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**Housing and living with a mental illness: Exploring carer's views.**

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Short Running Title: Exploring carer's views on housing.

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Key words

Carers, mental illness, housing, rehabilitation and consumers

## ***Housing and living with a mental illness: Exploring carer's views.***

### **Abstract**

Public policy and an increasing body of literature identify housing as a critical element in recovery. Without suitable housing people have little chance of maintaining other resources in their lives, such as supportive relationships and meaningful activities.

It is also public policy that carers are central to decision making. There is evidence in the literature that carers often make a significant contribution to consumers staying well. Unfortunately carers often feel ignored and /or excluded from decision making.

This study is part two of a two part study (see Browne & Hemsley et al., 2008). It used focus groups with seven carers to explore their perspectives on the recover with a particular focus on housing needs. Participants agreed that quality housing is a critical element of recovery. They identified "safety and vulnerability" and "Stigma" as the important issues to be considered. They recommended supported housing be stable and that services come to the consumer and that the safety of consumers be a priority.

This study took place in Australian and the findings have relevance there but there are also implications for mental health service delivery internationally.

### **Background**

Housing is considered an important aspect of community living by institutions interested in mental health and mental health care in Australia (Burdekin et al., 1993, Australian Health Ministers, 2002, Queensland Health, 1996, Australian Health Ministers, 1992) and internationally (World Health Organisation, 1990). The Commonwealth Department of Health and Aged Care (2000) described inappropriate housing as an important risk factor that potentially influences the development of mental health problems. This document argued that the provision of suitable housing for people at risk from mental illness was a key public policy.

Australia has been criticised for its treatment of people with a mental illness (Burdekin et al., 1993, Mental Health Council of Australia, 2005, SANE, 2003, Forster et al., 2005). State and federal governments, whilst acknowledging that housing is a critical element in the provision of service to consumers, have done little to encourage the development of suitable housing options (Browne and Courtney, 2005a). According to the Cochrane Collaboration there is an urgent need to investigate the effects of supported housing (Chilvers et al., 2007).

In a study examining the relative contribution of housing versus psychiatric services on hospital readmission in people with a long term mental illness, Rosenfield (Rosenfield, 1991) found that when people need both housing and psychiatric care; services for housing were a better predictor of success (that is, of not being hospitalised) than the mental health services. No component of a community mental health system is more important than decent affordable housing. Without the availability of quality affordable housing, other treatment and rehabilitation approaches are jeopardized (Moxam and Pegg, 2000, Stroul, 1989) and consumers risk becoming homeless (Schizophrenia Fellowship, 2005). This view is also well supported by research nationally (Browne and Courtney, 2004, Browne et al., 2004, Warren and Bell, 2000) and internationally (Hansson et al., 1999, Anthony and Blanch, 1989, Gupta et al., 2003, Moxam and Pegg, 2000, Rosenfield, 1991, Carling and Curtis, 1997, Carling, 1993)

### **Carers**

For the purpose of this paper carers include parents of adult children, partners, children and other carers of people living with a mental illness. It does not include paid carers. We will use the term 'loved one' to refer to the person, the son or daughter, parent, husband wife etc., living with a mental illness.

Public policy in Australia identifies the involvement of non-paid carers (family members and significant others) as central to the delivery of mental health services (National Mental Health Strategy, 2004). Carers make a significant contribution to the care of people living with a mental illness despite not being paid (National Consumer and Carer Forum, 2005). Public policy recognises this and states that carers should have a central role in planning, development, implementation, delivery, and evaluation of services (National Mental Health Strategy, 2003).

Consumers live with carers sometimes full time, sometimes episodically. Sometimes carers support their loved ones living in other accommodation and sometimes consumers are homeless. In a 15 year follow up study, of 134 people diagnosed with a psychotic illness in the UK, Brown and Birtwistle (1998) found 55% still lived with their families, 23% lived in institutional accommodation, 19% lived independently and 2% were homeless.

Findings from the above study indicate that people living with a psychotic illness use services less if they are living with carers. Authors argued this was as a result of the support given by the carers. Regardless of where their loved one lived, carers suffered ongoing distress. This distress was for many families severe. Unfortunately many carers feel ignored by mental health services (Brown and Birtwistle, 1998).

