for this designation. First, group homes as a transitional stage in the process of deinstitutionalization, rather than its end. In this sense, the transitional nature of the group homes is associated with the capacities of the service system rather than that of the residents. Second, group homes are considered by some as transitional homes where residents could be trained and then move out to live
independently (as in Donna’s story described earlier in section 6.6). In this sense, the transitional nature of the group home is associated with the capacities of the residents, not the service system, and the group home itself will remain part of the landscape - only its residents will change. Therefore, Natalie’s account suggests that while the agency is unhappy with the group homes it runs, it is aware that moving those people out will not solve the problem because other people will immediately move in to that house instead. This ambiguity regarding the group home model among people with intellectual disabilities and their families and among various professionals, advocates and other actors in both government and non-government sectors is reflected in the narratives discussed in this chapter. In a similar way, Figure 10 below presents some additional quotes from interviews which reflect diverse views as those discussed above, but have not been addressed separately to avoid repetition.
We also do a lot of work for people who are in group homes, CRUs… and there it’s always around the quality of care, not being given individual choices, their individual needs not being respected in group types situations. So basically it’s institutionalization (Arthur – disability rights advocate).

I was involved from a government perspective at the time when a couple of the big institutions were then closed and the people were moved into CRUs. And we thought it was wonderful… I wouldn’t say that I ever thought that group housing was absolutely the end, but we were so focused on how dreadful the conditions were [in the institutions – IV] and how much better these houses are going to be (Natalie – senior manager in a non-government support agency).

In the CRU you need to have your shower, have your breakfast, wait for the bus to pick you up at 8.30 and take you to your day placement. If you want to lie in bed feeling grumpy, you can’t do that, and that’s often when the aggression comes. I think that in institutions there is probably a lot more space for people to do things like that (Sam – senior officer, DHS).

There are not enough places that are available. Like, CRUs are really good places, but there’s not enough of them, and there is not enough crisis accommodation and it makes it really hard when people are becoming homeless (Emma - Intake and Response worker, DHS)

Group homes are mini-institutions and I hate to say that but I’m sure the ones that we provide are too – they have everything, they have group routines, people don’t have choice who to live with, and we can make it as good as we can, but it ultimately they’re living where they were placed, generally due to no other options (Tania – senior manager in a non-government support agency)

There should be a variety of choices. One type is not sufficient (Robert – parents association)

I think it’s good we’re broadening the service system but there’s still place for the group homes, for the people it works for, because we have lots of people who actually choose it and quiet like living in group homes. And there are other people who have been very unhappy about it, and hopefully they would have the choice to move on as well (Anna, senior officer, DHS).

I: Were you ever thinking of living in a CRU?
A: No.
I: Why not?
A: Because I don’t really need…
I: Support?
A: Yes, one-on-one (Aaron – person with an intellectual disability).

I: Do you remember how long you’ve been living here (in a CRU)?
S: No. I like it.
I: What do you like about it?
S: (No answer)
I: How are you getting along with the other people in the house?
S: Good.
I: Anyone a close friend of yours?
S: Yes, Beatrix is (Stephanie – person with an intellectual disability).
7.4.3 Independent living: pulling in a reluctant community

A move towards the independent living model is among the most significant aspects of the choice agenda. The government policy explicitly supports and encourages the move towards independent living, however in practice only for people who require very limited funded support (a theme which is elaborated in Section 8.3). Moreover, the government sees the move towards independent living as dependent on greater community involvement than was evident in the group home model. However, the community is divided in its stand towards independent living.

Alice, a DHS senior officer in a rural region, discusses the reluctance of some elderly parents to have their sons and daughters move into independent living:

You have elderly parents, very elderly parents who still have their children living with them. We've got one lady who's 95 and is still looking after her 50 years old daughter. And we feel that if she let her go, we can probably skill her daughter up to either live independently or to live with another group who could share the responsibility living in a small house. But the parents don't want to give her up. (Alice)

Alice’s account reflects a conflict between the government ('we feel') and some elderly parents. The individual parent is portrayed as being a barrier to her daughter’s independence ('if she let her go').

Doreen, manager of an independent living program provided by a non-government support agency, and Hannah, a planner in the same program, describe a similar difficulty to bring along some parents – particularly elderly ones – to allow their son or daughter to move to live independently:

D: Time is always against us, and that's scary. One of my fears is 'oh my god, something is going to happen to the parent and they're going to end up in a CRU'.
H: but people who haven't had this experience (of independent living), it's really hard to open them to other options.
D: This group of people (elderly parents) – they come from a period where traditionally CRUs and institutions were the only things on the menu. And in many ways, they were really innovative in a sense, like the group that initiated (a day program in Melbourne), they saw the need for a school for their children and they started it and found the funding, whereas other kids were put into institutions. And they chose not to put their children in institutions. (Hannah and Doreen)

Doreen and Hannah raise some of the most common claims made by participants regarding elderly parents who are reluctant to have their sons or daughters move into independent living. On the one hand, Doreen and Hannah claim that because such parents have had no other experience but caring for their son or daughter alone, they cannot make an informed choice about accommodation. On the other hand, the workers claim that ironically this is the same group of parents that several decades ago resisted the institutionalization of their sons and daughters. For advocates of independent living, it is not entirely clear why people who have once been ‘innovative’ and progressive, now refuse the innovative model that is offered to them. From the parents’ point of view, perhaps, they do not trust the same Government that once sought to institutionalize their sons and daughters, to now provide them an experimental and insecure form of accommodation and support. As Gleeson and Kearns (Gleeson and Kearns 2001) suggest, many parents’ sense of anxiety in light of deinstitutionalization can also be partly attributed to their awareness of the government’s withdrawal from its welfare responsibilities under a neoliberal philosophy (p. 65). Reported incidences of abuse of people with intellectual disabilities living independently have also contributed to concerns about this housing model being implemented without appropriate supports and protections (Fyson and Kitson 2007).

The practice of ‘support circles’ is the main strategy used by Doreen and Hannah’s program to both convince families to allow their relative to live independently, and to increase their active engagement in the provision of informal support. The support circles are meetings coordinated by Hannah, the planner, in which a person with an intellectual disability invites all people
involved in his or her life to regular meetings to discuss ways to improve it.
One example of such a support circle is Ron’s family:

H: Ron has three sisters and lives with his parents. He’s very active, has a very sheltered life, his family is amazingly supportive of him. He’s 48, and his support circle is 16-20 people, all family members – brother in laws, cousins, nieces, nephews. And they tell you everything.
D: Ron’s sisters are really good at challenging their dad, challenging him to allow Ron to do different things.
H: To even accept funding.
D: Or being able to go alone down to the shop. Because his parents are becoming ill – and he’s going to need to be able to do that on his own. Giving him the confidence, also to talk about what happens when his parents die (Hannah and Doreen)

Ron’s circle, according to Hannah and Doreen, allows the sisters to ‘challenge’ their elderly parents to consider new forms of housing and support for Ron. The father’s reluctance to accept funding and government services is typical of many parents of his generation. Moreover, the daughters’ and other family members’ involvement in the support circle and, consequently, in the provision of informal support, is also a way to overcome the limitation in funding. While Ron still lives with his parents, this circle provides a framework to plan a future move into independent living when the parents will no longer be able to care for him.

Lea is a manager of a similar independent living program, operating in a rural town. She tells that the smaller size of the community makes it easier to lead a cultural change among parents towards a greater acceptance of the model:

Convincing people to move away from the CRU model is part of the job, and it’s getting easier as more success stories occur, and because families know each other well in such a small community, these stories spread. (Lea)
The strategy described by Lea is based on the premise that the parents’ consent and active involvement is a significant factor that enables independent living for a person with an intellectual disability. However, not all people with intellectual disabilities experience such a close involvement of relatives in their life. Hannah and Doreen told me about Francis, another person in their program, who is much more socially isolated:

D: I think Francis is a good example of a circle that is very challenging, because I think all the people in the circle are paid [staff members], they are people from the day service and Hannah and I. They’re invited, but you’re not paid to actually attend – it’s voluntary, because people do have to care about the person. When you’re not paid, you’re doing it because you want to do it. It’s not like saying ‘I hate my job but I still have to do it for the pay’. One of the difficulties with Francis is that he doesn’t have a lot of people in his life that aren’t paid to be in his life. So that’s one of the things that we actually need to work on a lot more (Hannah and Doreen)

In Francis’s case, the people who are pulled in to engage in his ‘support circle’ are all professional support workers. They are paid minimal wages to work with Francis in the day program, but are not paid for their participation in his circle of support which is voluntary. It may be assumed that their participation in these circles is motivated by their genuine care for Francis, as well as explicit or implicit pressure within the support agency. This points to two main problems of the choice agenda: first, the lack of informal support provided by the community; second, the deteriorating conditions of paid professional workforce who are asked to play a double role – as formal support workers as well as informal community networks – for the same price, and a minimal one. Since the quality of services is very much determined by the quality of staff (Clement and Bigby 2008), deteriorating conditions may mean poorer and even negative outcomes for the choice agenda in the long run.
7.4.4 Individualization leading to reinstitutionalization

In the disability housing model debates, the community is perhaps most extremely divided in its perception of congregate care. On the one hand, several community groups oppose any form of congregate care vigorously, arguing that such practices are inhumane. On the other hand, definitions of what ‘congregate care’ is vary. Moreover, some groups of parents support congregated models, maintaining that these models entail several important advantages, and that allowing people to choose means allowing them also the option of choosing an institution. The latter group seems to have succeeded in influencing policy and maintaining the existence of congregate care facilities in Victoria.

Deinstitutionalization in Victoria reached a climax in 2008 with the redevelopment of Kew Residential Services – its largest institution. However, over 20 new group homes will be clustered on the site of the old institution, a number of other smaller institutions still exist and house residents, and other congregated facilities of above 10 residents in the form of nursing homes, aged care facilities (in which young people with intellectual disabilities are often housed), SRSs, rooming houses and clustered independent living units developments are abundant. Moreover, the option of re-institutionalization – though denied by policy makers - is feared by some of the people I have spoken with, as expressed by Patrick:

Because there is no investment (in CRUs) at all …we’ve got situations right now, in this region here, that people are going back into the institution here... because it is the only option. And in other regions, where there’s no small institutions still left, they’re taking up respite beds. And the Department will say very quickly ‘that’s only temporary’. But those places have been temporary now for 2 years for these people. ... So we’ve got something really tragic going on, that we’ve stopped building 5 bedroom places, because it seemed to be non-flexible and too restrictive, and we’ve got people who are
practically homeless going into institutions and into respite beds, because there is nothing else in the service system. (Patrick)

Patrick highlights the irony in a discourse of choice that is used to justify a move away from the group home model, in a way that he sees as leading to re-institutionalization. Patrick defines this option as ‘something really tragic’. This view of institutions as a dehumanizing practice is well grounded in current community perceptions since the deinstitutionalization movement has taken its first steps in the 1960s. Scholarly literature has played a significant role in shaping this perception, by exposing the living conditions in institutions (Blatt and Kaplan 1966) and by critiquing the social values that underlie the practice of institutionalization as being part of a eugenic project (Radford and Park 1995). Scholarly critique of institutions can be seen as another role played by the broader community in shaping the disability housing model debate. However, some groups in the community – mostly parents of people with intellectual disabilities - still hold their position that congregate care is a legitimate practice, and even entails some significant advantages.

Ella, an elderly mother and carer of a daughter with an intellectual disability and manager of a carers’ association in Victoria, argues that congregate care is a better option for her daughter than a group home. She believes her daughter, who is still living with her, would be neglected in a group home:

E: The scenario probably is that they will shower and dress her and give her a breakfast in the morning, and then sit her in a chair in the lounge-room and that’s where she’ll stay the entire day. Because she won’t ask for anything, she won’t demand, she’ll do nothing wrong while they’re chasing the other three very active and agitated people. My daughter will be neglected the entire day, save for providing her meals, doing her blood test, whatever. That’s a group home.
I: if you don’t want your daughter to be in a CRU, why would you advocate for places with even more people together?
E: ... a six-bed facility is staffed with two-three staff in the morning shift when it’s busy, then they’re all forced to go to a day program
and if there's no day program available they will create one for them because there are no staff there during the day between 9-3, two staff come in the afternoon and stay until 10 o'clock, and then you have one person staying an over-night sleep-over. And I'm here to tell you the amount of abuse and neglect that goes on in those CRUs when no one is watching is just as bad – if not worse – then any of the worst institutions that you can think of. So what we're suggesting is to multiply those beds by three, and get 18 beds. Then you get three night staff – not one – for the same money, which means you can have an awake night duty, even two. Two awake night-staff can adequately care for anyone who has a disturbed sleep during the night, and then you have sufficient levels of staffing during the day, you can have male and female staff on board on all shifts to care for all the personal care needs of male and female clients. And if they had the same level of service that is offered in aged-care – that is everybody is entitled to their own bed-sitting ensuite which aged care gets for a lot less money than disability, then each of our people would have some dignity living in a group setting. At the moment, if there's a group home in your regions, they are so few and far between, you get no choice whatsoever – if there's a vacant bed and you need a bed you have to go there, like it or hate it. Take it or leave it. No choice. And we have not given all of our lives to care for our sons and daughters to at the end of the day accept that which the department is offering which is crap. We won't accept it. I haven't raised my daughter to be 38 years old to get her to that point, only to have her framed to the wall in a group home with 3-4 people with challenging behaviours, simply because it's the only thing there, and with staff locking everyone in so that they can sleep through. (Ella)

Ella believes that through economies of scale it is possible to provide her daughter with better services in a congregated facility, with more staff and a private ensuite room. She uses a comparison with the aged-care sector, where congregated facilities are the norm, to challenge the dominant discourse in the disability sector where it is considered politically incorrect to support congregate care. Her critique on the group-home model and the lack
of choice within is also used as a way to advocate for larger facilities. Ella ‘jumps scale’ (Kitchin and Wilton 2003) to support her argument.

Advocates of the group home model emphasize the smaller size of a group home compared to an institution to explain why there is more choice for people in smaller facilities (Emerson 2004a; Emerson et al. 2000; Stancliffe 1997; Stancliffe 2001; Stancliffe et al. 2000; Wood 2004). Ella challenges this view by focusing on a smaller scale and emphasizing the larger ensuite rooms in congregated facilities. Indeed, her view may be supported by Stancliffe’s (2001: 95) reminder that most studies comparing quality of life in different types of facilities do not attend to more specific features of such living environments which may increase or decrease choice.

