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### **Abstract**

Deinstitutionalisation is represented as a major step toward social inclusion through the resettlement of disabled people residing in segregated large-scale institutions into community-based homes. By promoting the right to live in ordinary community residential settings, deinstitutionalisation fundamentally changes both the support services and housing arrangements of former institutional residents. In Australia, as in many Western countries, debates on community care have tended to focus on the location and nature of non-housing supports for people leaving dependent care. This focus, however, overlooks the fact that deinstitutionalisation involves a radical rehousing of people in care. This paper explores the character and implications of deinstitutionalisation in Australia as a rehousing process. It is based on a recent national research project that has examined the housing futures of people with intellectual disability who have been, or will be, deinstitutionalised. The paper considers the increasingly divergent socio-political perspectives that have emerged in recent discussions about social inclusion, institutional reform and independent living and their implications for housing and community care policies.

## Introduction

Debates on housing and social exclusion have drawn attention to the ways in which housing processes can be understood as processes that either promote social inclusion or contribute to social exclusion (Marsh and Mullins 1998). Somerville (1998: 772) states that social exclusion through housing happens 'if the effect of housing processes is to deny certain groups control over their daily lives, or to impair enjoyment of wider citizenship rights'. Clearly, long-stay residential care can be an extreme form of social exclusion, because it denies disabled people placed in this type of dependent care choice and control over where, and how, they live.

Deinstitutionalisation, on the other hand, has been represented a major step toward the social integration or inclusion of people residing in institutional care.

This paper will focus on the housing futures of people with intellectual disability who have been, or will be, deinstitutionalised. In 1999, throughout Australia, official data suggest that there were 4,340 people whose primary disability is intellectual, living in institutional accommodation (AIHW 2000). While research has highlighted the often-negative consequences of deinstitutionalisation for people with mental health problems, particularly the risk of homelessness (Human Rights and Equality Commission 1993; Lezak and Edgar 1996; Slade *et al.* 1999), few attempts have been made to examine the future housing and support experiences of people with intellectual disability living in institutional care (see Neilson Associates 1990).

Deinstitutionalisation refers to the large-scale restructuring of human services delivery, usually involving the closure and/or downscaling of institutions and their replacement by a variety of community care homes (Chenoweth 2000; Gleeson 1999). It represents one of the most profound social policy shifts in the history of Western welfare states (Mansell and Ericsson 1996; Pinch 1997) and since the 1960s, all Australian States have pursued their own deinstitutionalisation programs. These programs involve a shift in both the housing context and support arrangements for people living in dependent care. However, in countries such as Australia and Britain, debates on care in the community have tended to focus on the nature of social, financial and therapeutic supports for people leaving institutions rather than the type of housing in which people will live.

Implicit within these debates has been the role of housing (Franklin 1998). Yet, the housing dimension, though often submerged in the discussions about community care, has been central to deinstitutionalisation. Within the British policy context, Bochel *et al.* (1999) argue that while the much of the literature on community care does implicitly recognise the role of housing, few observers have made any attempt to explain its significance for service users and policy frameworks. They argue that this gap in scholarly literature 'fuels doubts about the extent to which housing intrudes into the

thoughts of those closely interested in community care' (Bochel *et al.* 1999:496).

Nevertheless, there is an emerging literature in Britain that is beginning to recognise and explore the fundamental role of housing. In 1995, the Joseph Rowntree Foundation launched its 'Crossing the Housing and Care Divide' Programme. The aim of the Programme was to stimulate service developments that would promote the integral role of housing within community care (see Cameron *et al.* 2001 for a detailed evaluation of the projects in this programme). In Australia, however, housing agencies continue to play a supporting rather than strategic role in the development of community care policies. There is little evidence in this country that housing has been a key focus of scholarly and policy debates about community care development.

This paper aims to address this gap and focuses on the housing aspects of human service resettlement policies in Australia. The focus of the paper is on the housing needs and experiences of people leaving institutional care rather than all disabled service users. It is based on an Australian study that examines both recent and future trends in deinstitutionalisation policies and patterns for people with an intellectual disability (see Bostock *et al.* 2000, 2001). The research was supported by the Australian Housing and Urban Research Institute (AHURI) and was intended to increase awareness and understanding of community care accommodation issues amongst state and territory housing agencies. The paper will address two main questions. First, what sorts of housing models and contexts has the shift toward community care produced? Second, what roles have key interest groups played in the rehousing of people in dependent care?

The paper is organised in four main parts. First, it reviews deinstitutionalisation as a human service reform program that aimed to rehouse the residents of institutions in community settings. The second section examines the socio-political 'countercurrents' that have conditioned the course of deinstitutionalisation and its housing outcomes in Australia in recent years. The third section draws on findings from the AHURI study and presents an overview of both the current context for resettlement programs as well as the housing futures of people expected to be deinstitutionalised. The final section considers the increasingly divergent socio-political perspectives that have emerged in recent discussions about institutional reform, individualised funding and how best to promote social inclusion.

### **Deinstitutionalisation as housing reform**

A major concern of deinstitutionalisation policy has always been the issue of where people live, whether that be an institution, a hostel, their own home or another form of accommodation (Bochel *et al.* 1999). Since the 1960s, disability movements across the Western

world have sought to have institutional care replaced by a variety of community care networks. Proponents applied political pressure to have residents of custodial institutional settings rehoused into the relatively unrestricted living settings afforded by ordinary housing arrangements in mainstream communities (Wilmot 1997). Gleeson (1999:156) argues that deinstitutionalisation has been promoted by advocates in 'social justice terms as a restoration to service dependent people of their basic right to a valued living environment'.

