

# ***'DEATH BY A THOUSAND CUTS':*** **PERSPECTIVES ON** **DEINSTITUTIONALISATION**

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## **ABSTRACT**

This paper discusses findings from an Australian study that looks at housing and support for people who have had long stays in psychiatric institutions. Using qualitative methods, the study was designed to offer multiple perspectives on client outcomes and on the process of implementation. The study demonstrates the advantages of methods that look at program implementation from multiple perspectives. In situations where policy directions are contested, as has been the case with deinstitutionalization in South Australia, multiple perspectives are particularly instructive. Here they show how programs designed to facilitate deinstitutionalization, if implemented without an explicit policy context and a publicized commitment to ongoing funding, can be experienced by those involved in their implementation as 'death by a thousand cuts'.

## **1 INTRODUCTION**

### **1.1 OUT OF THE INSTITUTION**

When psychiatric hospitals close, people residing in them need housing. Many also need support to enable them to live independently in the community. This paper discusses findings from a study called 'Out of the Institution', that examines a model of housing and support for people leaving psychiatric hospitals. The model was established in Victoria in 1995 as part of planning for the closure of several large psychiatric institutions. Its aim was to enable people who had spent many years in those institutions to live independently, and to sustain tenancies over the long term.

The model has three components: housing, clinical support, and psychosocial disability rehabilitation support (PDRS). Clients<sup>1</sup> live alone or in pairs, in their own homes, with most properties provided through the Victorian Office of Housing. Clients have security of tenure, and tenancy management is provided by a specialist community housing agency. Clinical support is provided by community-based mental health services, and PDRS support is provided by a specialist agency. PDRS workers support clients in improving their skills in areas the client identifies as a priority (for description of the support worker role see Wissmann 2003). Support will vary in intensity as clients' needs change, and it continues for as long as the client considers they need it. Variations on this model have been delivered by a number of agencies in different parts of Victoria, and in other states. It is of particular interest to policymakers in settings like South Australia, where stand-alone psychiatric hospitals remain at the centre of the mental health service system.

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<sup>1</sup> People who receive support under this model are known as consumers (by PDRS agencies), patients (by clinical agencies) or tenants (by housing agencies). To reflect their status as people for whom this suite of services is provided, I refer to such people as clients.

The study asks: 'Does the model work?' And, 'Is it transferable to other settings?' It examines outcomes for a cohort of 30 clients supported in Victoria since 1995, and implementation from 2005 of a similar model in South Australia. The study examines client experiences through semi-structured face-to-face interviews with clients and with their PDRS workers, supplemented (where clients give permission) by open-ended surveys from clients' clinical workers and family members. It looks at implementation through examining documentary evidence, and interviews with agency managers and staff.

## **2 DISCUSSION**

Evaluations of similar models of housing and support have recently been completed in New South Wales (Fisher et al. 2007) and Queensland (Meehan et al. 2007). Like the present study, these projects sought views from multiple perspectives in order to develop a rounded view of clients' experiences. Multiple perspectives have also been used in studies concerned with processes of implementation. For example, Gerrand (2005) used interview data that drew on the perspectives of key players in her study of mental health service reform in Victoria in the 1990s. Gerrand's analysis focused on congruences between respondents' accounts, to develop a detailed account of the processes by which policies entailing radical change were proposed, adopted and implemented.

In studies that consider the same situation from several points of view, multiple perspectives can offer more than just an aggregate picture. Analysis can focus on what different people notice and what they omit, and where accounts are discrepant. It can examine how different accounts fit together, and how particular views come to be seen as authoritative in a given situation while other views are discredited. These advantages of methods that use multiple perspectives have been discussed in relation to studies that consider dynamics in families (McCarthy et al. 2003; Warin et al 2007). Opportunities arising from multiple perspectives in program evaluation have had less attention (Markiewicz 2005).

Multiple perspectives can be particularly useful in studies that consider the delivery of services to people who experience mental illness. In an ethnographic study of hospital-based clinical staff Barrett (1996) showed how different views were asserted and disputed by staff from different disciplinary groups. That study examined the processes by which a dominant view about what schizophrenia is came to be established, while other views were submerged.