Brown and Birtwistle (1998) concluded that care with their families is the preferred option for many people living with a psychotic illness and even if their loved one is not living with them carers can suffer carer distress. They

recommended mental health services “for moral and pragmatic reasons should do as much as possible to support carers” (p143).

Studies in Australia exploring consumer’s views and experience of recovery (Browne and Courtney, 2005a, Browne and Courtney, 2005b, Browne et al., 2008, Lakeman, 2008) support this view and suggest that consumers find the support of carers and friends critical to their recovery.

Australian research on carers mostly explores their experience of participation in mental health services. In a study in which 86 carers and 129 consumers were interviewed, Lakeman found that some carers were satisfied with their involvement and others were not. Findings in this study indicate, from a consumers’ perspective, that carers make a significant positive contribution to their staying well. Support both material “mum brings me stuff” (p207) and emotional “just being there” (p207) was reported to be critical to some consumers’ stability. Other consumers liked knowing that the support was there but liked to be left to make their own decisions (Lakeman, 2008).

In the same study the author identified obstacles to family involvement. The main obstacle cited was poor communication, that is, their loved one was given too much leeway without input from carers. Carers argued that they were excluded from decisions that impacted on their son, daughter, partner etc. As well carers reported they were left out of decision making for confidentiality reasons. This made carer involvement difficult (Lakeman, 2008).

Goodwin and Happell (2007) in a study exploring carers’ views also identified access to information as barrier to participation. The participants identified being denied information or any opportunity to be involved in decision making as problematic. Further, this study found in rural areas that carers experience of participation in mental health service decision making was at best variable (Goodwin and Happell, 2007a).

In another paper by the same authors (involving the same focus groups) barriers were identified to participation. These included; changes in the pattern of service delivery (i.e. shorter stays in hospital); lack of availability of professionals and that information (on their loved one) was unavailable for confidentiality reasons (Goodwin and Happell, 2007b).

These authors found that carers are well aware of the contribution they make to service delivery and that their views need to be respected (Goodwin and Happell, 2007a).

Although, as discussed above, housing is a critical aspect of recovery and carers are an important part of recovery for many people living with a mental illness there is limited research exploring carers views of what is appropriate housing for their loved ones when they are discharged from hospital. It is

timely that a study was conducted that explored carers views on housing for people living with a mental illness especially when they are discharged from hospital.

### **The Study**

This study is part two of a two-part exploration of the views of consumers (see Browne & Hemsley et al., 2008) and carers on the housing needs of people living with a mental illness. This part of the project aimed to investigate carer's perspectives on the recovery needs of consumers who have experienced an episode of acute mental illness during reintegration into the community, with a particular focus on housing needs.

### **Method**

The study took place in two phases: 1) a literature review and review of current services and 2) Three rounds of focus group consultations with participants. This paper reports on the findings from the focus groups.

For this study an approach was needed that facilitated consultation, participation and empowerment. The commitment of this project to carer participation meant there needed to be some flexibility in the methodology. In an attempt to include the views of carers, a three-stage iterative process using focus groups was used. The first group began with a review of the literature by the research team. The aim was to give to the carer participants and overview of current researcher. Although there is a risk with this strategy that the carers' views are influenced by the literature, consistent with the principals of empowerment, the carers were thought capable of making their own decisions.

Focus groups are of benefit in exploratory research as they offer an opportunity to explore a variety of opinions and views. The dynamics of a group allows members to clarify and qualify their views as they are discussed (St John, 2004).

Ethics approval for this project was given by the Griffith University Ethics Committee and the Gold Coast Health Services District Ethics Committee (Queensland, Australia).

### **Participants and Recruitment**

The local branch of the Mental Illness Fellowship of Queensland (in Queensland the Mental Illness Fellowship has recently changed its name from the Schizophrenia Fellowship) was informed of the study and agreed to support this project by advertising for participants through their network. The Mental Illness Fellowship is a non-government organisation that provides services and support for people living with mental illness and their family members (Mental Illness Fellowship Queensland Inc., 2009).