In Australia, the increasing success of service reform politics has been witnessed throughout the 1970s and 1980s in major commitments by public and other service providers to deinstitutionalisation and the introduction of new community based, and user-focused, service philosophies (Chenoweth 2000; Neilson Associates 1990). While there is no national framework for the closure of large residential institutions in Australia, all states/territories have pursued deinstitutionalisation policies. The progress of reform has, however, been uneven: in some states (e.g., Victoria and Western Australia), the process of deinstitutionalisation has been relatively rapid, whilst in others (e.g., New South Wales and South Australia), it has been drawn out.

The focus of reformist politics within human services within both Australia and Britain has tended to centre on the location and nature of the support needs of residents in long-term care (Barnes 1997). This means that housing has not always received the explicit attention that it warrants (Franklin 1998). Yet, in Australia, and in other Western countries, resettlement policies involve not only an unbundling of particular kinds of dependent care but also effect a fundamental rehousing of people into new forms of accommodation (Bochel *et al.* 1999; Neilson Associates 1990).

A study commissioned by the Joseph Rowntree Foundation in the mid-1990s in Britain painted a bleak picture of community care housing (Watson 1997). The evidence was that disabled people were frequently shifted from institutions into accommodation that was characterised as 'grotty flats on high crime estates' (*The Guardian Society*, 2.7.97: 9). In addition, this research highlighted the over reliance on the 'group home' at the expense of other forms of housing. Simons (1995) argues that the small-scale residential care home or group home has become the blueprint model of housing provision. He states that:

...most people with learning difficulties have not had the chance to choose the kind of house they live in, the people they live with, how they are supported or who they are supported by. If people do have a choice, then it is either between different residential care homes that happen to have a vacancy (Simons in Watson 1997:21).

A move to address lack of choice in housing provision was recently announced by the British government. In March 2001, the British government released the White Paper, *Valuing People: A New Strategy for Learning Disability for the 21st Century* (Department of Health 2001). The paper recognises that housing is of central importance to the quality of lives of those with learning (intellectual) disability. In practice, this means that each local authority is expected to develop a housing strategy for people with learning (intellectual) disabilities by winter 2002/03 with the aim to enable people with learning disabilities and their families to have greater choice and control over where, and how, they live. This should increase the range of housing and supports available to people in order to enable them to live as independently as possible (Department of Health/Office of the Deputy prime Minister 2001).

The importance of housing choice is also recognised by some State Housing Authorities (SHAs) in Australia. Most notably, the Queensland Department of Housing has produced a comprehensive housing strategy aimed at meeting the housing needs of disabled people. The strategy was launched as *A Home to Come Home To: Housing Strategy for People with a Disability 1997-2000*. This strategy emphasises that disabled people should have the same 'opportunity as other people to choose where and with whom they live, and to choose housing from the range of housing assistance available to the rest of the community' (Queensland Department of Public Works and Housing 1997:13).

This recent attention to housing alternatives has, however, been restricted in nature and is hardly a universal feature of contemporary disability services in Australia. In Australia and New Zealand, there has been heavy reliance upon the group home model for community care service delivery, often based on the use of small, single residential 'family' dwellings situated in 'normal' suburban neighbourhoods (Gleeson & Kearns 2001). As Chenoweth (2000) explains, human service evolution in Australia during the 1980s was driven by a rather singular attachment of policy makers to the principles of normalisation, later 'social role valorisation', advocated by Nirje (1969) and by Wolfensberger (1972, 1983). The realisation of normality for service users was the chief object of reform, a normality rooted in conventional notions of home and family life.

An example of the rehousing process commonly associated with deinstitutionalisation in Australia in the 1980s and early 1990s is provided by the Victorian government's *Ten Year Plan for the Redevelopment of Intellectual Disability Services* (Community Services Victoria 1988). The *Ten Year Plan* recommended, *inter alia*, closure of all institutions in the state and the resettlement of residents into community-based accommodation. The nature of community housing was a key feature of this report, but the forms envisaged were clearly focused on the group home model. It

recommended that housing models developed be based on shared living arrangements. The report suggested that new community-based housing arrangements should allow for 'homes with live-in staff; homes shared by people with intellectual disabilities and others; and groups of people with intellectual disability' (Community Services Victoria 1988:24). Although supported by exhaustive research, the *Ten Year Plan* was never implemented and was succeeded by a three year *State Plan for the Development of Intellectual Disability Services* (Community Services Victoria 1989). Like its abandoned predecessor, the *State Plan* emphasised the role of group housing amongst a limited range of supported accommodation options for people relocating from institutional care.

A later study by Neilson Associates (1990) for the Commonwealth government provides the most comprehensive example of research that explores the housing impacts of deinstitutionalisation in Australia (see also Sach & Associates 1991).<sup>1</sup> The Neilson report suggests that, by the late 1980s, deinstitutionalisation had largely affected people with psychiatric disabilities. By contrast, more limited numbers of intellectually disabled people had moved from institutions into the community. The study found, however, that people with intellectual disabilities 'fared better than the chronic mentally ill, in that they have mostly been accommodated in hostels or in group homes in ordinary suburban neighbourhoods' (Neilson Associates 1990: 37).