Ella’s account depicts her daughter as a very frail, passive and vulnerable person, who has very little chance of enjoying a reasonable quality of life in the community. Advocates of independent living would argue, in contrast, that being given a chance to acquire independent living skills, her daughter may overcome her disabilities and be more actively involved in her life. Ella, however, dismisses this idea arguing that this is simply not realistic. Like Ella, in the current under-resourced system, many elderly carers, who see no other alternative and who carry the burden of care for every delay in policy response, seek to promote a solution of congregate care.

Thelma and Robert, managers of another parents’ association in Victoria suggest several other advantages associated with congregated and institutional living, when compared to group homes:

T: I know one man who’s son is currently living in a CRU and it’s unbelievable conditions. Locked in his room. No furniture because he breaks it all. You look at the photograph and its far worst than anything you see at Kew, at least in the last few decades.
I: Why do you think they would be better off in the institution?
T: I’m not saying they would be better off there, but instead of being contained in one small house, there’s more potential for them to have an actual greater degree of freedom.
R: In cluster housing, with a common area in the middle where they can move around – they wouldn’t be isolated in their own house. In
Kew people could have moved around more freely, and it’s not like that in a CRU. In the community you need a staff member to go out with you.

T: And no matter how far we’ve come forward in the community, there are some behaviours that are very difficult to manage in a shopping centre or an urban street. I know that it is all terribly ideologically unsound for me to be speaking like this, but in a smaller community where there’s a greater degree and understanding and acceptance, there’s more potential for individuals to be themselves. … Our position in the parents’ association is that it’s about the individual and what works best for the individual.

R: There should be a variety of choices. One type is not sufficient.

T: The thing about Kew Cottages that I find quite heart-breaking, about how we ended up and the stigmatization of the institution, is that it was a community, a very vibrant community in its past. Yes, there were bad things about it, but there were absolutely wonderful things about it too. Staff would be criticized today for being institutional in their thinking, and all these things are absolutely true, but it was a very very vibrant, very supportive and pretty unique community. And for some individuals I think that’s more important to them than just focusing on bricks and mortar … All the improvement that has come along with the CRU and the small living environment – which research and none of us had ever questioned – has improved, as you expect to be true, but the community inclusion, the sense of belonging and involvement and participation, that’s the area that they would acknowledge that they haven’t achieved what they’ve set out to achieve. (Robert and Thelma)

Thelma and Robert highlight the notions of ‘community’ and ‘choice’ – the very same notions most commonly adopted by advocates of independent living – to advocate for large scale congregated or clustered facilities. Such claims raise important questions about the nature of ‘community inclusion’, suggesting that there is more than one kind of community and that the vision of inclusion should be more specific about the particular kinds of communities it wishes to create, and those it wishes to move away from. It also calls for an
analysis of how choices of individuals contribute to or stand in the way of the implementation of such a vision (Clement and Bigby 2008).

In some ways, such parents’ associations taking similar stands have been successful in redirecting deinstitutionalization in Victoria. Their involvement in the redevelopment of Kew Residential Services leading to the formation of a cluster of CRUs in one residential suburb rather than a more dispersed geography, as discussed in the previous chapter, is their most obvious achievement. More importantly, they have managed to disturb some of the rigid assumptions and dichotomies which have characterized the debate about disability housing models during deinstitutionalization, and through that they have affected the development of new models indirectly. Indeed, some new facilities built by organizations in the community sector as independent living facilities, are in fact congregated facilities of over ten people. The size of these new facilities was not driven by an ideological motivation (in fact, the developers sought to keep them as small as possible) but by economic constraints (as explained Section 7.3). However, development of congregated facilities requires public legitimacy. The fact that such facilities are currently being developed in Victoria suggests that despite the opposition of disability rights advocacy groups and the ongoing controversy discussed above, such legitimacy exists. This legitimacy may also allow the future institutionalization of thousands of new people who are now cared for by elderly parents and will require urgent housing and support solutions in the near future.

7.5. Idealism, realism and choice: conclusions

This chapter has applied the three theoretical perspectives on the choice agenda described in Chapter Two to explain the distribution of different housing models for people with intellectual disabilities in Victoria. It shows that any single perspective alone – a focus on distribution, on community or on institutional structures of the state – cannot explain these complex processes in isolation. The logic of economies of scale, for example, is a significant factor in the disability sector; however it cannot explain deinstitutionalization,
the major change that has occurred in the sector over the last century which appears to have worked against this logic. Hence, in order to understand why particular housing models are adopted or rejected, one needs to consider how different factors work with and against each other. For example, the logic of economies of scale, coupled with the flexibility of individualized funding as a structural change in state bureaucracy, in the context of a cultural ambiguity around what is ‘institutional’ and what is ‘individualized’, all work together to produce new forms of congregated models. This understanding reaffirms Dorn and Laws (1994) call on researchers to take into account both subjective and material aspects of space when addressing questions of disability.

The dichotomy between material and subjective considerations is not only a theoretical analytical distinction. It is also a dividing line between conflicting sides in disability housing model debates – between idealists and realists. The idealistic approach is guided by the ideals of social inclusion and individuality. Idealists advocate for dispersed housing to make it easier for communities to integrate people with intellectual disabilities within them. They also call for smaller housing models, to allow more choice for their residents. A very different approach is the ‘realistic’ stance in the disability housing model debate. Realists emphasize a variety of constraints to undermine and counter the idealism often characterizing this debate. They emphasize the limited material resources available and the limited ability of the community to include people with intellectual disabilities within it.

The ‘realistic’ approach to the disability housing model debate often entails an assumption that the current context is not likely to change. It is a self-fulfilling prophecy: assuming that a deficiency in resources is inevitable, for example, may lead to the development of more congregated models involving economies of scale. This approach is perhaps more realistic in its perception of existing funding constraints, but it also serves to underpin some of these constraints by reproducing the housing landscape in which they are embedded. In contrast, advocating for smaller and more expensive models means an approach which is apparently less realistic, as it cannot truly achieve its aims within existing constraints, but at the same time it acts strategically to change this reality. In the short term, however, only a few can enjoy its outcomes.
Decision-making in the disability sector, however, does not seem to be guided solely by realism, nor by idealism. Rather, the choice agenda can be seen, in part, as a policy response attempting to please all parties, for obvious political reasons. The Government has settled to allow a diversity of models to exist side by side. Individualized supports for people with low levels of support needs have been increased, but also new group homes have been built for people coming out of institutions and even new congregated facilities were developed (enabled, ironically, by individualized funding). At the same time, care by parents is still the dominant model of housing and support. The rationale behind this policy is a notion that each person should be able to choose their preferred model. However, in practice, despite the existence of several housing and support models in Victoria, individuals have hardly any choice in housing due to the scarcity of housing and support, the inflexibility of location as explained in Chapters Five and Six, and also because of institutional structures which inhibit individual choice. Such structures are discussed further in detail in the following chapter about access and allocation policies in disability housing.
Chapter Eight
Allocation priorities and choice

This chapter concludes the empirical section of this thesis, continuing the task of charting a geography of housing for people with intellectual disabilities in Victoria, and analysing the role of the choice agenda within this geography. Chapters Five and Six focused on the location of housing as a particular dimension of this geography, while Chapter Seven looked at models of housing as another dimension or scale. Together, these chapters helped portray a landscape of housing in which people with intellectual disabilities may live. However, people with intellectual disabilities are a very diverse group, the differences among them often more significant than the similarities. The current chapter thus diverts from the previous three by addressing such differences.

As discussed in Section 3.2, accounting for difference when charting a geography of housing is not merely a more nuanced approach. It is an essentially different theoretical perspective into the links between power, identity and place (Jacobs and Fincher 1998: 2). The aim of this chapter is not just to map where and how different sub-groups of people with intellectual disabilities are accommodated. It is an analysis of the construction of such groupings through housing policy – mainly allocation priorities - and through the choice agenda.

The chapter investigates the formation and implications of eligibility criteria and allocation priorities in housing for people with intellectual disabilities. Setting up and enacting allocation priorities is one of the most central and most difficult tasks for welfare administrators, and an arena of passionate professional, personal and political conflict. It is also an arena in which the choice agenda is significantly influential. As ‘choice’ becomes a more central consideration in allocation priorities, the meanings and implications of other priorities such as waiting time, need and social mix significantly change, and, concurrently, changes the geography of people with intellectual disabilities.
Section 8.1 reviews some of the literature about allocation priorities in welfare services, with particular attention to studies in social housing which provide some very relevant discussions even though they are not specifically about people with intellectual disabilities. Section 8.2 looks at a particular category of people with intellectual disabilities who are granted priority in access to housing: people in crisis. It examines the implications of this practice on the housing landscape and on the experiences of people with intellectual disabilities, and considers the relationship between crisis and choice. In a similar fashion, Section 8.3 addresses the categorization of people with intellectual disabilities into sub-groups according to their ‘level of support needs’. Section 8.4 addresses considerations of social mix in the allocation of housing for people with intellectual disabilities, with particular attention to the category of ‘people with challenging behaviours’. Section 8.5 concludes with a more theoretical discussion about the relationship between needs, social mix and choice as currencies of priority in access to housing.

8.1 Time, need, mix and choice as currencies of priority to welfare services

Different considerations have been highlighted in different times and places as criteria to determine eligibility and priority in access to welfare services. Underlying each of these considerations is a different set of assumptions and ideologies about the role of the welfare state, about social justice and about difference.

Waiting time has traditionally been a central currency in access to welfare services. Within a typical waiting-list approach, applicants who have applied earlier are prioritized. In public housing, for example, until the late 1960s, this approach was implemented through the introduction of simple queuing systems (Fitzpatrick and Pawson 2007: 167). When an applicant has reached the top of the waiting list, he or she is offered the first available unit. However, critics of this system suggest that applicants with greater and more urgent need should perhaps be prioritized over applicants who have waited
longer for the service. Moreover, it has been argued that the queuing system results in applicants being offered services which are not always appropriate for them, because their particular needs were not taken into consideration (Kaplan 1987).

Thus, a need-based system of allocation was adopted in several welfare systems in the 1970s. Ideally, in a needs-based system an applicant is offered a service which best responds to their particular needs and applicants who are in greater need are prioritized. However, a number of problems associated with the need-centred approach are often raised by critics. First, an objective assessment of need is highly problematic, and is often enacted through decision making structures and status systems which reinforce disadvantage (Young 1990: 66). In disability services, a determination of need based on pathologizing medical notions of dependency is seen as a central oppressive feature of the medical model of disability. The needs-based system is also criticized for encouraging ‘point chasing behaviours’ by applicants and thus providing an incentive for dependency (Fitzpatrick and Pawson 2007: 169). Fraser (1989: 299) argues that a needs-based approach in welfare services is tied with crisis-driven practice. Needs which have not been satisfied under the ordinary provision of ‘domestic’ services are reframed as ‘crisis’ and handled under crisis-management to prevent them from becoming a political issue.

Another agenda that has grown increasingly central in welfare administrations, particularly in social housing, draws attention to geographic concentrations and mixes of disadvantaged social groups. Social housing developments may lead to high concentrations of disadvantaged groups in specific geographic areas, thus exacerbating spatial polarization and residualization (Fitzpatrick and Pawson 2007: 169). To avoid such concentrations, mix of service users has become a more dominant consideration in the administration of vacancies. For example, in some of the US public housing programs described by Kaplan (1987), new applicants were given assignment priorities if they were ‘willing to live in a project where their race does not predominate’ (p. 402). Another strategy to control the mix of residents in social housing has been the widening of the social profile of tenants in order to reduce the stigmatization of social housing, at the expense
of ‘squeezing out’ poorer households (Fitzpatrick and Pawson 2007: 177). While these examples relate to concerns about social mix from a broader urban perspective, driven by a motivation to oppose segregation, this chapter addresses concerns regarding mix of residents with an intellectual disability within a single dwelling.

The choice agenda offered another approach to allocation of social housing and welfare services since the late 1990s, placing emphasis on individuality and choice. This ‘choice agenda’ has been a response to the common ‘take it or leave it’ practices and the rising expectations of service users to be given more choice. ‘Choice based letting’ in the UK and the earlier ‘Delft’ model in the Netherlands, can be seen as the pioneering choice-based models of social housing administration. While such a model is perceived by service-users as more transparent and fair, it has also been a source of disadvantage for the most vulnerable applicants, because as Fitzpatrick and Pawson (2007) suggest:

The ‘ability to wait’ could become a more powerful force in a system where tenancy ‘offers’ can be refused without penalty, and this would operate to the disadvantage of the neediest. To this extent, a trade-off between need and choice is clearly inescapable within social housing policy (Fitzpatrick and Pawson 2007: 177).

In Victoria’s disability services, the various considerations described above – waiting time, need, mix and choice – come to play in the context of an extremely residualized and under-resourced service system, where vacancies are highly competitive and allocations are tightly controlled by the State. DHS’s attempt to balance need, mix and choice is undermined by increasing unmet demands. Vast numbers of people with intellectual disabilities have not been able to access housing and supports and are at risk of homelessness. As the administrative process determining allocation of vacancies shifted to respond to the growing number of crisis cases, in effect any other consideration of need, mix or choice is significantly compromised. The following sections illustrate and discuss this process, illustrating how crisis,
need, compatibility and choice are intertwined and why a careful balance between the various approaches should be devised.

8.2 Crisis as an institutional structure

Indeed, many individuals with disabilities are already in crisis, lacking the basic services they need to maintain their health and independence... But they, and those who will follow them, are ill served by the rhetoric of impending doom. A crisis may spur people to act, but it will not encourage them to be deliberate or compassionate in those actions. (Kennedy 2002: 226)

Crisis has become one of the most significant categories by which access to housing is determined in Victoria. Individuals who experience a crisis, mainly in the sense of being exposed to or in immediate risk of abuse or homelessness, are prioritized in policy and practice to access housing, and thus crisis has become a particular category of identity for people with intellectual disabilities. On the one hand, by no means should the real crisis experienced by so many individuals be underestimated, and it is only humane to prioritize their access to services. However, such crisis occurs because services are inaccessible to those that are not (yet) in crisis. Crisis, in this sense, is not just a category of unfortunate people; it has become a structural feature of the service system itself.