Following a presentation outlining the project to a group of consumers and carers, eight carers, seven women and one man agreed to participate in the project. One woman was the partner of a consumer the others were parents of adult children (aged 28-50) living with a mental illness. From the initial eight one woman failed to return after the initial focus group, the data from this participant was deleted and not used in the analysis. The participants ages ranged from 49 to 74 (mean 61.3 years). Their sons and daughters lived at home with their parents (n=1), in supported housing (n=2), in hospital long term (n=1) and independently (n=2). The participant partner lived together with the person with a mental illness.

Consistent with a philosophy that valued carer's views, participants were offered \$A30 per hour for their time. Settling on a rate for payment was a challenge, because there were few precedents. Funding was administered by Griffith University, whose finance system had no category for 'research participants' and thus participants were paid as 'research assistants'. This is worthy of note in light of mental health services current discussions around the status/role of carers.

### **Data Collection and Analysis**

The three rounds were moderated by the data collection/analysis team. The team consisted of the authors who were both experienced mental health nurses skilled in group facilitation.

Data were collected during three sessions each lasting between 60 and 90 minutes duration held once per week in a room supplied by the Mental Illness Fellowship. The Round 1, 2 and 3 focus groups were audio-taped and data were transcribed. Field notes were also taken during each group to assist in the analysis.

*Round 1* The group was given a brief presentation that included an overview of the findings from a literature review in relation to the housing for people living with a mental illness. Participants were asked to make recommendations for the recovery needs of people on return to the community after an admission to hospital. Initially a list of questions was prepared to encourage discussion, but these turned out to be unnecessary as the participants were happy to articulate their views.

*Round 2* A summary of the themes arising from Round 1 analysis was presented to the group. Participants were asked for comment and feedback, which led to further discussion and clarification of issues.

*Round 3* The findings from rounds one and two were presented to the group for final discussion and possible consensus.

Data were analysed by the research team for emerging themes after each focus group session and the questions revised in response. Finalised themes were validated by the group in the final session.

## **Findings**

As stated above, this study explored the views of carers concerning the recovery needs and challenges for consumers, with a strong emphasis on accommodation. All the participants spoke personally and passionately from their own experiences of caring for loved ones recovering from mental illness

Two broad themes emerged during the initial rounds of the data collection; 'Safety and vulnerability' and 'Stigma and the consequences of living with a mental illness'. During the third round the discussion the participants narrowed in on recovery based housing, with the carers sharing their strong views on this issue and making recommendations about essential elements of this housing.

### **Safety & Vulnerability**

Safety for their "Kids" (participant's word) with a mental illness was a high priority for the parent participants. They felt their loved ones needed protection both because they were vulnerable as a result of their illness and stigma from the community. Especially when they were ill, but also during the very long recovery from an acute episode of mental illness. The parents seemed to believe their sons and daughters needed protection from a number of risks in the community including:

- Protection from themselves when they are unwell. D, a mother of a 45 year old man with a long term mental illness, reflected a commonly (for this group) held view when she said "our sons and daughters are like children" and "Sometimes the kids think they are well but they are not". There was general agreement that there needs to be a balance between choice and compulsion in accepting treatment. Health services not the police should be responsible to make sure people cooperated with their treatment.
- Protection from drugs that were, reportedly, readily available from other consumers in some shared accommodation. Ja is the mother of a son and daughter with a mental illness, they have had numerous admissions. She reported ongoing problems for her son in shared/supported accommodation and argued that having support workers on site was a necessary part of supported housing ".....there's still need someone to watch over them because they won't stay well .... if they use drugs and alcohol as well, well they're going to go right back (to hospital) again".
- Carers agreed that it took a long time for their "kids" to be able to care for themselves after they leave hospital. B, a father with a 28 year old son, said ".....know its basically it's, they lose their confidence and you've got to get them up to speed again and that usually takes 12 months to do those sorts of things".