### **Countercurrents**

In the 1980s and early 1990s, the principal current of human service reform in Australia was expected to take people with disabilities from institutions (eventually) to community care settings, meaning largely the group home (Gleeson & Kearns 2001). Since the 1990s, however, it has become apparent that the rehousing aspects of deinstitutionalisation have become increasingly contested by a number of distinct socio-political interests. The following discussion considers the major countercurrents that have resisted in different ways the flow of human services reform, making it a more contested and divergent process and raising along the way a number of critical questions about the housing futures of disabled people in Australia and overseas.

#### *Reformative rather than transformative?*

The dispersed, group home model of community care housing has been countered by some parents/advocates, and by some policy observers (e.g., Christie 1989), with proposals to build housing complexes based on 'village' models. Such groups propose that the 'sheltered village' or clusters of small residential units should be established as alternatives to both large institutions and dispersed

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<sup>1</sup> Neilson Associates were also the principal consultants responsible for the preparation of the Victorian Government's *Ten Year Plan*.

community care networks (Gleeson & Kearns 2001). For example, one Queensland study revealed a desire of parents to see their disabled children housed in village-like complexes. Maddison (1998) reports that these families wanted the same kind of housing available to people with a disability, that is: single/two person dwellings, shared accommodation and group homes a maximum of four people staffed 24 hours/day. Rather than being scattered throughout the community, however, they wished to create their own community around a 'village green'; viz., a communal recreation area. The families used the term 'intentional community' to describe the concept because they felt that they were 'intentionally' creating a range of formal and informal networks by designing an environment where those networks could be maximised and encouraged. In this instance, the rhetoric of counter-reform reveals the deep-seated anxieties of some parent groups about a perceived lack of deliberation and intention on the part of community service designers.

Other relatives/advocates have also sought to retain institutional accommodation rather than see it replaced with either dispersed group homes or 'sheltered villages'. Lloyd's (1987) history of Melbourne's Kew Cottages (formerly called Kew Residential Services) – a large congregate care facility for intellectually disabled people – is openly partial, and expresses the values and views of the institution's parents' association. Gleeson and Kearns argue that this account reminds us of the 'enormous emotional *and financial* investment that parents and relatives often make in institutions' (2001:66, original emphasis). The Kew Cottages Parents' Association raised substantial funds in the postwar period that were used to improve many facets of the institution. Lloyd details the parents 'grave misgivings' about the downscaling of the institution during the 1970s and 1980s: 'Many believed that the needs of severely retarded and multiply handicapped residents had been ignored...' (1987:111).

In May 2001, the Victorian government announced plans to redevelop Kew Residential Services. The redevelopment of Kew means that all its residents will move to new homes either on the present site or elsewhere in Victoria. A new residential sub-division will be created on the Kew site enabling a development where some 50-100 residents can live in 'houses typical of any suburb in Melbourne' but at the same time be part of a broader community of people with intellectual disability (Victorian Department of Human Services (2001) accessible at <http://hnb.dhs.vic.gov.au/ds/disabilitysite.nsf>). This move appears to respect the wishes of some parents and relatives to retain the sheltered elements of institutional living.

### *Contesting formulaic housing futures*

Whilst some parents/advocates groups have found the housing options arising from deinstitutionalisation too transformative, other groups have simultaneously criticised community care programs as too 'formulaic', meaning, *inter alia*, too close to the institutional models that they sought to replace. Chenoweth (2000) notes that in Australia, and overseas, the group home has been characterised by some critics – including disability advocates – as a 'mini institution' that has transposed to community settings institutional practices and structures. The paradox confronting contemporary policymakers is that deinstitutionalisation programs are seen both as too transformative by some interest groups and too reformative by others. During the initial stages of deinstitutionalisation in the 1960s, the creation of group homes in many Western countries mirrored a homogenised model of white, middle class values and aspirations around accommodation options. In Australia, as with most other Western countries, this model of typical home life has, however, been rendered increasingly anomalous by broad currents of social and cultural change in recent decades (McKay 1993). Social pluralisation – measured by changes in household wealth, structure, ethnic background and cultural diversification – has been associated with a greater plurality of housing experiences and accommodation choices amongst the general community (Commonwealth of Australia 1991). This means that resettlement policies based on the group home appear increasingly at odds with wider housing trends.

In Britain there has been rising frustration in recent years among many interest groups within human services with the apparent limitations of group homes for many users (Lewis & Glennerster 1996). Consequently, the last ten years have seen increasing interest in the idea of 'supported living' (Morris 1993). This model focuses on enabling intellectually disabled people to live in 'homes of their own', providing flexible, individualised support to people wherever they might be (Simons & Ward 1997). From April 2003, the British Government will implement the *Supporting People* program that aims to provide a range of housing-related support packages that are tailored to meet people's individual support needs (Office of Deputy Prime Minister 2002 accessible at <http://www.spkweb.org.uk>).

This approach has been a feature of the United States service context for some time and is designed to move supports to where people live and adapt environments and supports to the needs of users. This stands in contrast to now conventional models of community care that aim to create specially designed residences and/or impel service users to adapt to their environment. Allard (1996) argues that there is a wide range of interpretations of supported living that all centre on 'having choices' as the first and foremost principle. For example, Taylor (1991: 108) notes in a review of individualised living arrangements in Wisconsin, USA that:



The concept is deceptively simple – find a home, whether a house, apartment or other dwelling, and build in the staff supports necessary for the person to live successfully in the community. Inherent in the concept is flexibility. Some people may need only part-time support or merely someone to drop by to make sure they are okay. Others with severe disabilities and challenging needs may require full-time staff support. There isn't anything in the concept that precludes small groups of people from living together .... this, however, should be because they choose to live together and are compatible.