The notion of crisis relates to the choice agenda in two ways. First, it is a matter of debate whether individualizing services will solve some of the issues causing the system to operate in crisis-mode, or whether the case-by-case approach of person-centred approaches is in fact one of the causes of a crisis driven service system. Second, when being categorized as a ‘crisis case’ is a condition to access housing, individual choice is significantly undermined.

The register for shared supported accommodation in Victoria in June 2008 listed 1,358 people in immediate need for a placement in a CRU (Department of Human Services 2008d). People who are not considered of
immediate need are no longer registered by DHS. Similar numbers of urgent cases on the register were recorded in 2002 (1068), 2003 (1178) and 2005 (1051) (Bigby 2007: 69). There are several explanations and interpretations for the growing numbers of people with intellectual disabilities in urgent need for accommodation and support. This include lack of resources due to increased life expectancy leading to growing demand unmet by investment in services; competition with elderly population over welfare resources (Parish et al. 2005); conflicting expectations of service providers and of the client population (particularly parents of clients); and, lack or inadequacy of long term planning. As argued by the Victorian Auditor-General, demand for services 'is increasing by around 4 to 5 percent annually and DHS has not accurately quantified future support needs or the associated need for resources. The reactive nature of DHS’s response to accommodation needs, combined with the stringent prioritization criteria, is likely to continue, and therefore perpetuate a crisis-driven system' (Victorian Auditor-General 2008: 2).

8.2.1 Individuals in crisis

While crisis is a systematic feature of disability services in Victoria, some individuals are more vulnerable than others to the risk of becoming ‘crisis cases’ due to their ‘challenging behaviours’ (which is another category that will be discussed with elaboration further on). Eva’s story, as told by Emma, an ‘Intake and Response’ officer at DHS, provides an example of how crisis emerges and how it is dealt with:

I’ve got one client at the moment, Eva, she is a 37 year old female with a mild intellectual disability, she’s quite an aggressive client and she’s been housed in an Office of Housing unit and her arguing with the neighbours led to her leaving and her being homeless … I referred her to homelessness agencies in our area. Most of them referred her back to us, because of her disability – they see that as not being their responsibility but ours to look after. But we don’t actually provide emergency accommodation ourselves. She had
been staying with some family and they really needed a break … I’ve arranged with the Office of Housing for her to go on a waiting list for Early Housing (public housing priority waiting list), so I’ve arranged an interview time, and I will support her to go through that interview, but in the meantime the relationship with the uncle with whom she stayed has broken down to crisis … Tomorrow I’m taking her to a caravan park where she will be staying for two weeks and if she likes it after that she might be able to stay in there longer until we get an Office of Housing unit. Even Early Housing waiting lists can be about 9 months wait … We do have some accommodation here – CRUs – they’re fantastic, but there’s not enough of them, and they are only for people who are so severely disabled that they really cannot be in any independent situation. This client is too high-functioning for that so she will not be suitable for these houses. Also the waiting list is long for that, because there are not enough places. (Emma)

Emma’s account illustrates both faces of the origins of crisis: on the one hand, Eva’s relationship breakdowns and difficulty to stay in a house with other people; on the other hand, the lack of appropriate long term accommodation options and support services. Eva moves from one place to another, each of them an ad-hoc solution that has little chances of lasting long. Eva falls between the chairs: access to mainstream services is often denied because of Eva’s disability, and access to disability services is often denied because Eva is not considered disabled enough to be eligible. The risk of homelessness is immediate and constant. In many other cases, people in such situations are also put at risk of being abused by others, due to their lack of skills to defend themselves, and in some cases due to their dependence on others for shelter, as can be learned from another account provided by Emma involving another one of her clients:

I had a client a while ago who has been in the community her whole life but previously she spent her day at her mum’s, and her mum used to cook for her. Her mum has got an intellectual disability as well, the whole family does. She managed like that because she was able to get support from her mum and go home at night to sleep. But
her mum has entered a nursing home. and she’s always had outreach support, and we increased her outreach hours, but we had to come to the conclusion that she’s really low functioning and can’t cope in this situation. So I put her on the register for one of our CRUs. I have applied for a guardian first because it’s really hard to gain a consent around that, because she thought she is independent, but she is not coping. She is not coping in the way that she can’t open a can. She has been sexually abused and she lets people in the house because she does not have the ability to say no. So she really needs to be living in a CRU setting, but there are no vacancies. So now she’s got a long term case manager, dealing with the same issues that I had case-managing her, and trying to manage that until a place in a CRU becomes available. And I don’t know when that will happen. So it can be quite heartbreaking. (Emma)

Emma discusses the difficulty to achieve the person’s consent to move into a CRU. A guardian has been nominated to effectively force her to move into a CRU against her will – however at the same time no CRU was even available. While this story, as many others, is truly heartbreaking as Emma maintains, the significance of this category of crisis goes beyond such individual stories. Because such individuals in crisis are prioritized in access to housing, for obvious humane reasons, and because their access to housing is managed in a state of crisis, crisis becomes the main driver of the whole service system and also affects people who were not in crisis in the first place.

For people with middle to high levels of support needs, one must be in a state of crisis in order to access government funded accommodation and long-term support services in Victoria (allowing that there is a vacancy available, which is rarely the case). Crisis overruns any other consideration within this administrative system of housing. Locational preferences are the first to be compromised, and applicants are often offered placements which are distant from their families or support networks. Social compatibility between residents in group homes is also compromised as most potentially compatible applicants are not even considered because they are not in immediate risk. The number of applicants that are considered shrinks
dramatically due to the double requirement of being in crisis as well as having a level of support needs that matches the staffing model in that house.

8.2.2 Crisis-mode affecting those not (yet) in crisis

Crisis-mode affects all people with intellectual disabilities in Victoria, those already receiving government funded services and those waiting for them. Crisis driven allocation undermines even the minimal and most basic forms of individual choice, such as the option to decline an undesired allocation and wait for a better one. Allocation becomes a ‘take it or leave it’ practice, as can be learned from the following account provided by Jane, a DHS senior officer in one of its metropolitan regions:

When someone is saying no (to an offer of a specific vacancy’)… If the family’s saying ‘no, I don’t want this – we’re OK at the moment’, one of the consequences may be that maybe their circumstances are not that urgent. We’ve identified their urgency above everybody else, but maybe they’re not. Maybe they’re just like everybody else, in terms of the urgency factor, they don’t fit in the small bucket of absolute urgency (Jane).

Jane’s account reflects two factors which undermine individual choice in housing. First, she refers to ‘the family’ (as opposed to the person with the disability) as the people making the decision whether to accept or reject an offer of a placement from DHS. The extent to which a family represents its member’s best interest could be questioned, but has seldom been discussed in literature (Bigby and Tait 2004: 211). Second, the notion that DHS penalizes applicants rejecting an unsuitable offer, by labelling them as not being of ‘absolute urgency’, and thus not in priority for housing.

Whilst an individual in crisis moving into a new house might still be better-off even in an incompatible placement rather than being exposed to homelessness or abuse, it should be considered how this placement affects the other 4-5 residents already living in that house. They were not in crisis,
and may have been quite happy in their home before that individual moved in. As explained above a significant portion of those individuals in crisis also present behaviours which affect the other residents. David, housing manager in a non-government support agency, suggests that by operating in a crisis-mode, the whole system turns from providing homes to providing crisis housing:

I think we have to look more to the critical situation, when you need critical housing, which is a lot different from home. These are two completely different ideas. One is when we need to find somewhere for this person to live here and now, because obviously there is a lot more need out there than what support could meet, some one in a critical situation has nowhere else to go, they are basically homeless…Our job in shared supported accommodation is to have people living in homes, it’s not houses – it’s homes. For them to feel safe, their place in the world where they want to come home to, where they’re not hassled, where they don’t have to run off to their rooms every time someone is having a bad day and starts throwing furniture around. It’s not a home, and people who live in these kinds of situations, are generally not very happy people. Whereas, the other side, is the people coming through – they need somewhere where they can chill out, be assessed when they’re in a better frame of mind, have professionals really look at what’s going on with them, and only then find an appropriate place for them…People need time to go through that kind of things. (David)

David suggests that a separation of temporary crisis housing from permanent housing might improve the quality of life for those in crisis as well as those who are not. Indeed, in social housing policies in the UK, where a Choice Based Lettings system has been implemented, a parallel system has also been introduced to cater for applicants classified as urgent, which is generally restricted to 10-20 percent of total allocations (Fitzpatrick and Pawson 2007).

The malign nature of crisis-mode is also evident in the circular process common in Victoria by which individuals in crisis are placed in respite facilities which were originally designed to provide temporary relief for families
supporting individuals. When respite beds are occupied for longer-terms (in some cases years) by individuals in crisis, they can no longer serve their purpose, and families then have no respite services available. The ongoing demands of care-giving with no respite sometimes results in relationship breakdowns, and consequently more people with intellectual disabilities in risk of homelessness and crisis.

Crisis-mode also affects the considerations made when planning to support people living in shared accommodation to move out into independent living. On the one hand, many service providers do believe that some of their clients would be better off living independently. On the other hand, managers know that any vacancy created will be filled by a person in crisis who is not necessarily compatible and that would affect the whole group of residents in that house. Natalie, manager of a support agency explains:

> We know that because of the system whereby people access housing in a crisis model, if somebody moves out that means there’s a vacant bed which means there’s already people lined up, people with nowhere to live. (Natalie)

Knowing that moving one person out of a house may be destructive for the entire house may deter agencies from actively promoting such moves, particularly for people in group-homes which are considered well-functioning in terms of compatibility. Thus, in the context of group-housing, an administrative crisis-mode is particularly destructive and infectious. It serves to disturb the fragile social relationships built between existing residents. Even in houses where all residents get along very well, the risks involved with any of the residents moving out, significantly limit their choices as individuals.

### 8.2.3 Crisis and the individualization of the service system

A strong connection exists between the crisis-mode in the disability service sector and the agenda of choice and individualization. Policy makers maintain that the crisis situation may be resolved by a more individualized service system. Critics, on the other hand, argue that both crisis-mode and
individualized services are based on a case-by-case ethos of practice and therefore the move to individualized services not only does not solve crisis, but is a systematic element of crisis-mode. At the same time, if a choice-based system of vacancy allocations were adopted in the disability sector in Victoria in a fashion similar to systems currently operating in the public housing sectors in the UK and the Netherlands, people who are in crisis would be disadvantaged, because their bargaining power compared to other clients would be undermined by their lack of ability to wait for better housing options than those offered to them (Brown and Yates 2005; Kullberg 2002).

The argument that individualized services will resolve the crisis-mode is based on an assumption that the register for shared supported accommodation is overblown by demands of people who may have otherwise been living independently with far less intensive support than the kind that is provided in shared supported accommodation. Similarly, placements in shared supported accommodation are believed to be occupied by clients who may move to live independently. This creates an exaggerated demand for placements in shared supported accommodation, and in turn leads to a very limited access to housing for any one who is not in crisis.

The counter-argument against this policy stand is that neither the shared supported-accommodation model nor the supported independent living model are sufficiently resourced in Victoria to meet demand, and that this is why demand exceeds supply, creating crisis for individuals. The register is not overblown by artificial demand, but on the contrary, argues Sue Jackson, spokesman of CIDA (Coalition for Disability Rights): ‘The official waiting lists are of course only part of the story. Many people simply don’t bother to put themselves on the list because they know there is no chance they will get the services or support they need’ (Jackson 2006), as applicants that are not considered high priority have been simply removed from the register.

Moreover, with regard to planning, the approach taken by DHS is considered by many service providers unrealistic and ineffective, as maintained by Natalie:

I see no evidence that the government is really even trying to plan for people with intellectual disabilities who are likely to need
accommodation in the next five to 15 years. It’s all a crisis model. They are planning for individuals, yes – but everybody else is being dealt in crisis. This is what I mean. As distinct from saying ‘we are going to have this number of people with intellectual disabilities in this state over the next 5 years, this is their current accommodation arrangement and this is what can be done in the future and we are going to do that’ (Natalie)

Natalie highlights the relationship between the discourse and practice of individualization and the lack of long-term planning for the client population as a whole and the service system as a whole.

8.2.4 Resistance to crisis

Several individuals and organizations within the disability service sector try to resist being drawn into crisis-mode. Peter, manager in a support agency commented:

We refuse to use our respite houses as emergency accommodation, much to the anger of the Department of Human Services. So that’s different. As far as I’m aware we’re the only ones who refuse to do that. We know of another local respite service which just closed down because it became full of emergency clients so they turned it into a Community Residential Unit. But we refuse to let that happen. (Peter)

This comment points to the difficult situations in which support agencies find themselves when trying to resist a State Government policy, as they are funded by the Department and are therefore subject to its policies. Maintaining their refusal to operate in crisis-mode, costs the organization – and subsequently its clients - in terms of deteriorating relationship with their contractors.

In a sense, the support agencies are closer and more committed to their existing clients, whereas the administrators in the Government agency have no direct contact with those clients on a daily basis. At the same time,
the support agencies are not familiar with the stories of those individuals in risk that are not receiving any service, who are in contact with DHS, often putting much pressure on its workers. Tania, manager in a support agency describes some of this pressure when making decisions about filling a vacancy and trying to resist crisis-mode:

I always go into this saying that everyone here is equally urgent, because I don’t like to put pressure into looking at someone that is more urgent than someone else, but not necessarily such a good fit. I will try to see if we can support that person, but if I don’t think they would make a good match than we won’t take that person. Because obviously we will need to be working with that person in that home and we need to work with all the other people… I find it very difficult because you’re reading profiles of real people with stories – they are usually in very crisis situations – so I like to… they always laugh at me, I always say ‘I don’t want to hear about their crisis situation, I just want to hear what their support needs are, and if we can support them.’ And that would be more about their personality and how they’ll fit within the house. But they do try to sell their urgency, all people do. (Teresa)

Teresa’s wish to ‘not hear’ the crisis stories provides insight into the relationship between knowledge, planning and crisis: knowing individuals’ crisis stories may invoke a humane reaction of empathy which may also bias planning. On the other hand, not knowing individuals’ stories may also create indifference to their suffering or risk. Furthermore, not knowing may create what Saugeres (1999) describes as an illusion of objectivity in social housing management. Similarly, Mountz (2003: 634) discusses how ‘coherent, publicized narratives’ of state policy often hide the emotion, passion, complexity and conflict through which such decisions are made. Mountz examines how Canadian officials address human smuggling, and describes tensions that often arise between individuals working in distinct locations along the hierarchy of state bureaucracy. Mountz’s study and mine are both examples of how the state shapes places through access policies, determining who enters the country in Mountz’s study or who receives state-
funded housing in mine. They are also both examples of how the state is shaped by the geography of its own bureaucracy, where some officials experience proximate involvement with the subjects of their policies, and other officials are more distant.

