



Mental illness recovery and place

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Abstract

This paper explores fifteen residents' perspectives on a supported housing program for people recovering from low prevalence mental health disorders in rural Gippsland, Victoria, Australia. It moves beyond the often unproductive institutional versus community care dichotomy to present a more complex consideration of the residents' perceptions of supported housing as a site for recovery. This paper contributes to the literature on consumers' experiences of mental health care in particular places. The residents' narratives highlight the importance of supported accommodation as an integral part of a recovery focused service system delivered predominantly, but not exclusively, in the community.

Keywords

recovery, rural mental health, place, mental health promotion, community care

Introduction

Place, care and recovery

Reading Australian mental health policy gives the impression that governments and their health services have a clear understanding of the relationship between place and recovery. Policy and service provision have been shaped by the deinstitutionalisation debates of the 1960s to 1990s when the 'healthy place', the place of recovery, or the most 'therapeutic environment' moved from the asylum or mental hospital on the hill to the 'community' (Barham, 1992). Mental health system insiders - practitioners, consumers, patients or clients and their friends and families - while as committed as governments to the new cultural norm of care in the 'community', express a more complex and nuanced understanding of the relationship between place and mental health. These insiders reported difficulty gaining appropriate care in the era of

large stand alone asylums and now say they find similar problems in getting effective treatment and care, beyond medication, in the community (AIHW, 2004; Deegan, 1996; HREOC, 2005; Prior, 1993).

Australian poet Sandy Jeffs (1993:22) has written in *The Revolving Door* about the problems associated with care and recovery in both the community and the institution:

*It will be hard when she goes
out to the hostile world.*

*It will be hard to survive dead-end boarding houses
or the half-way communities of suffering sufferers.*

*When the haunting delusions return,
and the way becomes unclear,
sadly it is back to the asylum with
the jangle of the keys and the closing of the doors.*

In Jeffs' poem both the community and the institution are seen as problematic. Jeffs doesn't really need to work hard on her image of the

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asylum as we are ideologically prepared by the deinstitutionalisation debates to shudder at 'the jangle of the keys and the closing of the doors'. But why does she represent life in the community in the way that she does? Where are the pleasant images of country homes or inner metropolitan houses or apartments shared with family and friends? She represents it that way, we believe, because many people recovering from low prevalence disorders (usually associated with psychosis) find recovery difficult because they have problems accessing stable community standard housing and supportive relationships (Burdekin, 1993; Harvey, Evert, Herrman et al., 2002; Robinson, 2003).

While the location of care is important so is the nature and quality of care. An important element of asylum care was the 'hotel services' such as beds, food, physical health care and recreation (Rogers & Pilgrim, 2001). Community care, we argue, must also include these key care elements. Services can't be adequately delivered or the recovery process commenced unless basic needs are met. Harvey et al. (2002:54) concluded that 'even the best clinical services will fail to meet the needs of those with the most complex problems unless there is close co-operation with housing, welfare and disability support'. On the other hand we contend that housing, welfare and disability support services will fail this low prevalence disorder group unless access to effective clinical services is facilitated.

There is significant homelessness and loneliness among people with mental illness (for examples see Burdekin, 1993; Harvey et al., 2002; HREOC, 2005; MHCA, 2003). However, service users, consumers, patients or residents' perspectives on these key issues are rarely published, although the work of Robinson (2003) is a welcome exception.

This paper offers some positive stories of residents of a psychiatric disability housing and support program in Gippsland, a region in south-eastern Victoria. We report briefly that our fifteen respondents reflect the well documented statistical profile of this population as presented in the literature. We then re-integrate nine key themes that emerged from our in-depth interviews into two key meta-themes, firstly the importance of a place to base recovery and secondly the lack of supportive, meaningful

relationships for this group. Housing and support programs provide stable, affordable housing. However, despite the support of workers and other consumers, the all important meaningful relationships prove more difficult to provide.