Reflecting international trends, there have been notable shifts in community expectations of housing outcomes from deinstitutionalisation in Australia (Ellis 1998). Family/guardian groups, in conjunction with some services users, have begun to question established community housing models, notably the 'group' home, on the basis that such options are 'formulaic' and unable to suit the diversity of client and family needs (Ellis 1998). A growing number of studies in Australia report examples of people 'moving beyond the group home' into accommodation of their own choice with support tailored to suit their individual needs (Cochrane 1999; van Dam & Cameron-McGill 1994).

This was the scenario envisaged by Sach and Associates (1991) in a contribution to the *National Housing Strategy* which reported that Australia was moving towards a highly disaggregated housing and support service system for people with disabilities:

Whereas past housing options included living at home or living in an institution, tomorrow they will include a bewildering array of all sorts of options ranging from full or part equity in home ownership, to cooperatives, to shared housing, to improved access to private rental housing, to fully supported 24 hour accommodation, to respite and crisis accommodation, to improved boarding houses and to a range of local housing solutions which have been developed in local communities. Life for people with disabilities will take on the same complexity as that of the wider community (Sach & Associates 1991:8).

#### *Independent Living and Individualised Funding*

The international disability movement has not only questioned the over-reliance of institutional reform on formulaic housing options such as group homes. The movement has also challenged the dominant assumption that the best way to provide housing and support for disabled people is for governments to give money to agencies rather than make direct payments to disabled people themselves (Hasler *et al.* 1999; Lord and Hutchinson, 2003). The disability movement has fought to determine their own housing futures, undermining perceptions that disabled people are passive

recipients of support services by emphasising principles of participation, inclusion, equality and the right to live independently. Independent living in this context means 'having **choice** over where and how to live, and who provides assistance and **control** over when and how that assistance is provided' (Carmichael and Brown 2002: 805).

In response to these concerns, there is a worldwide movement toward direct individualised funding which refers to the allocation of support dollars direct to the person rather than to a service agency (Dowson, S. and Sainsury, B. 2000; Largary 2002). In Canada and the US, specific projects and programs such as the Ontario Direct Funding Project (Canada) and the Michigan Self-Determination Project (US) have been set up to increase participation of people on their own terms. In other countries such initiatives have been backed up by legislation. In Britain, the Community Care (Direct Payment) Act 1996 enables disabled adults who need assistance with a range of daily living activities to buy their own support (Carmichael and Brown 2002). While in Australia, Western Australia was the first State to adopt individualised funding. In 1993, the government passed the *Disability Services Act*, which allowed grants to be approved to individuals in order that people with disabilities had the necessary funding to enable them purchase their own support services (Lord and Hutchinson, 2003). This means that once freed from agency-determined housing-related support services, people with disabilities and their supporters are in a stronger position to choose where, how and with whom they wish to live.

### *NIMBYism*

Another socio-political dynamic that has complicated the rehousing of people leaving institutions have been local resident opposition to neighbourhood facilities, often portrayed as the NIMBY ('Not-in-My-Backyard') syndrome. Several social psychological based studies have shown that such opposition has in many instances been motivated by prejudice and by erroneous beliefs about the nature of care facilities and the people who use them (see Dear & Taylor 1982). Dear and Wolch (1987) have shown that North American service agencies have responded to the prevalence of NIMBYism by adopting 'avoidance strategies' as part of their siting criteria for community care homes. The outcome of avoidance strategies has been the concentration or 'ghettoisation' of care networks in 'places of least resistance', frequently low income and declining inner city neighbourhoods. The strategy of avoidance has also been identified among service agencies in New Zealand (Gleeson *et al.* 1995).

In Australia, as deinstitutionalisation processes accelerated in 1980s and early 1990s, protests from residents against the siting of new community care homes in their neighbourhoods forced some service agencies to relocate planned supported housing (Foreman & Andrews 1988). In Tasmania, a vociferous public outcry against

plans to rehouse former psychiatric patients into community-based accommodation meant that the program was ultimately abandoned (Thomas 1991). In another instance, these sentiments were echoed by some state politicians who objected to the resettlement of residents from the Willow Court Centre – Australia’s oldest institution for people with intellectual disabilities. In both cases, complainants mobilised NIMBY sentiments to express their anxieties. After a Tasmanian government agency announced plans to place a new group home in the Howrah region, one parliamentarian remarked: ‘I wouldn’t want them living next to me’ (in Thomas 1991:18).

### *Organised labour*

Other voices of opposition to deinstitutionalisation have included organised labour. Institutions have long been bastions of highly unionised labour, including both non-professional and ‘lower order’ professions (e.g., nursing staff). Gleeson and Kearns (2001) state that although the circumstances differed widely at the national, regional, and even local, scales, deinstitutionalisation had potentially profound consequences for such workers. This includes loss of employment, redeployment, erosion of working conditions (including job security), reskilling, adaptation to new work practices, and deunionisation (in Australia, see Lloyd 1987; in Canada, see OPSEU 1980).

In Australia, poor training, high turnover and low morale, have been cited as serious deficiencies in the country’s community care networks (e.g., *Sydney Morning Herald*, 28.1.97:1). A perception of poorly trained, non-committal workers in group homes has heightened the anxieties of some parent/relative groups about community care in general. In New South Wales, the state government’s Community Services Commissioner observed in 1996 that community residences had become a ‘favourite source of jobs for backpackers working for a few months to save for the next leg of their journey’ (*Sydney Morning Herald*, 30.11.96:3).