Barrett and Parker (2006) observed that divergent views may appear *within* individual accounts, as well as between accounts from different people. In a study of clinical staff working in a community-based service these researchers identified a pair of opposing views concerning clients' experience of living in the community. The 'dominant' view associated community with ideas of 'openness, freedom, responsibility, integration and autonomy', while the opposing, negative values were attributed to the hospital. Alongside this view was a 'counter-narrative' that appeared mostly in casual conversations with staff. This account represented the community as a place in which clients were isolated and confined, and hospital as a place of asylum that offered freedom and companionship. The counter-narrative represented a view that was contrary to the 'authorised' understanding of deinstitutionalization. Although a single individual may assert both views, the 'counter-narrative' was unlikely to be articulated in a formal setting.

Analysis that identifies divergent views by drawing on accounts from multiple perspectives has proved to be particularly useful in the present study.

### **2.1 PERSPECTIVES ON IMPLEMENTATION**

The South Australian component of the present study considers a program called 'Returning Home'. Support under Returning Home is available to inpatients of extended-care wards of Glenside (a large stand-alone psychiatric hospital in Adelaide) who were

assessed in 2005 as being able to live in the community if appropriate services were in place. PDRS support is provided by three non-government organizations (NGOs), clinical support by community-based mental health services, and housing mostly through Housing SA. Returning Home operates within a 'Recovery Framework', which promotes client self-determination and independence (Pepper 2002).

Returning Home is not extensively documented in the public domain. Paucity of documentation means that reports from key players are a more important data source for the present study than would otherwise be the case. This has led to an unexpected direction in the research findings, as different players involved in implementation have different views about what Returning Home is, and the difficulties arising from it. In this instance multiple perspectives become an important tool for understanding the process of implementation.

Initial implementation of Returning Home occurred, as several respondents put it, 'under the radar'. Funds were committed in 2005 to enable NGOs to provide support for a number of clients, but there was no accompanying policy statement, no program launch, and although the funds were 'recurrent' there was no publicized commitment to ongoing funding. Returning Home was devised within the context of a plan for closing beds at Glenside (Parliament of South Australia 2006), but this understanding was not widely discussed. The issue gained some profile in March 2007 with the release of a report entitled *Stepping Up: a Social Inclusion Action Plan for Mental Health Reform* that outlined a vision for substantial downsizing of Glenside (Social Inclusion Board 2007). The South Australian government response to the report adopted its broad recommendations without giving details of its intentions for Glenside (Government of South Australia 2007). Detail was to be contained in a 'Glenside Master Plan', scheduled for release in August 2007.

Interview data suggest that a number of unintended consequences have followed from the 'under the radar' approach. Implementation of Returning Home has been slow, with processes being worked out as issues emerged. Logistics and strategies around housing were not included in initial thinking about Returning Home, and Housing SA was not involved in early stages of planning. Implementation was reported to be hampered by resistance from staff working in the wards from which patients were to be discharged. After the release of the Social Inclusion Board report nursing staff took industrial action and imposed work bans prohibiting any activity toward discharging patients under Returning Home. These bans were suspended (but not lifted) in late July. By July 2007 fewer than twenty patients had been discharged from Glenside with support under Returning Home<sup>2</sup>.

The following sections give examples of different understandings of Returning Home presented by parties involved in its implementation. They draw on data from interviews with managers and staff working in hospital-based and community-based clinical services, PDRS agencies and the housing sector. To protect confidentiality, I have not identified the organisation or position from which any individual speaks. I consider understandings in three areas: issues around housing, PDRS support, and difficulties arising in implementation.

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<sup>2</sup> A total of 127 patients were assessed for Returning Home in 2005. Seventy five were assessed as suitable for transition to community to commence immediately; 40 were assessed as currently unsuitable for transition but may be suitable in future; and 12 were assessed as 'community living is unlikely to be an option'. Some patients assessed were later discharged without support, or with support under alternative arrangements. Of the 127 patients originally assessed, at July 2007 approximately half remained at Glenside.