Affording care and recovery in the community

In a fourteen country study 'active psychosis' ranked higher than paraplegia and blindness as the third most disabling health condition (World Health Organization, 2001:x,33). Research in Australia indicates that 85% of the low prevalence disorder population receive a government pension or benefit (Harvey et al., 2002). A study by Lambert, Ricci, Harris and Deane (2000:5) found that the income levels of 87% of their respondents with a psychiatric disability were in the two lowest income quintiles compared with 36% of the rest of the Australian population. This study also showed that people with a psychiatric disability were much less likely to own or be buying their own home (27% as compared with over 70% of the Australian population as a whole). Significantly Harvey et al. (2002:xi) report on late 1990s survey data showing 42% of survey respondents 'living with psychotic disorders in marginal accommodation in Melbourne', compared with 21% of a similar cohort of respondents in a study in 1989.

In addition to low incomes and poor access to stable, affordable community standard housing many people recovering from low prevalence disorders are socially isolated (Harvey et al., 2002). As relationships such as marriage, partnerships and friendships are closely linked to housing affordability, especially home ownership, relative poverty in addition to social isolation is likely to result in dependence on parents, government support or residence in marginal commercial accommodation such as boarding houses and caravan parks. Marginal accommodation is often associated with increased use of alcohol and other drugs and increased exposure to violence and stress (Harvey et al., 2002; Robinson, 2003). Residing with parents, while often a cost effective alternative, is stressful for adolescents and older people as well as for parents acting as carers (Siegloff & Aroni, 2003).

Developing the principles of supported housing in the community

The debates around deinstitutionalisation have resulted in a powerful ideological commitment to community based services and living and have assisted the formation of a stronger consumer or service user movement as well as the development of a theoretical basis for supported community living (AIHW, 2004; Deegan, 1996; Howie the Harp, 1990; HREOC, 2005). When asked, consumers have shown a preference for independent living and ordinary housing in the community. As Howie the Harp (1990:85) reports, if you ask mental health clients or consumers where and how they want to live the overwhelming answer will be 'in my own place', or 'in a place shared with someone of my own choosing'. This strong and unequivocal commitment to western cultural norms of independence and independent living, tempered by the reality of service users need for support, encouraged Hogan and Carling (1992: 220-223) among others to try to define a new paradigm of 'supported housing'. The key supported housing parameters include the requirements that:

- Housing must be chosen by consumers
- Neighbourhoods should be chosen based on their likely ability to assimilate and support consumers
- The number of labelled or stigmatised residents in relation to the total number of residents in the overall housing unit is critical and should be limited and consistent with community norms
- The appearance of housing should be consistent with neighbourhood norms

They added that the distinctive nature of psychiatric disability 'dictates' three extra guidelines:

- Housing which keeps levels of stress manageable should be selected
- Housing should enhance stability, not be time limited
- Housing should enhance opportunities for control over the environment.

These classic 'supported housing' guidelines are underpinned by a theory of staff behaviour that recognises that it is the client, or resident who should control entry and day to day life style decisions (Ridgway & Zipple, 1990:19). These highly idealistic principles reflect ideologies of

normalisation, human rights and disability rights and continue to theoretically underpin the current provision of supported accommodation and government housing in Victoria in the 21st century.

Supported housing policy implementation in Victoria

In 1992/93 two sections of the Department of Human Services (DHS) in Victoria set up a coordinated Housing and Support Program (Robson, 1995). The Mental Health Branch and the Office of Housing worked with the newly emerging psychiatric disability rehabilitation and support services sector (PDRSS) to deliver housing and support programs (McKenzie, 1998; VICSERV web site). To date in Victoria, a state with a population of approximately 4.5 million, there are approximately 1,202 public housing properties in this program in regional and metropolitan areas (DHS Office of Housing, 2004:20). The support for residents in this program is provided by PDRSS's funded by DHS. The residents are (in most services) tenants of the Office of Housing and enter into semi-formal to informal negotiated support relationships with their designated PDRSS support service. Robson (1995:1-3) evaluated the program and found that the resident turnover was low, that residents enjoyed 'increased wellness, characterised by such measures as reduced hospital stays'. Harvey et al. (2002:x) reported that 'residents of supported accommodation seem to be doing better than [people living in marginal or institutionalised accommodation]'.