### *Transinstitutionalisation*

Lack of funding for housing in the community has led to the phenomenon of ‘transinstitutionalisation’ whereby disabled people are moved from institutions without adequate supports and then enter other institutional settings such as shelters, prisons, nursing homes or psychiatric hospitals (Hudson 1991). In Australia, Armstrong (1997) argues that rising numbers of people with intellectual disability within the criminal justice system corresponds with the deinstitutionalisation of state facilities. In New South Wales, according to recent evidence presented to a State Parliamentary Committee, one in five prisoners is intellectually disabled (*Sydney Morning Herald*, 28.5.00:5).

The use of mandatory sentencing in both the Northern Territory and Western Australia appears to compound this phenomenon. John

Lowes, a magistrate from the Northern Territory who sentenced an intellectually impaired man to 90 days in gaol, described how 'this court's hands are tied, of course, by mandatory sentencing'. Lowe said that while it was clear that the man had an intellectual disability, he could not give him a suspended sentence to keep him out of gaol (*Green Left Weekly* 2.8.01:3).

A similar picture of lack of housing and other support mechanisms emerges in other Australian states and territories. Reports suggest that a young man with autism had to spend six months in gaol because the New South Wales Department of Community Services could not find him a home. Aaron O'Doherty had been sentenced to three months gaol for malicious wounding but was refused parole for an extra six months because no suitable accommodation was available for him outside the prison (*Sydney Morning Herald*, 25.01.00:6). The scarcity of community accommodation options suggests that gaols have are becoming increasingly *de facto* congregate care facilities. However, the evidence of overall and subsidiary (i.e., facility specific) trends of transinstitutionalisation in Australia remains sketchy. Further research is needed to assess such trends if the progress of institutional reform is to be properly evaluated.

### *Homelessness*

The lack of appropriate housing and support in the community also appears to have led to a rise in homelessness among intellectually disabled people. This phenomenon has been well documented for North America in a set of landmark studies by Michael Dear and Jennifer Wolch. Both *Landscapes of Fear* (1987) and a follow up study, *Malign Neglect* (1993), emphasised how poor public funding and community opposition to care facilities had contributed to a rise in homelessness amongst deinstitutionalised people. In Australia, however, there is very little documented evidence on how many people with intellectual disabilities experience homelessness (Chenoweth 2000). Women with Disabilities Australia (WWDA) point to two government reports, one by the Commonwealth Office of the Status of Women (1993), and one by the New South Wales Department for Women that highlight this issue in relation to women with disabilities in Australia (WWDA 1996). Evidence does exist on the inaccessibility of emergency accommodation and the fact that many women with physical disabilities seeking refuge from violence are turned away from support services.

Other available data suggest that people with disabilities (especially people with acquired brain injury, psychiatric and intellectual disability) are significantly represented in the Supported Accommodation Assistance Program (SAAP) and Crisis Accommodation Program (CAP) services. For example, it is estimated that between July 1996 and June 1997 in Queensland, some 21,496 clients were accommodated by services funded under

the SAAP. Throughout Queensland, 21 per cent of people accommodated in SAAP services received a disability pension (Department of Public Works and Housing Queensland 1997:8). A survey of emergency housing providers in Queensland in 1994 estimated that seven per cent of SAAP users had an intellectual disability (Madden & Maples 1996:46).

A focus on deinstitutionalisation as a rehousing process reveals some of the dilemmas that have emerged during the restructuring of residential care in Australia and overseas. The increasing complexity of stakeholder interests within the deinstitutionalisation process has significant implications for the housing futures of people living in institutions. Some parents/advocates have sought to transform institutional accommodation rather than have their children housed in community group home setting. For others, housing reform resulting from deinstitutionalisation has not been radical enough. Some interest groups, including local communities and care workers, have also objected to the housing impacts of deinstitutionalisation. Further, inadequate housing and other supports in the community have meant that some service users have returned to institutional, in some instances custodial, settings or have found themselves without shelter at all. The next section will draw upon new empirically grounded research to further explore the current and future contexts for community care and housing policy in Australia.

## **Deinstitutionalisation and housing futures**

### *The AHURI study*

The research that informs the following discussion was conducted over a six month period in 2000 and was funded by the Australian Housing and Urban Research Institute (AHURI). The project aimed to provide a conceptually driven and empirically grounded understanding of deinstitutionalisation as a rehousing process. Specifically, the study examined the housing futures of people with intellectual disabilities to be deinstitutionalised in the 2000 - 2010 time frame. A focus on understanding the future accommodation needs and experiences ('housing futures') of different groups is a crucial component of government planning and policy development around housing assistance delivery (Commonwealth of Australia 1991). The study aimed to enhance policy analysts' and policy makers' understanding of likely future accommodation needs and demands among deinstitutionalised people.

An extensive set of primary and secondary data was drawn on in conducting the research. The main primary data were extracted from interviews conducted with 46 key informants in disability and housing agencies from each state/territory. The study findings are reported in schematic form here; a more detailed explanation of the research methods and results may be found in Bostock, Gleeson, Mcpherson and Pang (2000 and 2001).