Another case of resistance to crisis-mode could be found in the housing associations’ and the Disability Housing Trust’s reluctance to work under the pressure of DHS to enhance their growth more rapidly to increase the affordable housing stock available. The Disability Housing Trust, for example, is reluctant to work without a commitment to long-term funding for support arrangements before a house is built or purchased. The Department’s pressure is evident in the following account provided by Sam, a senior officer in one of the rural regions in the Department of Human Services:

The Housing Trust, to date, hasn't put a unit on the ground [in our region], despite being there for a couple of years. So they’re under some pressure. (Sam)

The housing associations’ reluctance to work in crisis mode, unlike the support agencies, does not derive from a commitment to existing clients but from a different organizational culture. These agencies, despite being non-profit, often work within a private-market ethos (McDermont 2007). Housing agencies in many ways bring more specialized expertise in housing to the disability sector and their increasing role may be also be seen as a potential move away from the crisis-mode in disability housing in Victoria.

To conclude, the prioritization of individuals under the category of ‘crisis’ in access to housing, has become a systematic feature of the service sector, over-riding other procedures and considerations. The individualization of services in some ways reinforces this process, when planning is carried out only for individuals and not for the system as a whole, as well as for ad-hoc short term solutions rather than long term planning. This often serves to turn homes into crisis-housing, and affect even those who were not in crisis in the first place.
8.3 Levels of support needs: an economic model of disability

A significant individual factor determining access to housing in Victoria is termed by professionals in the sector as ‘level of support needs’. This criterion is defined in very practical economic terms, referring to the amount of paid support hours that are deemed by DHS administrators as necessary for that individual (necessary in order to do what? To survive? To participate in the community? To make choices? This remains unclear, open to interpretations of gate-keepers to services and funding). Levels of support needs range between a requirement for constant presence of a support worker, in some cases even more than one, and a requirement of one hour of support each week or less. Assessment of the level of support needs considers an individual’s independent living skills, and their medical requirements. One of the major implications of the choice agenda in Victoria is growing disparities between people with different levels of support needs in terms of access to housing.

8.3.1 Individualization as a cost saving strategy

Certain housing models are linked to certain levels of support need. Independent living, either in public housing, housing associations or private rental, is accessible only for people with low support needs. This is determined by the policy to allocate predominantly individual packages of less than $70,000 a year, which enable only a certain amount of support hours each week for an individual living on their own. Patrick, manager in a non-government support agency criticizes this policy as a form of charity:

(DHS is) offering 70,000$. They offer these 70,000$ without any assessment of what the support needs are, they just say ‘this is the maximum that we can give you’, and they told the families that they should be grateful because other families don’t get this much. And I said I thought that when you gave money to people, and didn’t link
that to people’s support needs, and you said that they should be grateful, I thought that was called charity. And it is. (Patrick)

Patrick’s critique aims at the ethos of the modern welfare state, which has sought to distance itself from the more traditional charity-oriented practices of religious bodies and institutions. However, it is clear that there have always been limits to funding in the sector. Currently, one of those limits is that people with a higher level of support need than that which can be estimated as ‘up to $70,000’ cannot access independent living (with one exception that is described in the next section). Jay, a DHS senior officer, believes this is so because it is just not realistic for people with a more severe intellectual disability to live independently:

Someone with an IQ of 47, realistically, is never going to be able to live on their own, because there’s too much in society that they’re never going to be able to understand. They can’t even sign their name on a bank form. So independent living for that sort of person is never going to happen, we’re just going to be trying to teach them skills that they will never grasp. Most of the guys will be the 60-70 (IQ) group and I suppose that if you look at where we get our clients... the bulk of our clients are going to be up the 70 in the scale and less down the lower end. It’s just the way it works. So most of our guys probably could live independently with the right kinds of support. And I imagine, if they redistributed the CRU accommodation targeted at only the really low end of the scale, and free up the dollars for outreach support for the others to live independently or in a office of housing or something, it may work. (Jay)

Jay believes that it is not worthwhile to support people with high support need in the independent living model because they will never be able to live really independently. Jay was one of only two participants in this study who even mentioned IQ, perhaps because it is no longer considered politically correct in the sector today. It might be implied, therefore, that the move from a discourse of IQ to a discourse of ‘levels of support needs’, defined in dollars, implies perhaps a move from a ‘medical model’ of disability to an ‘economic model’ of disability. Jay’s account also reflects the policy rationale that tries to link CRUs
to people with higher levels of support needs and independent living to people with lower levels of support needs. However, in practice, people with moderate and high levels of support needs not only have no access to independent living, but also group housing or congregate care are inaccessible for them, unless they are considered crisis cases, and then only if a vacancy is available. Patrick maintains this situation is relatively new:

People with high-support needs, between moderate and high support needs, that may need 24 hours support to be able to be functional in their own lives, they have very few options, and the families they are with now have no options at all. So older parents are dying off without seeing any particular direction for their son or daughter. I think this it is really quite tragic...The only access you have if you’re medium to high support is in crisis. If you need one staff member to be your support, and you can’t spend any time on your own, because of the risks to you, or because you need to be supported to be in fact engaged with your life – there is no access to service... Access to small amounts of funding for people with very low support needs is much better now than it was ten years ago. The access to any support for people with moderate to high support needs is almost non-existent now, whereas it wasn’t non-existent ten years ago. (Patrick)

Patrick emphasizes the improvement in access to funding for people with low levels of support needs, as opposed to the decreasing access for people with medium to high levels of support needs. This highlights some of the disparities created by an agenda of choice. This policy is based on an assumption that the limited funding for support provided by the government will be complemented by informal support provided by families and communities. However, informal support is very limited in most cases, due to the social isolation of people with intellectual disabilities (Bigby 1997; Mansell and Beadle-Brown 2004). Also affordable housing in Victoria is inaccessible for people who do not receive a sufficient support package from the Department,
as can be learned from a written account provided by Joyce, manager of a housing association:

(Our association) will only house people who can live independently. If a support worker can help someone to do so, then they are not excluded from being eligible. In a number of cases, specific properties are set aside for agencies who have clients with intellectual disabilities. Where this is the case, (Our association) and the agency have entered into a ‘Housing and Support Agreement’, which requires the agency to provide ongoing support to any client they nominate to the property. (Joyce)

A person with high support needs, unless receiving a sufficiently large package of support from the Department, is not eligible for housing in most housing associations because these associations often do not trust the ongoing stability of informal support. Considering the very limited range of affordable housing available in Victoria, being denied access to housing associations means that people with an intellectual disability and a medium or high level of support needs, even if informal support networks are available to them, are less likely to find affordable housing. Often, people with higher levels of support needs have no alternative but to live with and be cared for by their parents. They will only gain access to government funded housing and support when they enter into a situation of crisis, most likely when their parents move into a nursing home or die, or if the relationship breaks down, as explained in Section 8.2.

For many people with low level of support needs, public housing and boarding houses have become almost exclusive sources of affordable housing. Public housing provides better living conditions, but waiting lists are enormous, and some applicants may wait years before they are offered a vacancy. However, when one is finally offered a public housing placement, this often means life-long security in terms of housing. For Brendan and Russell, two people with intellectual disabilities that I interviewed, access to public housing has brought a sense of stability after decades of very hectic housing careers.
Brendan was 56 years old at the time of the interview. He grew up in a large regional town in Victoria. He remembers his childhood as a series of moves between different institutions and his parents’ home. He does not remember any of these institutions favourably (‘a dump in my view’), but never asked to move out. Nevertheless, he was ‘transferred’ to Melbourne where he experienced numerous moves between various accommodation settings in different suburbs, including several boarding houses and a group home. He remembers these moves as driven by his own choices:

I: why did you move from place to place? Was that your decision or did people tell you to?
B: I moved out of (one of the places)… didn’t like the way it was being run. So I moved out into a boarding house.
I: how did you get to that boarding house?
B: through a guy who was working in the same place I was working at. And he was living there, so he got me through there. (Brendan)

Choosing new homes following friends’ advice has been a repeated theme in Brendan’s story. From the boarding house he had moved to a group home (for a ‘change of scenery basically’) and stayed there for 4 years.

I: Were you happy there (in the group home)?
B: Yes.
I: So why did you move out after 4 years?
B: Wanted to be more independent, I think. Then moved to (another place). Didn’t like the place much there, so I moved again. I had a flat, lived there for a while but the rent got a bit high (Brendan)

Despite his positive memory of the group home, after having experienced independent living, Brendan now says that he would never again be able to live in a CRU. However, his attempt to live a more independent life in private rental was undermined by the rising costs of rent in Melbourne over that decade. Again, Brendan was advised about another boarding house by a friend he had known back in the institution. After several years, in 1989
Brendan moved again, this time into a public housing unit. He has stayed there ever since. Brendan did not have to go through the waiting list, because he moved in with a partner who was offered the vacancy, and he stayed there without her after their relationship broke down. He says he is happy in that place, because it is relatively quiet and a good location close to public transport and a shopping centre. Comparing public housing to private boarding houses, Brendan says that the boarding houses that he had been to were ‘pretty good’, but were a bit more expensive than public housing. On the other hand, he is very unsatisfied with maintenance in the public housing unit in which he now lives:

I recently had to wait months to get the toilets fixed. …At the moment the rain’s pretty heavy, the water comes in through the windows in the lounge room, and the housing commission are saying it’s not their problem, and it’s a housing commission flat. ‘Cause at the moment I’ve got a whole lot of ice-cream containers on the shelves...
But apart from that it’s pretty good and pretty cheap. (Brendan)

Brendan is intensively involved in a self-advocacy organization for people with intellectual disabilities in Melbourne, and comes to work in its office 4 days a week, from 9:30 to about 4. He says it gives him a reason to go out rather than ‘staying in my flat and watching TV. I enjoy it.’ Apart from that he has a brother in Melbourne and another brother and his mother still living in the town where he grew up.

Brendan’s life course and housing career have been driven by changes in the disability sector, changes in the city’s housing market and changes in Brendan’s own capacity to be more independent and to make decisions about his own life. The deinstitutionalization movement has been the driving force behind his first move out of the institution, a move he himself played a rather passive role in. His life in the city involved many other moves between different suburbs and different kinds of accommodation, with growing confidence and ability to exercise housing choice. Brendan’s move to living in the private rental market would have been the climax of this process, however
this was undermined by the rising rent costs in the city, which meant Brendan was forced back to the public sector. This implies that for the choice agenda to be successful – even for people with very low levels of support needs – there is a need to make housing more affordable, through rent assistance, investment in public housing and other planning and policy initiatives to increase housing affordability.

Russell’s housing experience contains several similarities to that of Brendan’s. He came to Australia when he was 12 with his mother. When he was 19 he had what he terms a ‘breakdown’ and was institutionalized. He spent several years in three different institutions. Unlike Brendan, Russell remembers his first attempt to leave the institution as a decision that he himself had initiated, but describes the move out of the institution as a very difficult time in his life:

I was (in a boarding house in South Melbourne) for about 3 months, and I was starting to get a bit down and depressed, I was really angry. I don’t know why I was angry. I was sitting on Princess Bridge with my legs over the side, and I was looking to jumping in there, hoping that I’d drown, and the police came wanting to know what I was doing and everything. And I told them what I was thinking to do, so they said ‘come with us’. The next thing I know, I’m back in the institution again. About 6 months after that I applied to leave again. There was a new medication that was really wonderful, that was about the best thing that they put me on in that 5 years, and they said ‘yeah, you can go out again, but you’ve got to go where we put you’. So they put me in a special accommodation place. (Russell)

Russell spent 5 years in a CRU, and then moved to live with his mother for several years which were difficult for both of them. From then on, most of Russell’s moves from one home to another were related to his relationships with women:

Then I met someone, we moved into a flat together, I moved in with my girlfriend. That broke up, went to live in private accommodation, moved to Adelaide for about 10 years, found a girl that I fell in love
with, got married over there. That didn’t work out, so after 10 years I decided to go back to Melbourne. And I moved in with my wife now.

(Russell)

Russell’s independence has enabled him to experience independent living in the community, in private rental. However, again, the increased costs have meant that it became inaccessible for people living off their disability pensions. Russell now lives in a public housing unit provided by the Office of Housing. Their application system allows applicants to suggest three places they would like to live in, an arrangement that could theoretically allow some choice in housing. However, the waiting lists are extremely long, and waiting for years often does not guarantee a placement. Apart from the waiting lists, Russell is critical about the maintenance standards in the public housing units and the length of time it takes the Office of Housing to fix things even when it is urgent. Russell is also critical of the rent system which he considers unfair for couples living together, paying more than a single for a similar flat. Nevertheless, he finds a sense of balance between having some social connections in the neighbourhood and maintaining a level of privacy for him and his wife in their home.

Russell and Brendan’s stories attest to the great improvement in the lives of some people with low levels of support needs since deinstitutionalization, since now they can live in a home alone or with a partner. For people like Russell and Brendan, who have also become more assertive in their capacity to self-advocate, the choice agenda opens up life-changing opportunities. However, such opportunities will be lost unless an urgent decision is taken by Government to increase affordable housing in Victoria.