SNAP - a housing and support provider

In this study we focused on interviewing residents receiving services from one agency; SNAP Gippsland Inc. SNAP is a non-government organisation in regional Victoria that provides a range of services for people recovering from serious mental illness, principally low prevalence disorders and associated psychiatric disability. SNAP became involved in the state government's housing program in 1993 and is now responsible for 23 properties in Sale and Bairnsdale, and the nearby holiday and fishing town of Lakes Entrance. SNAP, DHS and the Office of Housing work closely together to run the local supported

housing program. The Office of Housing first identifies suitable properties that can be spot purchased (that is, they are stand alone properties, not part of public housing estates) and then SNAP workers and the Committee of Management, which includes past and present consumer representatives, inspect the properties. The aim is to find convenient properties in good residential streets, close to facilities and services.

The units SNAP has allocation rights over are all two bedroom modern brick single storeyed units. A lack of one bedroom units in these rural locations resulted in roomier and more comfortable properties being bought, and although the units have two bedrooms, SNAP made the decision to offer the entire unit to one person or one family group and received approval from the Office of Housing to do this. Having had experience with a group home, management and workers were convinced that single person or single family occupancy was more in tune with clients' wishes and housing needs, a conclusion supported by Robinson's research (2003:24). Residents have security of tenure and can continue to occupy the property irrespective of their support needs. Rental payments are based on a percentage of income and if residents need to go into hospital the rent is reduced to a nominal sum and the property remains for them to return home to when they are well.

Researching residents' experiences

Participants

In this Monash University-funded and ethics approved study, we were keen to hear how residents recovering from low prevalence disorders and coping with psychiatric disability managed in their supported housing. All twenty-one current and one immediate past client of SNAP's housing and support program were asked to participate in interviews. Four people declined to be interviewed, two were hospitalised and unable to participate and one could not be contacted. The fifteen service users who participated - eleven women and four men - were renamed Sheila, Jackie, Bill, Deanne (who had recently left a SNAP unit and bought her own house), Joanne, Cathy, Barb, Heather, Deborah, Anne, Helen, Paul, Maureen, Mick and Jacko. The ages of the residents ranged from the

late thirties to the mid fifties, except for Jackie who was twenty-six. All of the residents were of Anglo-European descent except Mick, who is an Aboriginal Australian. Three staff members were also interviewed. The residents lived alone, except for Jackie, Cathy and Deanne who live with their children, and Anne who has recently begun to share her house with another SNAP service user, Joanne.

Service users were referred to SNAP by the area clinical mental health service or by local general practitioners. While disability support services are not preoccupied with diagnosis, all respondents had a diagnosis of a low prevalence disorder such as schizophrenia, bipolar disorder or a personality disorder. No respondents had been long term residents of asylums or mental hospitals, but they were all 'known' to the mental health system and have made intermittent use of in-patient services, usually acute in-patient units that have been relocated from stand alone psychiatric hospitals to general hospitals. All fifteen participants reflected the statistical profile of mental health service consumers, that is they were all living on low incomes, usually disability pensions, and were either unemployed or underemployed. Before moving into their houses residents had either moved between caravan parks, hotels or boarding houses, or lived at home with parents, or with violent or uncongenial partners.

Interviews

In-depth, semi-structured interviews were arranged and conducted by RJ with the assistance of a male volunteer and mental illness service consumer advocate who conducted two interviews. RJ had no previous connection with the residents and she made her separation from the agency clear at all times. Interviewees could choose the time and location of the interview. In the interviews we asked a series of open-ended thematic questions and encouraged participants to speak about their houses/homes and the support they received from SNAP. Residents were asked to describe their house, or place (both physically and emotionally); what they liked and did not like about their house; if the house felt like home and why or why not; how their experiences of their houses changed over time; and their ideal house. They were also asked to give their opinions of the support

services they received from SNAP. The interviews, which took between forty-five and ninety minutes, were tape-recorded and deidentified before being transcribed (Denzin & Lincoln, 2003:74-77).

The interviews would fall largely into an 'emotionalist' framework (Silverman, 2001): they aimed to elicit subjective experience, and gauge personal attitudes, perspectives and lived experiences. The interviews produced highly subjective data about residents' feelings, thoughts, experiences and desires about living in a housing and support program house. We do not see subjectivity as 'bias' from the 'truth' but as important knowledge in its own right (as per Crabtree & Miller, 1991:146; Silverman, 2001:90-94).