- Women need extra protection they needed locks on doors in shared accommodation as the men were sometimes threatening. L the mother of a 42 year old daughter with a mental illness reported “the girls being frightened because when we first started out X [the name of a supported accommodation facility] there was a girl that came to us very distressed about being in there with the fellas. So what they did, they put a lock on the door, they didn’t like doing it but they put a lock on the door for them”. When the locks were installed at X the men preferred those rooms also. Apparently they felt safer and appreciated the privacy too. Participants thought there should be the option of separate accommodation for men and women. “They would feel safer” was the general view.

### **Stigma and the Consequences of living with a mental illness.**

Lack of money was identified as a significant problem by all carers. It impacted on all areas of the lives of consumers. It made finding accommodation difficult in a market where prices seem to be constantly going up.

Stigma is another major issue from the community in general, from estate agents but also from MH professionals. Stigma from the media is an ongoing problem and makes things worse. Participants’ reported that their children suffered discrimination both real and imagined. They also reported that their loved ones went to some lengths to avoid letting people know they had a mental illness. D said about her son that ‘now he catches the bus down to our place in ..... and he’s found out he can buy a weekly so that he doesn’t have to show his card (pension card)’.

Dealing with renting is fraught with difficulties, the stigma from agents, the need to be organised to handle agents. The paper-work and the records needed to secure rental accommodation was a challenge, often it was lost when their children were unwell. Some times the “Kids” suffered because of their own behaviours when they were unwell some times it was because of someone else with drug related problems. Jo, the mother of a son with schizophrenia, told a story

He..... play his music a bit loud and one of the neighbours found out through someone else that he had mental illness and the neighbours, talk about stigma, all got together, took up a petition went to the Landlord and she put him out. And he pays rent every time, his unit was spotless yet the guy next door was on drugs, kicking walls in, doors in, you couldn’t get him out, but our son!

Carers wrestled with the dilemma of; do you tell the agents about the mental illness? Some are sympathetic and help but most avoid people with a mental

illness. This is a dilemma experienced by most participants. Jo described hers:

We sort of we understand but you know because our own problems with our own its hard that they don't want to get involved, I find it a little bit daunting so you imagine people that haven't had any experience with mental illness how scary it is. So I understand how real estate people might feel, people that might have a unit to rent, naturally they are not going to, if I came along and my son had schizophrenia they don't want to give it to me, its just human.

That combined with the instability of rental accommodation made it very difficult to find and maintain reasonable housing "The rules are always changing" "Rents going up" "flats and houses being sold".

Participants generally agreed that existing health services do not provide adequate care - leaving people in the community whilst unwell. B felt strongly that present services were not adequate:

We find with our son that you've got just teach him how to you know how to, to umm cope I suppose. Just very basic things like, if you take them to see somebody, where you're going out to do something they'll say "what am I going to talk to them about?". You know and that's someone that they're close to normally when they're well. "What on earth am I going to say?" You know, "How am I going to get to" say we're going to go by bus, "What am I going to tell the driver?" You know, "How do I know where to get off?" You know it's all that sort of stuff, its all, all very basic stuff that they just lose their confidence completely..... I think in that initial recovery thing. Because all the hospital does is, they just push them down the front steps and they don't want to know about it right? Don't bother us again until you're really acutely ill. And this happens all the time. You get them home and then they're not well enough to be home.

Participants believed those they cared for need a high level of supported accommodation when they are in early recovery (when they leave hospital). This accommodation should offer the option of separate accommodation for men and women. It should offer something constructive to do e.g. gardening. The accommodation should give everyone their own space eg separate flats, their own room in houses on a farm or own room in a motel.

- The accommodation should support them to regain their living skills.
- Some people will require high levels of support for long periods of time.

- Supported accommodation should be stepped with a gradual reintegration into the community. That the process should include integration into independent housing, work and social activities.

### ***Carer's Vision for housing***

When asked about their ideal housing there was significant discussion around the idea of a farm. A farm - where the consumers could regain living skills in a safe, supported environment. There would be separate accommodation for men and women. It would need to offer constructive activities that encouraged self esteem. Gardening was highly recommended as it is healthy, natural and rewarding.