8.3.2 Changing support needs over time and space

A person’s ‘level of support needs’ is not fixed. People’s support needs inevitably change as they grow older or when their living contexts change. However, such changes are not addressed accurately in the documents which
label people’s level of support needs and are used by decision makers and gatekeepers to services. David, manager in a support agency, further explains:

Sometimes when the profiles are written…someone might tick a box ‘needs assistance’… so people have to fit into ticked boxes around support levels. But if you got a house, and someone comes from their home where they’ve got family around and they might be supported rather well, and when they come to a house with 4 other people, you could be left behind a little bit with what your support needs are. Once you’re in the house you find a lot more out. If this is about trying to remodel the process of how we best match, I think a lot more needs to be examined, how we group, how we categorize people, I think, again, we can’t do it on disability. That’s not politically correct. (David)

As David maintains, people are categorized according to their level of support needs, and their housing situation is very much determined by this categorization. However, as their support levels change, their housing situation is very often no longer suitable for them. David’s account reflects some of the frustrations of professionals in the sector, for whom the tasks of categorizing people and matching them up as co-residents are among the most difficult tasks they face, and yet they have not found alternative practices.

Changing support needs is also an inevitable outcome of ageing. Bigby and Fyffe (2007) argue that there is no policy in Victoria to adapt provision of support in response to increasing support needs. Particularly in CRUs, rather than adapt the service to the long-term clients’ needs, to enable them to age in place, policy documents explicitly maintain that clients are expected to move to another service (p.24).

While support needs often increase due to ageing and changing situations, promoting a more positive change to decrease an individual’s level of support needs necessitates a purposeful process of ‘skilling up’ which demands much time and resources. People with moderate levels of support
needs are seemingly able to gradually become ‘low level of support needs’, and that opens up new opportunities for them.

Diverting funding from accommodation and support services to skilling-up programs is a significant aspect of person-centred approaches. On the one hand, when successful, such programs enhance people’s capacity to be less dependent on disability services and therefore to live a more independent life. On the other hand, it appears that only a small group of people can enjoy these benefits because skilling-up is most commonly tried with younger people, who are considered more open to learn new skills, and for whom finding new housing is less urgent than it is for older people, therefore allowing more time for training.

To conclude, having a low level of support needs is highly significant in allowing better access to housing for people with intellectual disabilities, and greater choice. This is due to the individualized nature of housing which is becoming increasingly more available for people with low support needs as opposed to more restricted models based on group living. However, it should be emphasized that having a low level of support needs does not guarantee access to housing, particularly because of the lack of affordable housing in Victoria and because funded support is often insufficient even for people considered having low levels of support needs.

8.4 Compatibility: social mix in a domestic scale

The dominance of the group home model in Victoria has turned the notion of social compatibility into the third most significant category of access to housing. Unlike the other two - crisis and level of support needs - compatibility is not a category determining eligibility but one determining where and with whom those who are eligible will be placed. Assessing compatibility is an attempt to predict potential friendships or conflicts between residents sharing a house. Conflicts, in particular, have become regular routine in many group homes and congregated facilities in Victoria, an ongoing problem consuming much of the service system’s resources. With a desire to control such conflicts without abandoning the group home model altogether, DHS seeks to identify
people’s ‘compatibility’ as a major category of access to services. Such categorization is extremely difficult because it concerns not only an assessment of one individual, but also of all the other people with which they may interact. Moreover, it is often impossible to predict how people will get along with each other, even when plenty of information is known about them.

8.4.1 Assessing compatibility: ‘the science of matching human beings’

Professionals in the disability sector find the practice of matching up residents a difficult task for which there are no guiding principles, as expressed by David, manager in a non-government support agency:

I don’t think there is a recipe to get it right. Sometimes that happens. Sometimes you try to get very technical about things that you can’t measure, I mean you can’t measure if two people are going to get along, and look at society now around marriage break-ups, I mean, no one ever got into it knowing that they’re going to break up, you know. But they do, because things change, people change. Some things you can’t measure, those little things, and you say ‘that thing doesn’t worry me’, and then 5 years down the track you can’t speak to him anymore because you’re so fed up with it. So the science of matching human beings has never been created. (David)

David is concerned with the changing nature of relationships as a main difficulty in trying to assess compatibility between clients. Advocates of the choice agenda would argue that the obvious solution to the problem of assessing compatibility is to simply allow people with intellectual disabilities to choose with whom they live. However, even when such choice has been granted, people and relationships change and sometimes reach the stage of break down. David told us the stories of several group homes under his management in which residents, who did not choose each other at first, eventually do get along well. In contrast, if, for example, an applicant is given the option to choose between two or three homes with other residents she has no desire to live with – her choice does not appear any more real.
Shirley, a senior DHS officer who has been involved in the closure of a large institution in Melbourne, provides an example of a process in which DHS did seek to provide people with an intellectual disability more choice about their future co-residents. She describes the difficulty in matching up new groups of residents to move out together into group homes:

Trying to work out for a person with a disability who their individual friends are – which on the face of it sounds very simple – is actually very complex. We asked the families, and the families could sometimes tell us information about their relative’s friends, but more commonly they couldn’t do that because they didn’t see them in those circumstances. So we asked the direct care staff who were working with them in the units, and we asked the staff working with them in the day care centres – and typically you would get 5-6 different views... The advice that we got was absolutely irreconcilable, like ‘John hates Jack’ and then ‘John loves Jack’ ... if you want to do it thoroughly without a pre-perceived view – it’s actually quite difficult ... But as well as considering friendships, one of the things we had to avoid was incompatibility. Now, it’s not very sexy and it doesn’t sound politically correct in terms of choice, but the most important thing is that you don’t end up living with someone you dislike or are afraid of. So avoiding the incompatibilities became the critical thing. We were almost more focused on that. (Shirley)

Allocation of groups based on friendships was not a choice given to the residents but an administrative decision, based on consultations with families and staff. It may imply a move towards a choice based model in the sense that friendships can be seen as an indication of individual choice for people who have difficulty in expressing their choice in other ways. However, as can be learned from Shirley’s account, these assumptions are not necessarily correct for people who have spent their lives in an institutional setting in which their social life was closely controlled by others. While these difficulties were evident in the context of a closure of an institution, the difficulty to match residents is even greater in the more common context of people with disabilities living with their families and applying for a placement in shared
supported accommodation, for two main reasons. First, they do not know each other. Second, the funding that has been made available in the closure of institutions to initiate a process of consultation is not available in the regular process. Nevertheless, as Shirley maintains, while it is difficult to tell who will get along with whom in a positive sense, it is easier to foresee that some people are very likely to be ‘incompatible’ with each other, particularly when one or more of them are known to have behaviours which are considered ‘challenging’.

The notion of ‘people with challenging behaviours’ is commonly used among professionals and policy makers in Victoria’s disability sector. I use it too in this thesis, despite its problematic nature. This notion emphasizes an individuals’ behaviours rather than the inappropriate living conditions which may be their source. However, from the perspective of housing managers, as explained below, in the current context it must be acknowledged that certain people do present behaviours that raise significant challenges. Therefore, the label of ‘people with challenging behaviours’ has become a significant identity construct, and I use it as such in this chapter. People categorized as having challenging behaviours are more likely to be placed in a group home or a congregated facility because of the high levels of staffing that are required. Also, they are more likely than others to be in crisis, so they have better access to government funded accommodation in general, as explained above. However, at the same time, it appears that group-living is the least appropriate model for them. Mansell (2007), in a study conducted in the UK, argues that community-based services are often unequipped to provide services for people with challenging behaviours, resulting in break-down of placements and distress for them as well as their families, co-residents and support workers (p. 5).

8.4.2 Independent living and social compatibility

Independent living is inaccessible for people with challenging behaviours because they often require support which exceeds the funding provided by DHS. Moreover, they are less likely to be able to share a property with
another person with similar support needs due to their behaviours, unless provided sufficient support. Also, their access to affordable housing is more limited, as some housing associations will not accept a tenant with challenging behaviours, as can be learned from the following accounts of two managers in housing associations, Joyce and Harris:

We conduct an assessment interview before agreeing to house anyone and if we believe that a person’s behaviour will prevent them from being able to live independently and communally, then we will decline to house them. If a resident does begin to display challenging behaviours, then we have protocols in how to manage it – this mostly involves enacting our powers as a Landlord and applying the Residential Tenancies Act. Whenever we are required to take such action, we always refer the tenant to a support service for advocacy and assistance. (Joyce)

I: are there clients that you wouldn’t take, like people with challenging behaviours?
L: it depends, we need to make sure that they are receiving the right support, and if they are than we can sort of match them up with the right neighbours and provide a property. There’s no barrier to that. But we need some evidence of that support being there. And people do need to be able to live independently. (Harris)

Joyce and Harris both maintain that their associations require that people with challenging behaviours will receive sufficient support in order to access their housing. However, in most cases such formal support arrangements cannot be guaranteed. Also informal support to complement the limited support packages provided by DHS is more difficult to access for people with challenging behaviours, as it is more difficult for them to establish on-going relationships with others. Similarly, access to generic services is very limited for them:
Other services don’t engage very well with our clients usually if there are behavioural issues. (Emma, Department of Humans Services)

With insufficient funding, insufficient informal support and no access to generic services, independent living is not an option for people with challenging behaviours. In some exceptions, people living in group homes present behaviours which are so difficult for staff and co-residents to cope with, are provided by DHS with individualized housing and 24-hours one-on-one support. Again, such a path of access to housing is the exception rather than the norm.

8.4.3 Congregate care for people with challenging behaviours

Due to the inaccessibility of independent living for people with challenging behaviours, the only housing that is accessible for them is Shared Supported Accommodation or congregated care. People with challenging behaviours are more likely than others to be institutionalized. Institutions are not explicitly considered by DHS an accommodation option open for applicants, but in fact, as long as they exist, they are still an option of last resort for people with challenging behaviours. This ambiguity is evident in the following account provided by Sam, a senior manager in one of DHS rural regions:

S: The institutions are mainly [filled] with people who left home in a very young age, they have been there for years. We’ve almost abandoned them in the institutions. In [one institution in Victoria] there are 45 people there. Probably 25-30 of those are middle aged or older. They probably have a fairly severe intellectual disability. And there’s also a handful of younger people who have not succeeded too well in the CRU system, have been aggressive.
I: are they doing better in the institution?
S: well, they have done better. I can think of one reason why, in the institution there’s no pressure to do things. In the CRU you need to have your shower, have your breakfast, wait for the bus to pick you up at 8:30 and take you to your day placement. If you want to lie in bed feeling grumpy, you can’t do that, and that’s often when the
aggression comes. I think that in institutions there is probably a lot more space for people to run and do things like that… in the CRUs there are 5-6 people, and when they all come together to the dining area with 2 staff members, and if somebody gets a bit angry it makes a lot of pressure.

I: but are institutions considered an option when you sit in the vacancy coordination panel?
S: no. they should be closed. (Sam)

The sense of ambiguity is apparent in the contradiction between the notion that ‘they’ve done better’ in an institution, and the assertion that institutions ‘should be closed’. This ambiguity, and the linking of institutional care and challenging behaviours, was also apparent in the 1994 closures of the institutions Janefield and Kingsbury in an outer-ring suburb of Melbourne. 150 of the 250 residents of those institutions moved into new group homes. The remaining 100 residents moved into a new institution that was built even further away into the fringe of the metropolitan area – Plenty Residential Services (PRS). These residents’ challenging behaviours were explicitly stated as a reason for continuing their institutionalization (Coalition Against Segregated Living 2000).

8.4.4 People with challenging behaviours in group homes

Despite the relatively large number of people with challenging behaviours in congregate care, group housing is still the major model of housing for people in this category. Having challenging behaviours does not immediately grant priority in the waiting list for CRUs in Victoria, however, people with challenging behaviours are more likely than others to be at risk of homelessness or abuse when their relationships with carers break down, as in the following example provided by Emma, a DHS officer:

(We have) a younger client that doesn’t look like she’s got an intellectual disability, she looks quite normal. But because they have an intellectual disability they become homeless. They often have behavioural issues, so I have agencies saying like ‘don’t mention
that name, don’t make a referral, don’t talk to me about this person’. They don’t want to see her again because of her behaviour. So I’m trying to find a solution, she lives with an uncle, I suspect that he has previously sexually abused her but there’s no way I can stop it. This girl was over 18, so I can’t... like, part of it is that our service is voluntary, so I can’t tell clients what to do. I can talk to them about their decisions and try to help them get to the right decision, but ultimately it’s their choice. So she ended up living there. We have a lot of trouble with homelessness – there doesn’t seem to be enough suitable accommodation for people... So we try to do all that sort of stuff, to manage the situation until a solution becomes available. But sometimes we do not have a solution so they end up living on the street. (Emma)

Because of their particular vulnerabilities and difficulties in sustaining relationships, people with challenging behaviours often find themselves in a situation of crisis. Therefore, most people accessing shared supported accommodation in the last few years are people with challenging behaviours as well as high levels of support needs. Moreover, as people with lower levels of support needs move out of CRUs under the program of ‘exit targets’, the proportion of people with challenging behaviours in shared supported accommodation grows, as explained by David, manager in a support agency:

It’s fair to say that in the current climate of those who are a priority for shared supported accommodation, these are basically people with challenging behaviours. People with mild intellectual disability are now looked at through the (individualized) support packages. (David)

8.4.5 The dilemmas of group-housing for people with challenging behaviours
The more the group-home model becomes associated with people with challenging behaviours, the more it becomes clear that it is the least
appropriate model of housing for them. A person with challenging behaviours, by the very definition of this category, has difficulties dealing with other people, more so sharing a home with them. That person as well as their co-residents will all suffer from such an unsuitable placement, as can be learned from the following accounts:

There was that story in the paper where a parent whose son is living in a CRU is complaining about the quality of his son’s life being destroyed by another client who is too noisy and his behaviour destructive … what that highlights is institutionalization, even if there are only 4-5 people in the house, people may not be compatible and that’s a really big problem. Many of the complaints we get are similar to that and we get it from all directions. (Arthur, disability rights advocate)

Arthur’s account suggests that placing a person with challenging behaviours in a group setting is likely to turn the place into something closer to an institution than a reasonable home. Tania, manager in a support agency, provides a similar account:

One of our clients who live in one of our active-night houses, wants to move to live on his own. He hates to live with other people, and we have a lot of issues in supporting him because he can be really cranky and if the staff are busy with someone else, he will just scream. And the others just had enough. But we’ve had an assessment of him, and he has such high needs, that the department just can’t provide a package for him. It’s very difficult. (Tania)