Analysis

The interviews were analysed using Strauss and Corbin's (1998) description of open coding, Silverman's (2001) description of the development of themes and a modified version of Colaizzi's (1978) seven steps of phenomenological analysis (the seventh step was omitted). Nine key themes emerged from the interviews - identity, privacy and autonomy, stability, physical comfort, domesticity, support, homeownership and love and loneliness. These themes were identified, separated, introduced and briefly discussed in a previous article (Jones, Chesters & Fletcher, 2003). In this paper we want to focus on two key meta-themes that emerged from our analysis of the interviews: the importance of a place to base recovery; and the issue of loneliness and the lack of supportive meaningful relationships for this group. We have done this by re-integrating the themes and focusing on stories that represent the experiences of all fifteen residents.

Results

The importance of a place to base recovery

Fourteen of the residents reported that they were happy with their units and all felt supported by SNAP support staff. Like most people they daydreamed about living in different and more luxurious homes, some also dreamt of owning their own home. They also spoke about their hopes of finding that 'someone special' to live with them in their house and make it more of a

home. Most residents felt an increase in control of their lives and stability since moving into their unit. They were able to decide who came in to their home and who didn't and were keen to make their mark on their house. Two male residents didn't decorate and one found the two-bedroom unit model too small, too sterile and too restrictive, and yearned for room for children to play, wood to cut and animals to feed.

Nine of the women residents had experienced either physical or emotional violence that had resulted in homelessness. The women reported that they had moved in with people to escape homelessness and loneliness but then had to deal with physical or emotional violence. Sheila was asked about the sort of places in which she had lived in the past:

Mainly caravan parks. I lived in a house up in the mountains... for a year. That was a horrendous time in my life. I met this fella... He was just bad news. I've stayed in heaps of caravan parks 'til I got the SNAP flat.

Sheila continued to be threatened by her ex-boyfriend and was offered the choice of moving to a unit in another town to help her break the cycle of violence. Housing 'swaps' can be used to aid recovery and also to enable neighbourhood conflict to be resolved, one of the few advantages that public housing has over home ownership.

Before moving into her home, Heather had been living with her parents. Despite her generally positive experiences with her SNAP home she had some anxiety about the security of her housing. Heather chanted a mantra to remind herself of what she felt she needed to do to keep her unit:

You know it belongs to somebody else. But you keep the place clean and tidy, keep yourself clean and tidy, showers... vacuuming, just do your washing and clean up. Human Services they come round and make sure everything is clean and tidy. That you've dusted and vacuumed. Garden's looking good and the front's been swept up. Everything that you do at home. If you had your own little home you'd keep it nice and clean and tidy.

Significantly Heather said 'you know it belongs to somebody else', and 'if you had your own little home'. SNAP workers say they need to repeatedly reassure some residents that the unit

is theirs and that they will have security of tenure as long as they abide by the public housing regulations. However in a culture that understands security of tenure most clearly in the context of home ownership, it is not surprising that people who have struggled with the uncertainty of recovery would be fearful of letting their guard slip and inadvertently doing 'something wrong'.

Sheila expressed the same anxiety in different terms:

It's my home, they can't take it away from me unless I do something drastic, which I have no intention of doing... I get scared sometimes that I'm not going to be able to keep this place but I don't know what it is that scares me about losing it. I'm doing nothing wrong. I just get scared that they're going to take it away from me because I'm so happy. I mean I'm happy I've got it, but I'm unhappy most of the time. It has got nothing to do with where I live. It would kill me if I had to leave. I love this place.

Sheila made it clear that she was happy to have her unit but that she was not happy in herself. She said that it was a friend's support that gave her the will to keep living.

Most residents connected a discussion of their housing and support experiences to periods of hospitalisation. They concluded that just as access to supported housing programs helped recovery so did timely access to acute in-patient care. Jackie was 'hospitalised' not long after she moved into her SNAP unit. When she returned home she found her unit needed a major clean up and a cleaning team was sent in. Jackie said she 'didn't know how it got into that state', but recognised that she 'was that ill' she didn't 'realise how bad it was getting'. Deanne also moved in and out of hospital and was pleased that her support worker could organise someone to clear the letterbox and feed the animals.