## 2.2 HOUSING

Although all respondents acknowledged the importance of housing once the topic was raised, only one identified Housing SA as a partner in the implementation of Returning Home. As one respondent said when I mentioned housing, 'I forgot them, they're very important'. Three difficulties around housing were identified by all respondents: access to properties, arrangements for tenancy management, and the configuration of housing.

Most respondents said availability of public housing was a problem. In some areas there was a long wait for housing, even for clients assessed as eligible for priority under 'Category 1' of the public housing waiting list. It had been widely assumed that Returning Home clients would be automatically eligible for priority under 'Category 1', but this had not been negotiated uniformly with Housing SA.

Respondents expressed different views about desirable arrangements for tenancy management. One view maintained a preference for clients to lease directly from Housing SA. This was often not possible to achieve. Some clients were considered unlikely to be able to maintain an independent tenancy, even with support under Returning Home. Views about individual clients were often disputed, and some respondents felt that NGOs' assessments of clients were unduly optimistic. They expressed concern that:

At the end of the day [Housing SA has to] assess whether that tenancy is going to be successful. With all the supports in the world people get dumped as soon as they get housed, and then the housing managers are left to manage.

Some NGOs had leased properties directly from Housing SA and sublet to the client, taking on a tenancy management role themselves. While some respondents saw it as essential that tenancy management should not be done by same agency that provides Psychosocial Rehabilitation Disability support, others saw this separation of roles as desirable but were willing to compromise in order to secure properties (for an outline of debate around this issue see Cox and O'Neill 1996).

Differences in views about desirable configurations of property were more acute. The idea of a 'core and cluster' model – denoting a cluster of units in proximity to a 'core' unit which housed staff - had been suggested as a response to concerns that some clients leaving hospital would require a high level of support. This idea had been discussed at many meetings, but what it might actually look like was never elaborated. In interviews I found the idea meant different things to different people, especially in relation to the number of units in a cluster, how they would be located, and what staffing arrangements would be. Some respondents said onsite staff would be PDRS workers, and others that they would be clinical staff; some said staffing would be daytime only and others that staff would be present on a 24-hour basis.

Most respondents spoke of core and cluster as a positive option that should be investigated, but they identified as positive very different things. For some, potential for increased 'supervision' was a benefit. Others saw onsite staffing as contrary to the 'Recovery' objectives of Returning Home - potentially creating a 'mini-institution' in the community - but saw some benefit in units being located near each other. In practice, the idea of core and cluster represented an opportunity to overcome obstacles that had prevented clients being discharged. It was a pragmatic response to the consensus view that 'It's tragic that a person needs to be in an institution because there is no housing available'. As one respondent put it: 'I don't mind how they do it, as long as it works'.

Where clients did have independent housing under Returning Home there was disparity in views around whether program funds paid for set-up costs such as purchase of furnishings. Among the Psychosocial Rehabilitation Disability agencies one view was that this was clearly part of Returning Home funding; another was that funds were available but their practice was to seek support from other sources wherever possible; and a third was that Returning Home did not include funds for furnishings. The views of respondents

in other sectors ranged from certainty that funds for purchase of new furniture and white-goods were part of a Returning Home package, to: 'I don't know. I'd be curious to find out'.

### **2.3 PSYCHOSOCIAL DISABILITY REHABILITATION SUPPORT**

There were divergent views about many different aspects of PDRS support, including the duration of funding, what funding does or does not cover, and the nature and boundaries of the support worker role. The most significant of these concerned the intended duration of PDRS support provided under Returning Home. Some respondents were confident that support would be ongoing.

We had as a foundation principle that these people may need services for life. People might have lifelong disabilities or support requirements that mean for them to safely maintain that they're going to need a modicum of support forever.

More respondents felt the intended duration of support was unclear. Some providers planned their services on the assumption that support would be short-term, with clients then transferred to 'mainstream services'.