Tania explains the difficulty in moving people with challenging behaviours out of group-homes despite their behaviour which often severely disturbs the other residents to the extent that they have ‘just had enough’. While Tania and Arthur refer to cases in which one client with challenging behaviours is placed with four or five other people who have no challenging behaviours, the account below provides an opposite case, where one person with no
challenging behaviours is placed in a house with four other people who have challenging behaviours. The consequences are just as harmful, if not worse, as explained by Natalie, manager in a support agency:

All of the people in this house don’t communicate very clearly, and have a tendency to behaviours that are difficult to deal with. We had a tragedy in this house with one young woman who was copying the behaviours of everybody in the house in order to get attention. The result was that there was great pressure on her to move out, which she did. We put a proposal to the Department of Human Services to do a short-term trial in her own flat, which we felt that if we can do that for a period of 6-12 months and work out what was going on with her, maybe in the long term it would be better for her and also cost effective. It won’t be effective in the short term and it didn’t fit in with the process that the government had available to provide money. So she went off to a more restrictive environment somewhere else, which was rather tragic I thought. (Natalie, manager in a support agency)

The accounts above raise the question of what proportion of people with challenging behaviours would be most appropriate in a group home. A similar dilemma is explained by Michael, manager in another support agency:

We have 3 residents in one of the houses which is a purpose built house, who have challenging behaviours, and can be quite aggressive...in the same house. It’s not such a great design in terms of what the research tells us. That’s why we have three residents in a six-bedroom house. And we’re supposed to have a fourth person in there, but we are not prepared to move another person with a challenging behaviour into the house, because we don’t believe it will serve anyone’s needs. And we’ll be willing to talk about taking two people into the house, and adjusting our targets with DHS, who didn’t have challenging behaviours. But we’re concerned about people being subjected to abuse, and so that has to be the right two people who will be strong enough (Michael)
Michael’s account raises extremely difficult moral dilemmas. First, whether it is fair to house two people – even if they are ‘strong enough’ – in a house with three people who may be abusive. Second, whether it is fair not to fill up the vacancies when so many people have been on the waiting list for years. Third, whether it is fair to cluster people with challenging behaviours together – which may also be an outcome of a policy allowing people to choose, if people with no challenging behaviours will choose to avoid living with them. This relates to a tension raised by Brown and Yates (Brown and Yates 2005) concerning allocation of public housing in the UK, between an attempt to achieve a balanced social distribution in different neighbourhoods and an attempt to increase choice for public housing applicants (p. 351). David, manager in another support agency, addresses these dilemmas too:

And there’s that question around whether someone with challenging behaviour should go into a house with someone without challenging behaviour. I don’t have an answer to that, I don’t have a view whether or not there should be houses with better skilled staff to deal with challenging behaviours. I sit on the fence. (David)

David’s difficulty to find answers to this dilemma attests to the lack of policy guidance and coherence. In practice, many of these decisions are left to be negotiated by DHS and support agencies on a case by case basis. While DHS controls the allocation procedure, some agencies are more inclined than others to accept people with challenging behaviours into their services. Peter, manager in a support agency, explains:

P: For some reason, particularly in (one of the metropolitan DHS regions) there is a culture here that we’ve taken on clients that present a lot of behaviours that we find to be difficult whereas in (another metropolitan region) we got a lot more long term very stable clients.
I: why is it?
P: I don’t know. We became known for providing support for people with behaviours that are found to be challenging, so when those
people come up they tend to send them to us. And we have a philosophy that is fundamental to our mission to welcome anyone. So in a sense we are much less likely to turn them away. (Peter)

Peter refers to a ‘culture’ that has developed in the relationship between his agency and DHS, which has led to the clustering of people with challenging behaviours in the agencies’ group homes. Therefore, even though there is no explicit policy to cluster people with challenging behaviours together, it often happens because of patterns of relationships between DHS and the agencies it contracts. In contrast, Perry and Felce’s (2003) study conducted in the UK found that various support agencies did not differ in terms of the characteristics of their clients. It may be inferred from this comparison that Victorian state policy is less clear and systematic about the question of people with challenging behaviours in group homes. This is a clear example of what Mountz (2003) describes as ‘the state as an everyday social construction’ (p. 626). Mountz argues that state policy – despite its appearance as a coherent narrative in policy documents – is in fact developed and enacted in a more ‘messy’ and fluid process of conflict and difference, made up of numerous quotidian bureaucratic decisions and interactions taking place in specific places. In this case, the policy of housing people with challenging behaviour is negotiated between DHS and non-government support agencies. Such negotiation takes place in specific geographic contexts, mediated by the construct of DHS regions, the localized relationships between agencies and individuals within them, and the unique way by which individuals and agencies interpret and respond to similar dilemmas.

Linking group-housing to people with challenging behaviours does not benefit them, and also takes this housing option away from people who have no challenging behaviours. In the current situation, it is unfair to place anyone in a group home with other people with challenging behaviours.

8.4.6 Overlooked differences in the management of access

The emphasis put on challenging behaviours as the main issue related to compatibility, has meant that other forms of difference among people with
intellectual disabilities are often disregarded in the management of access to housing. The following account is taken from an interview conducted with Marg, a 25 year old woman from a regional town in Victoria, who is now living in a CRU with four men. Marg expresses a deep sense of unhappiness with the fact she is the only woman in the house:

Now I’m in a CRU and I don’t like it. A CRU with just boys which is a bit of a pain … only boys … They do a lot of grumpiness. I can’t really stand it. (Marg)

Marg does not see life in the CRU as her own choice, but a decision made by her parents:

I: Did you want to move into this CRU?
M: No.
I: So why did it happen that you moved in there?
M: Mum and dad put me in there …This was a long time ago I think. I Moved in with all these boys. Just boys. (Marg)

If she had choice, Marg would have preferred living with her parents:

I: So when you imagine the place where you would like to live, how would it be?
M: With my mum and dad.
I: Why do you think you can’t live with mum and dad?
M: They say they’re working too much. I wish I was with my brother and sister – I miss them.
I: What about living on your own?
M: I have to have lots of people with me because of my seizures.
(Marg)

While Marg does not see living on her own or with her parents as realistic options for her, she asks to at least have some choice of flat mates:

I: How would you imagine a better place for you to live in – like the CRU, or with just one or two other girls?
M: Like my CRU, but not all boys and only one girl. Boys and girls.
I: Is there anyone particular of your friends you prefer living with?
M: I don't know. I don’t have that many.
I: Do you think it would happen that you would actually move to a new place?
M: I think I’m stuck. (Marg)

Marg emphasizes the importance of gender as a form of difference between the other residents and herself. This difference was disregarded by DHS when assessing her ‘compatibility’ with the other residents. Because Marg and the other residents were not considered having challenging behaviours, they were almost automatically considered compatible.

The theoretical notion of intersectionality may be useful to analyse how gender and disability come into play in Marg’s story. As discussed by Valentine (2007), attempts to theorize how different categories of identity interlock often involved the use of metaphors from geometry and mathematics. A disabled black woman, for example, would be described as experiencing a *triple* disadvantage, where each of these identity categories adds to the other. Such ‘geometries of oppression’ are problematic because they involve an essentialist understanding of identity categories as separate and fixed differences. In contrast, the concept of intersectionality is based on an understanding of identity as something more fluid, where various differences are constantly ‘made and unmade, claimed and rejected’ (p. 14), and where identifications and disidentifications are ‘simultaneously experienced by subjects in specific spatial and temporal moments through the course of everyday lives’ (p. 18). Geographers may contribute to the theoretical understanding of intersectionality by shedding light on the significance of space in this process.

Following this understanding, the intersection of Marg’s gender and disability should not be seen as a fixed and essential state of ‘double disadvantage’, but rather examined as a process occurring in particular places and moments. It occurs in particular ways in her home and in other ways in other places. Moreover, the reason that Marg was required to share a home with four men in the first place may be attributed to the fact that she lives in a
rural town with far fewer CRUs available compared to Melbourne. The extent to which compatibility considerations could be applied in the management of access to housing is thus more limited, and such differences which are not directly related to disability are more likely to be overlooked.

The role of Marg's gender in her relationships with the four men in the CRU should also be understood in the context of a cultural perception of sexuality among people with disabilities as a 'threat to the gene pool' (Meekosha and Dowse 1997: 56). The very potential of sexual relationships between male and female residents in a group home is a sensitive issue, and in some cases a cause for conflict between clients, carers and parents (Brown 1994). Marg does not suggest her difficulties with the other residents are related to sexual issues - in fact, she calls them 'boys' despite the fact they are all adults, thus in some ways neutralizing sexuality in her discourse. However, it is clear that all interactions between Marg and the other residents in the CRU are experienced under close supervision of support workers for whom the potential of sexual relationships among the residents is a very sensitive issue.

8.4.7 Strategies to reduce conflicts: internal moves, domestic design and individualized housing models

The two main strategies used by support agencies to minimize the implications of social incompatibility in group homes are internal moves and redesign of houses. Several support agencies initiate a practice of internal moves of existing clients to reconfigure the groups in their homes in ways that will reduce conflict among co-residents. This practice in many ways bypasses the formal procedure controlled by DHS of allocation placements through a 'Vacancy Coordination' process. By practicing internal moves and swapping placements, it is often easier for a support agency to allow its clients more choice about where they move because of the smaller scales in which these moves are practiced. Also, crisis, which is the dominant criterion considered by the Vacancy Coordination panel led by the government, is not as
significant in internal moves, since all those involved already have a placement.

Beth, manager in a large support agency operating in Melbourne tells of a project that involved a reconfiguration of placements of residents in various group homes operated by the agency. Residents in one house who ‘weren’t happy’, because of incompatibilities between them, have all been moved to other group homes also managed by the same agency, and some reconfigurations have been made in those houses as well. The clients have been asked to make a list of people they would and would not like to live with, and that list was used to decide who will be placed where. This has increased their housing choice to some extent:

I: Did they have choice of which house they want to go to?
B: More so of who they would like to live with.
I: So everyone made a list?
B: Yes. Who they want to live with. Their friends, who they like, who they didn’t like. And for most of them we were able to kind of match, but there were a couple who were not... there are constraints around the number of vacancies and the number of moves that you can do internally, and there were a couple of matches that we weren’t sure about but they were fine. We didn’t think these would be the greatest matches and it took a while for people to settle down, but it went really well. There was only one client who... we needed to remove – he showed us he was unhappy... So when we moved him that’s all settled down. (Beth)

The practice of internal moves opens up a very important opportunity for choice even within an inflexible system such as that of shared supported accommodation: the choice to move out of an unwanted placement. At the same time, this in many ways compromises the more equal and transparent procedure that is centralized by DHS, that considers all applicants for the vacancy, and not the clients of only one organization, as argued by Jane, a senior DHS officer:
What happened most in the past is that organizations sometimes managed their own vacancies – so a vacancy came up in a house, and they would have pulled in someone they were supporting in another facility, and they wouldn’t necessarily consult with the Region about the vacancy being available, for us to consider other individuals. That’s probably the biggest shift, because now we don’t go down that road, we basically say … we’ll have a look at everyone and we’ll identify the most urgent people for your vacancy, and make a decision. … We drive it now…with my involvement with the two ways of doing that, I think I like this way, not because we control it, but I like the principle of the equity, the transparency and the decision making process is a whole lot better now (Jane)

Jane’s account makes clear that the Government and the agencies it funds struggle over the control of allocation of placements. The government sees its role as promoting democratic values such as transparency and equity in allocation. The agencies, in turn, claim a more personalized and less bureaucratic approach which could therefore allow more choice, however only for a limited group of people. Perhaps a practice in which such reconfigurations are made not only internally within a single agency, but involving the cooperation of several organizations may help overcome the current limitations of internal moves, and allow more choice as well as a more inclusive and transparent procedure of access to housing. However, this is currently limited by the relationship between agencies competing over very limited resources, as explained by Beth:

I: Did you try to make internal moves in cooperation with other NGOs?
B: We haven’t explored that in this point in time. And I’m sure a lot of NGOs haven’t explored that. There was talk about clients that we can’t support, to work in liaison with other agencies. But I would say that the biggest problem there is – because resources are so tight, you have to be very careful about who you move and who came into your services. Because there could be impacts for you as well. You have to have alike organizations, people having the same goals in
mind rather than somebody just trying to move somebody on who
was giving them problems. It has to be for the right reasons, not to
move somebody just because they had problems (Beth)

Beth’s account suggests that a very high level of cooperation and trust should
exist between agencies to allow such a process that would allow clients more
choice of where and with whom they live, however a number of barriers to
cross-organizational cooperation – referred to by Fyffe (2007) as competency,
attitudinal and systemic barriers - mean that currently such relationships are
not in place. From a broader theoretical and historical perspective, these
barriers to cross-organizational collaboration are the result of the
decentralization of the welfare state.

Moreover, both internal moves initiated by support agencies and
compatibility considerations made by DHS when allocating a new vacancy,
are limited in the extent to which they can reduce conflicts among residents
because of the large proportion of people with challenging behaviours in
group homes. This often leaves vacancies in group homes unfilled, as argued
by several managers in support agencies, and by Rita, a disability rights
advocate:

The vacancy rate in CRUs is huge … if you've got an
accommodation sector that is so unusable that you've got vacancies
that you can't fill, because you know that if you move somebody else
in there you're just going to be creating new problems, so what's the
point in shuffling the deck chairs on the Titanic of the list when what
they really need to be doing is something major about this stock and
redeveloping it into half-houses, permanent 2-bedroom units instead
of 4-bedroom houses, whatever is necessary to make the stock
usable so that people could actually move into these place. (Rita)

Rita emphasizes the relationship between the group home model and the
difficulty of creating appropriate matches between residents. For her, internal
moves are like ‘shuffling the deck chairs on the Titanic’ and the only useful
strategy to reduce conflicts is to redevelop the housing stock itself rather than
relocate people living in it. Some attempts to redesign group homes to reduce
conflict, as well as the limitations to such remodelling, have been discussed in the previous chapter.