Participants came up with a number of recommendations they thought were important to consider when planning accommodation for people recovering from mental illness. There was discussion around a number of issues but general agreement that:

- Safety for people is one of the cornerstones of rehabilitation housing. Safe from exploitation by the world, safe from other consumers, and safe from their own danger to themselves. Sometimes health services may need to take charge of the children's lives to maintain their safety.
- Consumers need a high level of support in their accommodation when they are in early recovery (when they leave hospital). This accommodation should offer the option of separate accommodation for men and women. Something constructive to do e.g. gardening. The accommodation should give everyone their own space eg separate flats, own room in houses on a farm or own room in a motel.
- There should be support to help them to regain their living skills.
- Supported accommodation should be stepped with a gradual reintegration into the community. That the process should include integration into independent housing, work and social activities.
- Stability in housing is integral to the mental health of people living with a mental illness; it helps them to have a feeling of belonging, to feel safe and to set down roots. People should be able to return to their homes following hospitalisation.
- Stability in housing is important so a Brokerage model like in Project 300 could work. Support workers need to have knowledge of mental illness.
- Rehab services have decayed in recent years. Existing local services could expand rapidly with some injection of funds.
- Flexibility and choice in accommodation are important.

## **Conclusions**

The literature and public policy clearly indicate that carers have an important role in the delivery of mental health services. Carers are often the main supports for consumers when they leave hospital. Their views on housing should inform decisions about where consumers go when they are discharged and future planning around supported accommodation.

A high priority for carers (especially carers who were parents) was safety of their loved ones. Although the idea of having a farm is not new (they were part of the care at many Australian psychiatric hospitals until the late 1980s) it is probably not feasible. The interest in the idea does demonstrate clearly that carers believe that current community and rehabilitation services are inadequate and leave their loved ones vulnerable and unsupported.

The safety concerns were a result of the mental illness but also the stigma from the community and vulnerability from unscrupulous people in the community. Carers were concerned for the physical and sexual safety of their loved ones and also for their vulnerability around money.

Carers felt women needed extra protection. This was evident from the discussion around locks on doors in supported accommodation. Interestingly Participants reported that the male consumers also preferred that their rooms have locks.

Stigma was also a concern for participants. The stigma meant they had a dilemma when helping to find accommodation. Whether, to tell real estate agents about the mental illness or not. Carers felt they as well as their loved ones suffered from the stigma.

Of concern also is the participants' experience of stigma from mental health professionals. In a study exploring the experiences of mental health nurses living with a mental illness the participants (nurses who were also consumers) suffered negative attitudes towards them (Joyce et al., 2007).

## **Implications for Service Delivery**

As discussed above quality housing is critical to the delivery of mental health services. Especially so, when people are discharged from hospital. The question is what is appropriate housing? Current philosophies of service delivery are rightly informed by the notion of recovery and participation. Therefore studies, such as the one presented here, which explore issues of concern to carers are particularly relevant. In the past supported housing has included use of 'half way' housing. Housing that is provided with support but for a limited time. The carers clearly believe, as do consumers, that housing is best if it is stable and the services are brought in. This seems to be

consistent with recent literature (Browne et al., 2008, Browne and Courtney, 2005b).

Carers also clearly believe that not only support but also some level of control is needed to help their loved ones to stay safe and well. This is interesting as it contradicts consumer's views expressed in another part of this study (Browne et al., 2008). At this stage there is only limited formal acknowledgement that consumers and carers may well disagree on what is the best way to deliver service. It is valuable and timely to acknowledge the dilemma confronted frequently by mental health professionals, when the need to support carers in their crucial role is set against the right of self-determination and confidentiality of consumers. Sadly there seems no ready resolution to this dilemma.

Perhaps of greatest importance for service delivery is how this study can contribute to the debate that policy makers and agencies providing funding for mental health services need to have. Where inpatient services struggle with patient populations swollen with numbers of consumers presenting multiple times (the "revolving door syndrome"), the need to allocate funding to support the recovery needs of consumers with appropriate housing is recognised as cost effective where the very high cost of acute inpatient care is considered. Therefore understanding of this at government - level is critical, where funding of public housing can be allocated without forcing health bodies to allocate vital funds to expensive housing options.

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