### *Future deinstitutionalisation trends*

The first set of findings from the study relate to future patterns of deinstitutionalisation. The significance of these data lies in the fact that they represent the first attempt to estimate deinstitutionalisation trends at the national level. Before the study, the only national data on deinstitutionalisation were the estimates of institutional bed numbers collated regularly by the federal government's Australian Institute of Health and Welfare. The Institute's data, however, are historical (based on reports from the states/territories), do not include forward estimates, and include beds assigned to a variety of people in dependent care. There was, therefore, no way for policy analysts to assess the impacts of future deinstitutionalisation processes on either housing supply or the housing futures of people with intellectual disabilities.

The research found that in 2000 there were approximately 6,000 people with intellectual disabilities living in institutions in Australia (Table 1). This figure must be treated with caution as it is based on self-reported definitions of institutions. Definitions of institutions vary by state/territory and can denote both different types of institutional facilities and different kinds of disability amongst residents.

**Table 1. Projected numbers leaving institutional care by target date**

<b>State/ Territory</b>	<b>Current nos. in institutions</b>	<b>Projected nos. leaving institutions</b>	<b>Percentage of those leaving institutions</b>	<b>Target date</b>
NSW	2,500	2,500	100%	2010
Vic	822	462	56%	2011
Qld	1,284	125	10%	2003
WA	735	261	35%	2003
SA	688	75	11%	2002
Tas	160	TBA	TBA	TBA
ACT	NA	NA	NA	NA
NT	NA	NA	NA	NA

TBA = to be announced. These data were not available during the study period.

N/A = not applicable

*Source: Bostock et al. (2001)*

The study found that deinstitutionalisation processes appear to be slowing in many jurisdictions across Australia. According to state/territory agencies, this slowing is attributable to a number of factors, in particular, the fact that most current institutional residents have high support needs and are therefore 'harder' to place in community settings. Earlier phases of deinstitutionalisation in the 1980s and 1990s tended to involve the relocation of residents with

lower support needs. Institutional reform continues to occur, however. In Tasmania, for example, Australia's oldest institution for people with intellectual disabilities was closed in November 2000. New South Wales the government is committed to closing all its large residential care centres by 2010. Almost 2,500 people will move into community based options over the next ten years if current devolution plans are realised in New South Wales. Victoria announced plans to redevelop Australia's largest institution in May 2001. Over 460 people will move to new homes either on the existing site of the institution or elsewhere in Victoria. Reports from other states suggest that another 450 people can expect to move to smaller, more appropriate accommodation in the community by 2003.

The findings also suggest that congregate care will remain a significant feature of disability and accommodation support services in Australia. Some states have established new congregate care facilities and/or reversed decisions to close existing institutions. The State Government in Victoria, for example, has built a new congregate care facility to house people with higher support needs whilst continuing to pursue deinstitutionalisation in other service domains. Queensland has developed two new cluster-style developments viewed as centre-based rather than congregate care.

#### *Policy dilemmas*

The research identified a number of policy dilemmas that will confront future attempts to rehouse people in institutional care in Australia. The development of joint working initiatives between housing and disability agencies are crucial to the success of accommodation solutions for service users with complex support needs, especially people leaving institutional care (Cameron *et al.* 2001; Watson & Conway 1995). This interdependency is recognised in Britain. The recent learning disability White Paper states that two lead agencies, the Department of Health and Department of the Environment, Transport and the Regions, are to issue a joint circular and detailed guidance on 'commissioning the range of housing, care and support services required to expand housing choice' (Department of Health 2001:73).

Our research revealed that in Australia the strategic role of housing providers in community care is still largely underdeveloped by the State Housing Agencies (SHAs) themselves and is insufficiently acknowledged by other key human service agencies. Disability agencies have tended to dominate the landscapes of deinstitutionalisation policy in Australia with housing agencies playing a significant but supporting role within community care. The lack of coordination between the major housing and disability policy frameworks indicates a broader disarticulation of housing and social policy in Australia. This problem is exemplified at the national scale where the two main housing and disability funding frameworks – the Commonwealth State Housing Agreement (CSHA) and the

Commonwealth State Disability Agreement (CSDA) – exist largely in isolation from each other.

The Commonwealth Government and the state governments and territories regularly renegotiate both agreements. Earlier arrangements did appear to foster synthesis between the two key policy frameworks, but these articulating mechanisms were abandoned in more recent agreements. The (now superseded) 1991 CSDA was designed to be prescriptive and emphasised collaboration between different commonwealth/state programs in order to bed down new administrative arrangements, roles and responsibilities and consultation mechanisms. In particular, SHAs were singled out as important providers of services to disabled people. The 1991 CSDA highlights the importance of consultation with the 'relevant housing authorities to ensure coordination with the Commonwealth/State Housing Agreement' (section 6 (4)).

By contrast, the 1998 CSDA aimed to be more 'enabling' and to facilitate variations in service delivery within each state/territory. Consultation mechanisms included in the 1991 CSDA were not replicated in the second CSDA. This means that the second CSDA no longer explicitly requires consultation between disability and housing agencies. Thus, the focus in disability appears to have shifted to non-housing support needs whilst the profile of disability within housing appears to have diminished. Evidence of the latter shift is to be found in the current CSHA which aims to provide appropriate, affordable and secure housing assistance for those who most need it. The CSHA highlights the importance of linking housing assistance mechanisms with other national and state/territory social policy frames in order to support a public housing client base with increasingly complex needs. Within the CSHA, however, it is the Crisis Accommodation Program (CAP) and the Supported Accommodation Assistance Program (SAAP), rather than the CSDA, which have been prioritised. Neither of these programs relates directly to disability.