Another strategy, which is rarely practiced due to perceived costs, is to provide people with challenging behaviours with individualized accommodation on their own. The following story is an account of one of the rare attempts to try this strategy. Naomi was referred to me by Hannah and Doreen, a planner and the manager in an independent living program. As discussed in Chapter Three, Hannah asked to take part in the interview and was very much involved in the conversation when she thought Naomi was having difficulty answering a question on her own. Knowing Naomi’s story closely, Hannah also prompted her to talk about events in her life that I could not have known and asked about. Naomi, a 51 year old woman with an intellectual disability, told me of her own behaviours which are often violent towards other people. As a child Naomi used to live in an institution for children run by a religious organization. When she was 15 she moved out of that institution. Naomi remembers a meeting with a doctor as the event where it was decided that she would leave the place:

I: Why did you move out of (the institution)?
N: I went to see the doctor who asked me.
I: What did the doctor ask you?
N: You can’t have forever. (Naomi)

Naomi remembers the doctor telling (‘asking’) her that she can’t stay in that place forever. Her impression that she had to move out because ‘you can’t have forever’ reflects perhaps also her fears today of losing her current accommodation which she is happy with. This fear is based on a long unstable housing career, in which she has often been moved from place to place with very little control.

After leaving the institution, Naomi moved back to live with her mother, but their relationship broke down shortly after:

I: Do you remember why you moved out of your mum’s house?
N: Because I’ve been hitting her, and hurt myself.
I: Did you want to move out?
N: Yes. (Naomi)

After moving out of her mother’s place, for many years Naomi moved between many different accommodation settings, some of them respite houses which are not designed to provide long-term accommodation. The place where she spent the longest length of time – 8 years – was a CRU also staffed by the same agency for which Hannah works. Despite the relative stability, Naomi tells of her difficulty living in that house:

N: Because the street is noisy, Georgie screaming and Nick.
Hannah: Why didn’t you want to live at J Street anymore.
N: I wanted to move out.
H: Why did you move (out)?
N: Because I was beating people.
H: And you weren’t happy?
N: No.
H: But what was it about J Street that you didn’t love living there anymore?
N: I want to live by me own.
H: Did you like the people you lived with?
N: No, I want to stay where I am. (Naomi)

Naomi is aware of her own challenging behaviours and how these shape her experience of moving from place to place (‘because I was beating people’). Perhaps due to her experience of being moved out of places because of her behaviours, she feels that her last move was also for the same reason, and not driven by her own choice. Her fear that the interview was part of a plan to move her back into the house in J Street illustrates her sense of having very little control over her life. However, she is clear about what she wants (‘I want to live on my own’, ‘I want to stay where I am’), and indeed – after many years of wandering between different types of unsuitable accommodation, she now lives in a place she does not want to leave.

I: What is good about living on your own?
N: Because it’s quiet.
I: are you happy to stay there forever?
N: yes. (Naomi)

Living in a quiet place on her own, as opposed to the group home with the shouting and screaming she described above, is the most significant change for Naomi. However, she also expresses some of the difficulties of living alone:

I: are you happy at your new house?
N: I’m scared of dying.
H: at your new house?
N: yes, if I watch the news it upsets me.
H: but it’s not because you’re scared of living in your new house?
N: I watch it sometimes. (Naomi)

Naomi’s fear of dying is not directly related to her new house, but her responses might suggest that watching the news on her own in her new flat is difficult for her.

She goes twice a week to a day program, once in a taxi and once in a ‘Travel Training’ program in which she learns to use public transport with a personal guide. Her brother in law and his wife are the closest relatives in her social network, and she has some friends in the day program and in a ‘community kitchen’ – another program organized by Hannah and Doreen to strengthen the social networks of people living independently. Naomi’s support workers take her out to dinner sometimes, and help her with shopping. Naomi cooks for herself, a very diverse menu including ‘beef pie, white rice, chowder, fish, sausage’.

Naomi’s hectic housing career has been driven by her challenging behaviours, on the one hand, and the ongoing insistence on housing her in group settings which are clearly inappropriate, on the other. Her story reflects the absurdity of this practice and its grievances. Naomi was able to access individualized housing thanks to the availability of individualized funding and individualized planning mechanisms, as well as her relatively low level of
support needs (which was not as low when she lived with other people as it is when living independently). She spent decades in inappropriate housing because of being considered unable to live independently, and because there were no structural mechanism to enable her to do so. Only lately she has finally reached her own place, a real home and a safe haven of a ‘quiet’ life where her obvious difficulty living with other people is not constantly tested.

To conclude, the notion of ‘compatibility’ provides insight into a different aspect of the tension between individuality and community. Here, the community in question is not the broad ‘community’ commonly referred to, but one that exists within the house, a smaller and more intimate community of people with disabilities and their supporting staff. The notion of social compatibility refers to the relationships within this community. Social compatibility is perhaps third in significance, after crisis and level of support needs, as a criterion of access to housing in the Victorian disability service system. In particular, the category of ‘challenging behaviours’ has been closely linked with the models of congregate care and group homes, in effect reinforcing the disadvantages involved in such categorization, by providing inappropriate accommodation that only increase the very behaviours considered challenging. This affects not only people within this category, but also people who are not considered to have challenging behaviours, and for whom access to group homes has declined significantly. It serves to isolate and reproduce each of the different categories.

8.5 Categorization and prioritization: conclusions

To understand how allocation priorities affect the housing landscape, one must not identify people with intellectual disabilities as a single homogenous social group, but rather consider more nuanced processes of differentiation among them. A strong correlation exists between the particular logic under which allocations are prioritized (a logic of needs, social mix or choice), the sub-groupings of people with intellectual disabilities into different identity categories and their location in particular places within the housing landscape. A focus on choice tends to bias towards prioritization of people needing low
levels of support, unlike a needs-based approach which is biased towards people requiring with higher levels of support. While a mix-centred approach should have led to more individualized approaches for people considered as having challenging behaviours, a crisis-driven approach leads to ad-hoc placements of such people in group homes. However, many of these groupings and biases are contextual rather than inherent, and result from a lack of resources and inappropriate planning rather than intrinsic contradictions between choice, mix and needs.

It is only humane to prioritize people experiencing crisis in access to housing and supports. Such a policy also meets the principle of prioritizing those who are most vulnerable and disadvantaged. The main challenge, however, is to avoid becoming a crisis-driven system as a result, as has occurred in Victoria. One strategy to meet this challenge may be to separate crisis-housing from long-term housing. This strategy should be carefully considered, bringing into discussion a variety of questions regarding the kinds of crisis housing that should be established and their proportion within the housing system as a whole. Such a consideration must acknowledge the risks entailed in labeling people as crisis-cases, and in labeling dwellings as crisis-housing, as these may easily turn from short-term solutions to on-going new forms of institutionalization.

Despite the problems involved with categorizations based on needs (as discussed by Fraser 1989), so far no alternative has been devised with which to measure the kinds and volumes of support that should be funded by the state for individuals with different kinds of abilities, with different desires and in different contexts. The notion of ‘level of support needs’ is the Victorian way to address this challenge, and appears to be less stigmatizing than the use of medical diagnosis, and more flexible in allowing a diversity of supports, constrained only by their costs. This form of categorization, as used in Victoria, puts more weight on economic value than medical or other social values. The problem, in my view, is not the use of this notion itself, as much as the very limited resources attached to it, and the lack of policy or regulatory commitment to provide sufficient levels of support to meet the needs that are assessed, particularly when these are extensive.
Unlike need, the notion of compatibility does not place emphasis on an individual’s characteristics but on relationships and conflict. This way, rather than labeling individuals, compatibility assessments could potentially be used to tackle more systematic problems related to group housing for people with intellectual disabilities. However, the category of compatibility should be broadened to embrace a diversity of identities, beyond that of ‘people with challenging behaviours’ and not only as a means to reduce conflict. People may be given a choice to live with other women or with other men, or with other people their own age or ethnic or cultural affiliation, or with one partner only, or on their own. Obviously, this entails supplying more housing and support services than currently available in the disability sector, but it also means a different management of access to those that already exist.

Some of the most significant problems evident in the disability services sector in Victoria are the result of an improper balance between needs, mix and choice. Too much weight given to urgency of need, with little respect for compatibility and choice, has created the vicious cycle of a crisis-driven services system. For a better balance to be created between needs, mix and choice – each of these notions should be understood in a new way. The meaning of need should be understood with concern for choice – the question of ‘what a person needs in order to survive’ should become a question of ‘what a person needs in order to achieve their choices’. As Wilmot (2007: pp. 64-65) argues, the outcomes of welfare services may only be assessed in terms of particular values and choices which differ from one person to another. However, the meaning of choice must also be understood differently, with concern for compatibility – no longer as a matter of what one person’s choice is, but as a question of managing multiple choices of various people sharing spaces and resources; and, finally, the meaning of compatibility is to be understood with relation to need – that a person’s compatibility in any setting will very much determine and be determined by their level and kind of needs.

Following this understanding, I would like to conclude this chapter by offering an alternative approach to allocation of housing and supports in Victoria, which balances needs, social mix and choice. This approach includes two main principles: first, that the choices of those who are least able to
access housing and support otherwise should be prioritized; second, that choices which may reduce conflict in the system as a whole, and thus positively affect more than one individual, should be prioritized. These two principles may perhaps be related to quite different ethical strands – the first egalitarian and the latter utilitarian - but may be reconcilable in this particular context, where prioritizing those most vulnerable also achieves greatest utility for a greater number of people, as explained below.

In current practice in Victoria the choices that are prioritized are those that seem least difficult to implement. People with lower support needs are more likely to be granted individualized support packages because these are smaller and cheaper. In theory, this practice not only allows them to live a more independent life, but also liberates resources to be invested in those with greater need (Felce et al. 2008: 99). However, when more difficult challenges are not dealt with, they do not disappear but rather grow bigger and impinge on the whole system. Such is the process described in this chapter, wherein mismatches in group homes increase conflicts, reducing the quality of life for so many people with intellectual disabilities and limiting their choice by creating vacancies that cannot be filled. Although it might seem too expensive to provide support for all individuals considered as having challenging behaviours in more individualized models of accommodation of their choice, in effect this would open up many more opportunities of choice for a far greater number of people by reducing conflict across the whole system. New vacancies would be created, and choice-based internal moves would be made possible for those who already have placements but are unhappy with them. Nevertheless, this should not be used as a way to socially isolate people with challenging behaviours. As Mansell (2007) argues, it is not ‘simply a matter of switching the service model and expecting the problem to disappear’ (p. 8). A highly specialized and intensive support program should be provided to avoid negative implications and risks for people with challenging behaviours.
Chapter Nine
Where place and choice meet

This thesis has examined three seemingly contradictory claims that could be made about the choice agenda in disability policy: first, that it is a logical progression of the disability rights movement after deinstitutionalization; second, that it is a neoliberal strategy taken by the state to withdraw some of its welfare responsibilities; and, third, that the choice agenda is no more than empty rhetoric with few practical implications. Analysis suggests that each of these propositions is valid to some extent.

As for the third proposition, much of the evidence presented in this thesis shows that the notion of choice plays a significant role in the rhetoric of policy documents and in the discourse of professionals, activists and scholars in the disability sector in Victoria. Beyond rhetoric, analysis shows that in practice the most significant implication of this emphasis on choice has been the application of individualized funding schemes, which are still very limited in their scope. Practices such as Person-Centred Planning and the provision of housing by non-government agencies are also tied with the choice agenda. Nevertheless, the scope of these practices and their proportion within the overall activity taking place in the disability sector is still limited. The choice agenda can thus be seen as a restricted policy experiment still in its early stages. However, even as an experiment, it is one that has life-changing implications for many people. Moreover, because the rhetoric of choice has captured the minds and hearts of so many people in the disability sector – policy makers, professionals, activists and scholars - it seems to be only a matter of time until the choice agenda is further extended in practice. Therefore, precisely because the practical implications of the choice agenda are still minor and experimental, it is timely and worthwhile to examine them closely.

The argument that the choice agenda is a logical progression to deinstitutionalization driven by the disability rights movement is also valid to some extent. It could be argued that deinstitutionalization had exhausted much of its potential to generate change when it reached a point at which the
unlikely coalitions that had once driven it were no longer viable. This movement has created new ‘haves’ and ‘have nots’ among people with intellectual disabilities and gaps that have become too wide to bridge within its framework. In Victoria, as Chapter Eight shows, these gaps appear between those who are considered as having a ‘high level of support needs’ and a ‘low level of support needs’; between those considered having challenging behaviours and those living with them under the same roof; between those who are considered crisis-cases and those who are not; those who are already clients of State-funded housing and support – as limited and inappropriate as these sometimes are – and those who are not yet so. Such gaps also appear between people with intellectual disabilities and other citizens who pay the taxes on which most disability supports rely, and who compose the communities that will either include or exclude them. Any attempt to reignite a movement of change in the disability sector should divert from the path which has created such gaps. This might mean abandoning the discourse of moral superiority that has often characterized deinstitutionalization campaigns (Gleeson and Kearns 2001), in favour of a discourse acknowledging differences and using choice as a means to allow them without discrimination.

However, the proposition that the choice agenda is a neoliberal strategy also finds much support in this study. First, the rhetoric of the choice agenda is highly characteristic of neoliberalism (Larner 2003: 511). Second, some of the practices of the choice agenda are typical of neoliberalization projects. Ironically, neoliberalism appears in its most explicit and familiar form in an issue which is almost peripheral to the subject of analysis. Section 5.2.3 discusses the decline in support workers’ employment conditions due to the individualization of services. Support workers’ rights are not the subject of this study, and yet I find that this seemingly marginal comment tells more about the tight relationship between the choice agenda and neoliberalism than any other piece of analysis in this thesis. Other examples of the close links between the choice agenda and neoliberalism are found in various discussions in the thesis about the quasi-market logic of individualized funding and the use of non-government service providers. Growing emphasis on economic efficiency – at the expense of equity principles – are also evident in
the way individualized funding is implemented in Victoria. The funding packages distributed are significantly smaller than the average expenditure per individual in group-homes (Section 8.3.1), and are often used to reduce expenditure on people who are perceived as requiring lower levels of support.