Heather, like most of the residents, wanted to avoid being sent to hospital and for her, she believed that means taking medication and not upsetting her doctor. But, like most of the residents, she said that if you are unwell then hospital might well be the best place to be:

I see the doctor now and again; I haven't seen him for a while because I haven't had any problems. I think the doctor's pretty happy with me. ...if you are sick you shouldn't be too afraid

to go to hospital over it - get treated. I know it's hard. Once they get some medication into you and the nurses and doctors talk to you. You really do feel a lot better.

Loneliness and lack of supportive meaningful relationships

All of the residents had experienced the kinds of homelessness that is common for people dealing with psychiatric disability. Jacko's story was typical of the male residents. He moved from his parents' house to an inner city pub where he said the publican helped him manage his money. Jacko had also lived in a city boarding house where most of the other residents had 'psychiatric histories':

That's the trouble - half these people that get out of psychiatric hospitals end up in these boarding houses and most of them will stay there unless someone comes along and does something for them, helps them out.

Jacko came home to live with his parents in Bairnsdale on the promise of a SNAP unit of his own. However, the first unit he moved into was shared with a succession of other men who drank, took illicit drugs and, in his terms, 'played up something shocking'.

Jacko finally got a place of his own and has succeeded in making a stable home that provides him with a sense of identity, a private space over which he could exercise control. However, for him there seemed to be a significant aspect missing from his idea of what a home should be. Segal and Baumohl (1988:249) theorise home as a place with 'a matrix of desirable and highly valued attachments'. In similar vein Somerville (1992) identifies seven key signifiers of home: shelter, hearth, heart, privacy, roots, abode and paradise (Jones et al., 2003). Jacko's home provides shelter, hearth, privacy, roots and abode but it does not provide heart or paradise as he has no one with whom to share his home. His lack of a relationship or intimate attachment clearly affects his recovery. For Jacko, place, space and attachment make a home. However, he said he was 'a very lonely person' who 'didn't know how to join in conversations'. Jacko moved the interview along at this point and clearly didn't want to dwell on what he saw as an important gap in his life.

Having a place of your own can relieve pressure on families and friends. A home of your own might be more costly, involve more work and perhaps increase feelings of loneliness but it can improve relationships between family members. Deborah, like most of the residents, had some unhappy experiences of living at home as an adult. Deborah lived with her mother before moving into her SNAP unit. As she said:

[I] wouldn't move back with my mother unless I had no other choice because I found it very stressful. We've both got our own ideas of the way we want things done and sometimes they clashed. One thing that used to annoy me was that my mother would keep talking while I was trying to watch telly... she just wouldn't be quiet... Also she used to nag me about the way I spent my money. It wasn't really helpful to have someone telling you that you are doing the wrong thing all the time. I know she was right, that I wasn't spending my money wisely... On the whole I get on with her better [now].

All fifteen residents expressed varying degrees of social isolation and reported relying on SNAP support workers for both friendship and links to community as well as the more conventional support associated with housing and support programs. For example, Cathy said she hated her birthdays, but she was pleased when a party was organised and her support workers came along with their children. She said 'they could have left work at work and gone home to their kids, but no they bring their kids along and they came to my birthday party'. In Robinson's (2003: 15) terms all of the residents in this study had experienced 'relational exclusion', 'inadequate social participation' and a 'lack of social integration'.

Moving on from housing and support

The residents are physically located in their community. However, their main sense of community connection comes through networks of other residents and SNAP workers. These disability and health-mediated networks are reminiscent of the asylum and hospital. The community of residents and other non-residential SNAP members is so strong that often judgements about wellness and recovery are associated with moving out of the SNAP community to engage with mainstream community groups, either in work, housing, recreation or friendships. For example, service

users might say to other participants or to staff that they haven't seen someone for a long time, and generally the response from staff is that the service user in question has resumed school, got a job or has a new partner and is no longer in need of SNAP support and the community of fellow residents and service users.