There have been recent attempts to address this lack of cross-policy coordination. In February 2001, the State/Territory Housing Ministers Advisory Committee (HMAC) met to explore both stable accommodation for people with complex support needs and strategies for preventing homelessness. The seminar was attended by a variety of senior policy makers, including representatives from disability agencies, in an attempt to develop joint working initiatives and reduce policy divergence.

Our study also found evidence of limited documented cooperation between disability and housing agencies within some states. For example, a partner arrangement exists between the Disability Services Commission (DSC) and the Ministry of Housing (Homeswest) in Western Australia. This is known as the Community



Disability Housing Program (CDHP) which provides community managed accommodation options for people with disabilities that require support to live independently in the community. Nevertheless, these partnership arrangements are still driven by disability rather than housing agencies. In Queensland, agreements between the Department of Housing and Disability Services Queensland focus on meeting individual housing needs through modification, relocation or rent assistance. While it is recognised that this increases support costs, both agencies in Queensland have attempted to move away from continuously reinforcing the group home as the major model of community based housing.

### *Resisting reform*

Our study confirmed that socio-political ‘countercurrents’ continue to play an influential role in determining the pace and nature of institutional reform in Australia. Some parents/advocates have conditioned the course of deinstitutionalisation policy in unexpected ways and reopened the policy space for congregate care facilities. But these facilities are not like the institutional facilities of the past. They are based on ‘community village’ models, cluster housing developments and ‘centre-based care’ – clusters of residential units established as alternatives to both large institutions and dispersed community care networks. In both Victoria and Queensland, certain relative/advocate associations have successfully countered community care models based on the individual house scattered throughout suburban neighbourhoods. This countercurrent seems to have influenced disability policies in both states, whose governments now aim to retain some congregate accommodation on sites previously designated for closure.

In 1996, the newly elected conservative government in Queensland abandoned its plans to close one institution, the Basil Stafford Centre, after strong public pressure from the families of some service users. This lobbying continued to influence policy settings after the demise of the conservative state administration. Chenoweth (2000:89) recalls that when the Labor Party regained power in 1998, ‘the active and effective resistance to community living by approximately 30-40 parents, met with a commitment to build two centre-based options for remaining residents’. Our study showed that, Disability Services Queensland has established two new cluster-housing developments, accommodating 37 people with higher support needs. The cluster developments reflect the wishes of some parents to have their children accommodated in centre-based care. Unlike institutions of the past, however, the new congregate facilities have been designed to encourage involvement of residents in the local community.

### *Direct routes to independence*

At the same that some interests are calling for ‘sheltered villages’ or centre-based care, parallel demands for direct or individualised

funding have emerged in Australia (Dowson and Sainsbury 2000). Many disability groups have been demanding more individualised approaches to the provision of disability supports, particularly the allocation of funds to purchase supports directly to the service user rather than a service provider (Ellis, pers. comm. 2001). The needs of the service user are still assessed by disability services as they would be for the direct provision of community care services. Based on this assessment, users are provided with regular cash payments instead of services. Depending on the level of funds available, this can enable the customising of support to individual needs, allowing, for example, individual choice of service provider and housing type. It can be used to support people who live within a group home setting as well as to promote access to a wider range of housing options (Dufty, pers. comm. 2000). In other words, individualised funding may enable people:

...to choose for themselves the types of housing that they want (and can afford) and the types of supports they wish to use within the range of available options, just as any other member of the community (Sach & Associates 1991:8).

While individualised funding is not necessarily a panacea for the challenge of meeting complex individual service needs, our study showed that it might be part of a differentiated support framework that is already evolving in some states/territories. Such a framework would offer a range of accommodation types in different places. This will allow some service users and/or families to choose accommodation forms – including in some instances congregate facilities – that would transcend the current tendency of support mechanisms to enshrine (if implicitly) the ‘group home’ as the only housing alternative to institutional ‘care’. The move toward ‘person-centred’ planning, service user-driven initiatives and individualised funding would mean that more users would have the ability to determine their own accommodation and support packages, opening up a much more complex housing-support scenario.

#### *NIMBYism and locational strategies*

Our research revealed that the states/territories have adopted a variety of strategies to reduce the impact of ‘NIMBYism’ on deinstitutionalisation policies. In some states, such as Queensland and South Australia, great efforts have been made to consult with local communities about future plans to site community care homes in their neighbourhoods. In Western Australia, an explicit policy of opening group homes without prior consultation with neighbours has been adopted. The Western Australian Disability Services Commission (DSC) argue that people with disabilities are like any other member of the community and therefore entitled to the same privacy.

Past experiences of NIMBYism means that Tasmania pays special attention to siting strategies for group homes. Care homes are now built as part of new housing initiatives, including social housing developments. This means that from the moment of initial occupancy, group home residents are part of an already established social housing client mix. While ostensibly a positive move, this indicates a somewhat defensive strategy whereby new group homes may well be located in 'places of least resistance'. The move away from siting care homes in 'places of least resistance' (poorer suburbs) within the South Australian human services means that NIMBYism may become an increasing problem as plans to site group homes in more advantaged neighbourhoods are developed. Community responses to the location of new care homes may also be an issue in New South Wales. This reflects the scale of the rehousing project (2,500 people to move to community living) in this state.