These last two propositions about the choice agenda – that it is a neoliberal strategy and that it is an expansion of the disability rights movement - are not necessarily as contradictory as they may initially appear. While the disability rights movement is considered a left-wing grassroots movement, and neoliberalism is considered a right-wing governance approach. Indeed, these two movements are very different in their values, concerns and aspirations. At the same time, it should be acknowledged that both movements, at some points, have joined forces to achieve shared goals, such as the closure of institutions during deinstitutionalization. From a disability rights perspective, the state’s control over the lives of people with disabilities, with its total institutions and the ‘medical model’ approach, is all too often oppressive. Therefore, the disability rights movement’s actions are often aimed at reducing this level of control. From a very different point of departure, mainly for economic reasons and a strong conviction in the superiority of the free-market over state bureaucracy, neoliberalism as a movement has also aimed at diminishing the role of the state in welfare provision.

Thus, although the neoliberal and the disability-rights interpretations of choice are very different, both ‘sides’ (a contested dichotomy that will be further discussed below) adopted it with much enthusiasm. As many discussions in this thesis demonstrate, like any other abstract word, different people can use the notion of ‘choice’ with very different meanings in their minds. Why ‘choice’, then, of all words? As various commentators suggest, choice is a very appealing value in contemporary culture and therefore a particularly convincing rhetoric (Clarke and Newman 1997: 50; Harvey 2005: 5). However, in my understanding choice is not ‘just another word’ as Harvey asserts. There is something that is particular to the logic of choice that allows people to ‘agree to disagree’, making it an appealing compromise in a situation of conflict and difference. For example, rather than continue the decades-long debate on which housing model is most appropriate, the logic of choice offers a compromise that may potentially appeal to all – that a diversity
of models should exist side by side to serve various preferences and needs (Chapter Seven). Furthermore, particularly in the context of housing for people with intellectual disabilities, choice is not just a word: lack of choice is a major symptom as well as a major cause of their disadvantage, as evident in the cases of people who have no choice of location in housing (various examples in Chapter Five and Six), and people who have no choice of their co-residents in group-homes (various examples in Chapter Eight).

The analysis presented in this thesis disturbs the dichotomised juxtaposition of ‘the disability rights movement’ versus ‘neoliberalism’. While these are helpful as analytical constructs to describe overarching social, economic and political processes, they are more difficult to apply within the everyday localized geographies of the disability sector in Victoria. Policy makers, professionals, activists, families and people with intellectual disabilities that have participated in this study cannot be easily divided into these two simplified categories. The coalitions and divisions among them are far more fluid and contextual, their discourses and ideologies far less coherent. This is where the spatial analysis that was applied in this study has been particularly useful – in seizing specific moments where such coalitions and divisions occur around particular places. Moreover, highlighting the role of place in shaping such coalitions and divisions provided a useful critical perspective to address the individualism implied by choice.

Coalitions and divisions in the disability sector form around specific questions such as the location of housing and whether clusters are appropriate (Chapter Five and Six), development of particular models of housing (Chapter Seven) and allocation priorities (Chapter Eight). Ideally, ‘coalitions of choice’ could have been formed to bridge conflicts and differences, with an agreement that each individual would receive housing that meets their personal preferences. However, a major geographic barrier to the formation of such coalitions is the long term implications involved with placing a group home or a congregate care facility on the ground and accommodating people in it. Built facilities become ‘strategic’ sites (De Certeau 1984), creating path dependencies from which it is difficult to divert, even decades later. As discussed in Chapter Four, the lasting effects of institutions that were closed
more than a decade ago may still be found in the location of group homes today.

An acknowledgement of the strategic implications of housing makes it more difficult to achieve consensus and to achieve choice. It is no longer just about the individual making a choice - allowing an individual to choose to live in an institution means creating a geography which will inevitably have future implications for many other people who may have chosen otherwise. As argued by Bigby (2004b), ‘cluster housing… might reflect the choice of a few now, but will live behind a legacy of bricks and mortar that will restrict choice and segregate people with intellectual disability for decades to come’ (p. 204).

The notion that people with intellectual disabilities should have the right to choose to live in an institution or cluster housing, should these options better meet their personal preferences as individuals, relies on the premise that what matters is the subjective wellbeing of an individual and not any objective criteria by which to compare different housing models (Cummins and Lau 2004: 200). This premise may be contested by an understanding that place making - in this case, the construction of housing – is not just a matter of the subjective wellbeing of an individual as suggested by Cummins and Lau. Nor is it a matter that could be resolved by seemingly objective criteria as implied by Emerson (2004b). Place is a locus of interaction and negotiation between multiple subjectivities. Attending to one individual’s subjective wellbeing will inevitably affect that of others. This, perhaps, is where the ‘strategic’ nature of place clashes with the individuality implied by choice.

Coalitions and divisions in the sector are also mediated by the geography of state administration. Mountz (2003) argues that state policy is developed in a ‘messy’ process made up of numerous quotidian bureaucratic decisions mediated by relationships and interactions between state officials and others in specific places. This thesis has shown various examples in which housing policy is negotiated between various actors within the state and beyond it. It has also illustrated the role of place in mediating such interactions. In particular, the regional divisions of state bureaucracy affect the formation of coalitions and division within the sector and contribute to various forms of uneven development (see for example discussions in Sections 5.2.1, 8.2.5 and 8.4.5).
Spatial analysis of uneven development, as presented in Chapter Four, is useful as critical evidence to challenge the logic of choice. Geographers have critiqued people-centred policy approaches for failing to acknowledge disparities between places and the bias in policy outcomes they create (Stimson et al. 2003). The dispersal of disability housing could be seen as an important step in fixing some of these disparities, but is insufficient on its own. In a study conducted by Metzel about the location of group homes in Maryland, US, she concludes that the ‘dispersal of services was well intended, but has resulted in social poverty’ (Metzel 2005: 101). Similarly, previous chapters have shown that the decentralization of housing for people with intellectual disabilities in Victoria is not just random dispersal but rather follows very particular patterns creating new kinds of locational disparities which - coupled with overall deficiency in resources for people with intellectual disabilities everywhere - pre-empt much of the rationale behind the choice agenda. Such disparities appear in Victoria within regions - between centre and periphery, low-income and high-income locations. Disparities also appear across regions, depending very much on their histories of State-run institutions. This, along with the systematic mismatching between the location of informal support networks and the location of housing vacancies, means that housing choice is constrained by the geographic location of housing opportunities to the extent that a formal recognition of the right to choose will change very little in outcomes.

Any agenda to increase choice in housing should maintain a balance between place-centred and people-centred approaches. It should be place-centred in the sense that it acknowledges spatial disparities and the histories which have created them, and tries to fix these. The notion that people are always able to ‘choose with their feet’ and move in search of opportunity, a notion that Jordan (2006) relates to neoliberal philosophies, is too simplistic. Spatial disparities and, again, lack of services and housing everywhere – could not be fixed by individualizing access to funding but rather by placing houses on the ground where they are most needed, houses which cater particularly for people with disabilities.

Moreover, as argued by Mansell (2007), failing to develop local services where needed leads to dependency on out-of-area placements which
are eventually more expensive. These ‘hidden costs’, which are not often considered by decision makers when planning the service system, point to the necessity of place-centred planning. At the same time, this should be balanced with a people-centred approach, paying attention to the preferences of individuals, and considering a greater diversity of differences among them than now acknowledged, some of which are not necessarily related to disability (as discussed in Section 8.4.6).

It is clear that the extent to which each individual’s preferences may be met is very limited. It is thus easy to argue against the choice agenda that it is not realistic, and that encouraging people to make choices will only bring about disappointment and frustration. Moreover, the philosophical justification behind the choice agenda is that people place different value on the services provided to them by the state, and therefore one size does not fit all. However, for the very same reason, applying the principle of equity in a choice-based system is very difficult, as one person’s values may be very different (and more expensive) than another’s (Wilmot 2007: 68).

Nevertheless, people with intellectual disabilities I have interviewed for this study have all expressed very modest preferences in housing. Despite living in accommodation settings which may be considered as constituting the bottom end of the housing market, many of them did not extend a desire to move into better and more expensive housing. Those who did express a preference to move out of their current accommodation often asked for alternatives which were not more expensive, such as moving from one group home to another with a different configuration of residents - but even this was not an option for them. Even though these participants cannot be considered a representative sample, their modest but unfulfilled desires suggest that unreasonable choices expressed by individuals are not the main barrier to the implementation of the choice agenda. However, this modesty may be the product of a sense of powerlessness and a lack of experience and knowledge that better alternatives even exist (Bigby 2007: 70). As observed by Clarke (2006), in a study conducted in the UK, social care providers make significant efforts ‘trying to construct ‘responsible consumers’ who would have ‘reasonable’ expectations of what services could provide’ (p. 436). Such providers are also concerned that a focus on choice would in fact inflate
consumers’ expectations. In this sense, the choice agenda is made possible by the very oppression which it supposedly sets out to counter, because such oppression constructs subjectivities whose choices are manageable.

Nevertheless, there are ways to define the extent and range of choice, and extend it. This means, in my view, a better way of conceptualizing the conditions essential for people with intellectual disabilities to lead a more fulfilling life in terms of choice. Choice is but one of the conditions that are essential for people with intellectual disabilities to lead a more fulfilling life, and not necessarily first among them. This thesis has attempted to go some way in linking the question of choice with other concerns such as quality of life, community inclusion, social mix and needs. This not only allows a more careful conceptualization of choice, but also a more careful conceptualization of each of those other issues, through the lens of choice.

First, although this may seem almost too obvious to mention, housing choice should be understood in quantitative terms, as a question of having more than one option to choose from for each individual (Stancliffe 2001). The first condition for housing choice to exist is that supply matches or exceeds demand. Second, in spatial terms, the first condition should be sought in different scales and places (it is not enough that housing supply is sufficient in one region when it is short in another region or across the state as a whole). It is possible to frame a scale for choice - a commitment for housing within a certain distance from a person’s first preference. Such a scale could be devised with consideration for the spatial experiences of people with intellectual disabilities, and not just for administrative constructs (such as DHS regions in Victoria). Third, choice should be conceptualized as a question of an individual’s control over the decision making process. This aspect of choice may be significantly improved through practices such as person-centred planning (Holburn and Vietze 2002) as well as strengthening independent advocacy for people with intellectual disabilities. Fourth, choice is also a matter of quality. Stancliffe (2001: 92) suggests that choice is an uncoerced selection between two or more options. In my view, it is not only a question of the number of options – it is also about their quality. Choice between two or more undesirable placements is not really a choice.
models should exist in order to allow choice, but they must all meet similar quality standards for this choice to be meaningful.

Choice is also about being able to choose where not to live (see discussions in Chapter Six on exclusion by confinement as opposed to exclusion by rejection). At the very least, every person with an intellectual disability should be given a choice to move out of a placement in which they are unhappy. This may solve many of the problems discussed in this thesis, such as mismatches and disputes between residents in group homes, and does not necessarily demand excessive extra resources – in fact it may be more economically efficient. Successful practices of internal moves that have already taken place in several organizations in Victoria testify that this kind of right to choice is feasible. What this affirms is the proposition made in Chapter Two that choice is not merely a question of redistribution. Yes, redistribution of resources is an essential condition in order to offer housing choice for people with intellectual disabilities. But this alone is insufficient. Other institutional barriers as well as various forms of community exclusion must also be addressed in creative ways.

Indeed, some choices are more difficult to prioritize. Can residents in shared supported accommodation be given a choice, as a group, not to accept a certain applicant who wishes to move in? Would that be any different from other forms of exclusion enacted towards people with disabilities in the wider community? This dilemma touches the very essence of the question of what a home is. Unlike a suburban community opposing the formation of a new group home in its public sphere, a group of residents sharing a house are sometimes reluctant to share their most private living spaces with someone who may directly disrupt their daily lives there. Therefore, in my view, residents in a group home should be allowed to make such a choice about who joins their home. At the same time, the vulnerability of the person that is rejected must be acknowledged, and the government’s responsibility to find an alternative placement for them must be strictly enforced. Allowing groups of residents the choice not to accept a person into their home must be accompanied by a policy which promotes individualized housing for people who are not likely to find a place in congregated facilities under such a scheme - mainly people considered as having challenging behaviours.
Similarly, certain rights to choice of stakeholders other than people with intellectual disabilities themselves – mainly family members, support workers, neighbours and landlords – are very difficult to define and prioritize. Moreover, some of these groups are not likely to be willing to accept any policy that would restrict their own choices. On the one hand, attentiveness to a variety of perspectives of a range of stakeholders is an ethical duty for policymakers and all those who are engaged in the disability sector (Gleeson and Kearns 2001:77). On the other hand, if the state takes a seemingly neutral role as a mediator between various interests, this would only serve to underpin existing power relations in which people with intellectual disabilities are too often marginalized. When such conflicts of interest arise, the government’s responsibility is to actively support those who are least able to achieve their choices otherwise by creating new opportunities for them.

The extent to which these conclusions are relevant to places other than Victoria could be challenged by the following anecdote. In Chapter Five I wrote that explicit occurrences of NIMBY enacted by communities are not a significant factor affecting the location of housing for people with intellectual disabilities in Victoria as much as more subtle forms of exclusion and rejection. Just several weeks after I wrote these lines, the community organization in which I was a member in Israel finally completed the construction of a new respite house in a small suburb near Jerusalem, after more than five years of relentless search for an accessible house or at least a vacant affordable location. Several weeks before the planned ceremony to open the new house, someone deliberately burnt it down at night. While it is still unknown who lit the fire, this event implies that some of the findings and analyses presented in this dissertation may not be representative of other places. Indeed, the very point emphasized here is the importance of place and differences between places. Nevertheless, just as the conceptual framework of this study leans on empirical and theoretical work carried by scholars in countries other than Australia (mainly the US, Canada and the UK), it may also contribute some specific lessons and broader conceptual ideas to future research on disability and housing in other places.

These lessons and conceptual ideas may also be applied beyond disability studies. Much of the discussion presented in this thesis leans on
literature about public and social housing, and may therefore contribute to this particular field of enquiry. Furthermore, I find that some of the central debates in the geography and urban planning literatures, such as those around urban sprawl, while at first they may appear quite irrelevant to the subject of this thesis, in fact share several central themes: a tension between individual choice and efficiency in the provision of public services and infrastructure; a tension between centralized planning and market-driven housing development; and, the focus on density as a central feature of the housing landscape. Therefore, even though these themes are explored in this dissertation within a very specific and unique context, this discussion is not isolated from broader discussions about housing, about the city and about the state.
References


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