Deanne is an example of someone moving away from the specialist services offered by SNAP. She is recovering and has moved out of her SNAP unit and bought her own home. She described her recovery process as:

Outgrowing SNAP in stages... it [SNAP] served a really valuable purpose in my life and does for many people. I guess I'm really lucky that I was able to find a way of buying a place. The irony is that the SNAP housing - I could have stayed there the rest of my life if I wanted - it was affordable, better condition and twice the size of the place I'm living in but there is something about - it was cleaner and more modern and had more storage and central and all of that - but you know what, buying my house is the most wonderful experience. It's mine. Now I'm extremely pleased that we are closing my file at SNAP for support.

Deanne is a young mother who had recently separated from her partner when she first came to SNAP. She needed the security of stable, clean accommodation in order to continue to have access to her young son. She described the unit as a 'catchment' that brought her and her son together in a supportive environment. In those early days in the unit, Deanne was still far from well. In her first twelve months she had five admissions to hospital for periods of from one to six weeks. Deanne felt that the only thing missing in the mix of services provided by SNAP was a really intensive home based service that could help people who 'were still not really well' avoid hospitalisation and remain in their homes. Deanne, like the majority of residents, appreciated the leisure and drop-in programs that were offered. She recalled that one aspect of that program she really valued was a creative writing course that ended up with a number of participants publishing a book of poetry. Deanne summed up:

So I guess SNAP is about not just safe and affordable housing, it's about support to meet people's changing needs, to help them to live independently, to reintegrate back into the

community, to keep – I guess the biggest thing was having a support worker that never stopped believing in your ability – I don't think there's anyone else, not even my mum, that really believed that I could do it.

Deanne sees recovery as a return to normal life in the community. Hogan and Carling (1992: 219) argue that the concept of normalisation 'remains an excellent tool for operationalising community integration', but suggest that it has not been used effectively in the mental health field. 'Normal' desires and needs for homes, interesting work, relationships and friendships, as well as appropriate medical care when necessary, are the very basis of mental health and wellbeing for everyone. There is no reason why people recovering from mental illness and coping with psychiatric disability shouldn't maximise their mental health in the same way.

Gaining equity in her own home enabled Deanne to take advantage of increases in land and house prices in the growing coastal town into which she had bought. When prices increased she sold her home and moved to a smaller and cheaper inland location. The price differential enabled her to gain more equity in her new home and buy a better car to deal with the increased distances she needed to travel. However, if she needs to access clinical services she will find this very difficult in the quite remote inland location into which she has moved.

Some residents stay in their units but find they can manage alone without the support component. Helen commented that she wasn't receiving much support 'because I'm giving them the flick', quickly going on to say that she was 'well enough not to need them now'. She then added 'if you want to know what support I did get – heaps and heaps and heaps'. Helen strongly believed that if she needed help in the future, the service would not let her down.

Conclusion

Because of the socioeconomic status, stigmatised position and relational exclusion of people recovering from low prevalence disorders and dealing with psychiatric disability, many will find a lot of truth in Sandy Jeffs' poem *The Revolving Door*. It is often hard in the 'hostile world' and sometimes it will be 'back to the hospital with the jangle of keys and the closing

of the doors'. But for these residents in this study there is a home and even if they need to go to hospital for a time, there will be a place to return to when things are better.

SNAP's housing and support program meets all of the supported housing principles and the residents certainly 'control the keys'. These residents have homes and they can stay there for life. They have all the 'normal' benefits of public housing – security of tenure, affordable rents, maintenance plans and the possibility of relocation if neighbour relations deteriorate. As well, residents have well situated, appropriate properties and the benefit of a support program that they regulate. Their home provides a sound base for survival and for recovery. But there are limitations. Housing and support programs are not always available, some communities and neighbourhoods are not always welcoming; and vital elements of home like love, friendship and relationships are not as easy to provide as a housing unit and a support package.

It is less than helpful to continue to talk about deinstitutionalisation as if the asylum and the community were dualities with little in common. Both of these treatment and living places are venues for attempts to put together the right ingredients to help facilitate recovery. A place to live, support to live there and social engagement are essential to recovery. These elements were an important ingredient of asylum care and they must be an important ingredient of community care if it is to succeed.

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