### *Industrial relations*

Although local objections to community care housing appear to have dissipated in some states in Australia, recently, resistance to human service reform continues amongst some elements of organised labour. For example, industrial action recently delayed the closure of the Willow Court Centre/Royal Derwent Hospital in Tasmania. This action centred on workers' fears about loss of livelihood and diminished staffing levels required in the replacement community-based housing. Regional effects were also noted. The institution was based in a geographically isolated area and was one of only two major employers in this area. The closure of this institution, and redeployment of staff, has major implications for both families of employees and the for the local economy in this region. The dispute was eventually resolved and Willow Court closed in November 2000.<sup>2</sup> The potential for further disputes of this type cannot be discounted as remaining institutions are nominated for closure. Such conflict may delay and/or reshape the rehousing of the people with intellectual disabilities who remain in Australia's surviving institutions.

### **Conclusions: contested housing landscapes?**

People with disability have campaigned for the right to participate in community life long before the concept of 'social inclusion' became popular. Since the 1960s, the right to live in a 'socially valued environment' has been a driving force behind deinstitutionalisation, forcing the down-sizing and in many cases, closure of large-scale institutions and their replacement with community-based living arrangements, generally in the form of 'group homes'. More recently, however, there has been a comprehensive critique of the way in which community-based housing and support services act to maintain the social exclusion of people with intellectual disability.

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<sup>2</sup> Tasmanian Government Media Release, 'Royal Derwent Dispute Resolved', 6.10.2000

In the last decade, the rehousing aspects of Australia's human service resettlement policies and programs have been confronted with a series of socio-political dilemmas. First and foremost, is the failure of policymakers to recognise the adverse socio-political and policy consequences of not coordinating housing and disability service frameworks for the social inclusion of people with disabilities. Housing is a focus of grassroots and service user anxiety in the disability field, partly because it is treated as a subsidiary issue in community care. Yet, control over where, how and with whom one lives is crucial to a sense of social inclusion. Nevertheless, the fundamental role of housing within community care policy has yet to be fully articulated. All Australian states and territories have attempted to restructure human service provision, involving either the downscaling and/or closure of institutions. At its core, this direction has represented a massive social rehousing project. Community care, therefore, can no longer be seen as a specialist area tangential to mainstream housing policy. While housing agencies in Australia are moving to address the issues posed by a social housing clientele with increasing complex support needs, disability agencies have tended to be the principal policy drivers behind the development of community care accommodation. The two policy domains have often overlapped at the practical operational level, but remain disarticulated at the strategic and programmatic levels.

A consequence of this policy disarticulation is that disability agencies often focus on support requirements of clients at the expense of housing needs. Accommodation has often been an afterthought, meaning, in practice, a frequent reliance on simple housing models such as the group home. Although it is recognised that group homes are an important source of stable accommodation for people with complex support needs, there is the danger that they have become the blueprint (and often only) model of community-based housing provision. As our study, and other commentaries (e.g., Chenoweth 2000; Ellis 1998), have noted, however, this blueprint housing model has become the focus of increasing criticism in Australia for its failure to promote choice, control and a sense of inclusion in the community.

On the one hand, some critics have argued that deinstitutionalisation has resulted in at best, reformist housing models and at worst, exclusionary housing processes that have 'transposed the same structures, routines and cultures of institutions out into community settings' (Chenoweth 2000:85). By contrast, other groups feel that deinstitutionalisation has been too transformative. In particular, some relative/advocate associations have sought to counter community care debates with an alternative construction of 'reform' that centres on the 're-creation, not closure, of institutions through systematic improvements to infrastructure and services' (Gleeson & Kearns 2001:66). As we have noted, such countercurrents have successfully (re)conditioned the course of human service reform and,

in some states, reopened a policy-political 'space' for congregate care.

In summary, Australia's future phases of deinstitutionalisation are certain to be contested by different socio-political interests. As a consequence, the housing futures of current institutional residents are likely to be contested and – for some service users – may not involve significant change to the place and form of their care. Moreover, the rehousing of some institutional residents may be delayed by the multiplicity of interests and support claims that will confront policymakers and service agencies in the future. Whilst we do not support the continuation of orthodox forms of institutional care, the contest over housing futures that is increasingly apparent in Australian policy realms may not in itself be a bad thing for service users.

Indeed, promoting participation by all stake-holders in decision-making is a cornerstone of social inclusion and essential to ensure that everyone can gain access to housing and support services they need to achieve their own potential in life. This means that a contested rehousing process will be constructive if it produces reflective rather than conflictual service reform. Much will depend on how service agencies manage discussions and consultations about policy development (see Gleeson & Kearns 2001 on this). A more reflective mode of reform is, in our opinion, more likely to produce heterogeneous not formulaic housing and support options for people in care. A diverse and flexible community care housing landscape will be better equipped to meet the individual accommodation needs and desires of service users and thereby enhance social inclusion.

Finally, what cannot be doubted is the fact that a much more demanding accommodation services scenario seems to be settling upon Australia, driven both by demands for self-determined supports that promote social inclusion and by parallel demands from other interests to support the choice of some disabled people and their families to live in 'sheltered villages' or centre-based care. The housing futures of people in care will emerge from a complex, and perhaps at times antagonistic, intersection of these two perspectives, overlaid by the familiar institutional imperatives of resource constraint and political sensitivity. The chances of fair and satisfying outcomes for services users will be immeasurably improved if housing agencies contribute their resources and expertise to a collaborative process of rehousing people in institutional care, a process based on principles of participation, self-determination and a commitment to the social inclusion of disabled people.

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## Personal Communication

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