My understanding is that the funding is ongoing. But when you test that I think it's about five years. There's no way you can release these people without support being ongoing. We couldn't leave these people without support.

We don't see our service as being for life. Our role is to move people, over time, into independence, whatever that might mean for them. Maybe three to five years, not forever.

As we saw in the previous section, for some respondents uncertainty about duration undermined the credibility of the model. Other respondents further elaborated this view.

If this [program] runs out there's not a lot we've got to turn to. We're potentially taking out a lot of complex high needs people without a lot of certainty about what might be happening in five years time.

Support is ongoing but only for as long as the funding is there. There is a concern that if the funding is ceased, who's going to pick it up?

A minority of respondents expressed a view that clients who had spent a long time in Glenside would be unable to live in the community even with support available through NGOs.

Some of these people can't even brush their teeth. You don't just take them from this setting and put them in accommodation and have a PDRS worker to integrate them into the real world. It's unrealistic.

Respondents who advanced this view argued that hospital offers 'asylum' to patients and safety to families, and that most patients would prefer to stay there. In this view, Returning Home was seen as 'driven by [a political agenda], but not by what the consumer wants'.

### **2.4 DIFFICULTIES WITH IMPLEMENTATION**

Respondents' views about obstacles to implementation were more consistent. All identified the lack of an explicit statement of intention as a central concern. Some attributed this to an absence of 'political leadership'.

The Minister is supportive [but] we don't have a [former Victorian Premier] Jeff Kennett who stands up and argues, we don't have a Marie

Teehan who said her political career would stand or fall on this change. We don't have any of that.

Once the Glenside Master Plan's released and people actually see it in their face [things will change]. At the moment it's a bit like death by a thousand cuts.

Several respondents noted that a lack of clarity had contributed to perceived obstruction by hospital-based staff. They observed that planning for discharge of patients with support under Returning Home had become an adversarial process, and that supporting implementation was difficult for managers as well as staff.

If it was an open and transparent process, and you could have discussion and debate, it would be a lot easier. Staff always thought this was about closing Glenside down, so they were never co-operative. If there was some clear decision about what was going to happen at Glenside it would have made life easier, because people would have had to make a decision [about what to do], instead of the trench-digging that actually happens. That's the hard bit. That's been very successful for the last fifteen years, why should it change?

Because the Glenside plan is not known there has been no [opportunity for] change management. The whole process then becomes adversarial. Everybody feels they're completely in the dark, they haven't been given any information. It's very difficult for [anyone] to manage change if you don't know what's the change you're managing.

Respondents' conclusions about the prospects for Returning Home ranged from pessimism to optimism.

Nothing's ever going to work. There's too much administration, too many meetings, too many layers. At the end of the day they spend too much time worrying and not actually doing. Nothing's ever going to get off the ground, that's my opinion.

When you think where we were two years ago compared to where we are now, it is a long way in a short space of time. I should remember that.

We need to give this time. When support needs are so high it's going to require some exceptional work, so there's got to be some longevity [to it]. Let's not panic. We've got people who are making significant progress. Keep some faith in the model and work with it, because from our point of view it is working.

## **3 CONCLUSIONS**

### **3.1 A THOUSAND CUTS**

Respondents' various perspectives show how the process by which Returning Home has been implemented has led to disparate understandings of what's going on, among people who have responsibility for making it happen. Implementing 'under the radar' has meant that significant concerns about the credibility of the model, particularly in relation to its intended duration, have not been able to be addressed. Several respondents argued that given the historical, social and political context in South Australia this strategy for implementation makes sense: publicizing the program could have led to unfavorable media attention, earlier industrial action, and could possibly have put funding at risk. However, the strategy had unintended consequences. This study demonstrates the advantages of methods that look at program implementation from multiple perspectives. In situations where policy directions are contested, as has been the case with

deinstitutionalization in South Australia, multiple perspectives are particularly instructive. Here they show how programs designed to facilitate deinstitutionalization, if implemented without an explicit policy context and a publicized commitment to ongoing funding, can be experienced as 'death by a thousand cuts'.

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