Mental Health Community Coalition ACT

Peak Body for Mental Health in the ACT

response to:

Inquiry into Appropriate Housing for People Living with Mental Illness

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Mental Health Community Coalition - Background Information

The Mental Health Community Coalition is the peak body for mental health in the ACT representing community groups, consumers and carers who are involved in the mental health area. It provides a central body for advocacy, representation and information.

The Vision of the MHCC is:

To be a Dynamic Focus for Better Mental Health

The Aims and Purposes of the MHCC are to:

> *enhance co-operation and information sharing among all stakeholders including consumers, carers, community organisations, service providers, health professionals, government agencies and other interested parties*
>
> *represent mental health consumers, carers and community sector organisations who share a common goal of enhancing the wellbeing of people affected by mental illness, and promoting the mental health interests of the ACT community and surrounding region*
>
> *advance and promote adequate and high quality mental health services in the ACT*

In order to meet the objectives the MHCC encourages a flow of information into and out of the organisation. The flow in is facilitated in diverse ways. The MHCC holds forums on issues of significance to the mental health community the last was 'Raising the Roof' dealing with issues of accommodation. The MHCC also holds focus groups and accommodates individual representation. Forums so far have attracted over 60 individuals.

The flow out is facilitated by the creation of a fortnightly e-bulletin. This supplies adequate and timely information providing a central information source for consumers, carers, community organisations and others who are interested in mental health in the ACT.

The MHCC represents the mental health community locally and nationally within government agencies and the community sector. It provides submissions on issues of concern to its constituency.

Within the first nine months of operation the MHCC has aimed to make significant inroads to addressing the objective of the organisation. This submission forms part of that objective.

Part 1

A right and a need for safe, secure and appropriate housing

Human Rights

'Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.'[1]

After the atrocities of the Second World War the United Nations defined those things which were non-negotiable to the human condition. Article 23 states clearly the right of human beings to be housed. Australia is a modern westernised country with adequate reserves. Canberra is the capital city of that country with greater wealth that the rest of the population yet there is still pressing need nearly 60 years after the Geneva convention was written to highlight the needs of people with a mental illness who are not housed or inadequately housed in the ACT.

Maslow

Maslow wrote about the needs of human beings, all human beings not just those with a mental illness. It is salutary to read of those needs and compare them to the experiences of some people who have a mental illness in the ACT. Maslow identified physiological and psychological needs including the need for food, water, sleep and a feeling of safety. Without adequate accommodation offering safety, security and feelings of connectivity the needs will not be met.

In terms of Human Rights and in terms of psychological and physiological human needs accommodation is an essential component of good mental health. People with a mental illness are more in need of adequate housing than the rest of the population.

Existing Housing Options

Private for Purchase

The private for purchase section of the market is often inaccessible to people with a mental illness. The nature of the disability often prevents mental health consumers from obtaining and keeping consistent employment. People with a mental illness are often excluded from the private sector by nature of not being able to access or retain a mortgage.

House prices have increased significantly in Australia in the last five years and Canberra is no exception.

Private for Rental

The path to private for rental is also hard to navigate. Private rental requires a substantial bond and fortnightly rental payment. Many people with a mental illness are on low incomes and unable to acquire sufficient savings for a bond or pay the higher fortnightly rental.

Since the 2003 Canberra fires the private rental market has become more expensive thus less available.

Community Housing

A number of groups in the ACT provide community housing. Community Housing varies in nature and quality but is widely sought after because of its culture and modest rents.

It is often unavailable because demand exceeds supply.

[1]Universal Declaration of Human Rights, Article 25

Supported Accommodation

Supported Accommodation Assistance Program (SAAP) services are one of the mainstays of people with a mental illness and services are in very short supply. SAAP services cover a wide range of service provision.

In March 2005 the Institute of Health and Welfare publication 'Homeless People in SAAP' highlighted the level of unmet need in the ACT. Unmet need increased by 86% in the 2003-4 financial year. The largest increase in unmet need was for single women. One thousand requests for help were refused in the financial 2003-4 year. This is over double the declined requests from the previous year.

Public Housing

Public Housing is the largest sector of housing available to people with a mental illness in the ACT. Housing stocks have significantly decreased in the last few years partly because of the demolition of some units such as Lachlan Court and Burnie Court which have not been replaced and the refurbishment and evacuation of some blocks such as Frazer Court.

The housing stock at February 2005 stood at 11,510 properties with a waiting list of 2,950 applicants. Priority One applicants (i.e. those deemed in need of immediate housing) have a wait of 8 months *(Maureen Sheehan – 'Raising the Roof Forum' May 9th 2005*). The community sector estimates a longer wait.

Specialised Housing / Accommodation

Specialised housing or accommodation is essential for people with a mental illness. It may be accessed for short stays or much longer stays. Specialised housing and accommodation places are in short supply. One such establishment is Brian Hennessy Rehabilitation Centre and is auspiced by MHACT. Recent changes in forensic policy will reduce the accommodation for mental health consumers at BHRC. The secure unit at BHRC will now be used exclusively for forensic mental health consumers.

Specialised Housing and accommodation is available within the community sector by providers such as Richmond Fellowship, the Mental Health Foundation and others.

Part 2

1. The flexibility of criteria for gaining access to public housing

While part one highlights the type and availability of accommodation and housing in the ACT, this section will look at the process of accessing public housing for a person with a mental illness and look at some of the added problems associated with this.

People who live with a mental illness do not exhibit one set of behaviours at any one time, nor do they continue to exhibit the same behaviours. However at various times and in various degrees people with a mental illness can exhibit behaviour and thought patterns which inhibit their access to and sustainability in public housing.

> *'The mental illness and or psychiatric disability can affect basic abilities required to access and sustain tenancies, such as completing an application form for housing.'*[2]

Form filling, keeping appointments, retaining appointment cards and making adequate use of the telephone especially when in telephone queues can inhibit a person with a mental illness and act as preventatives to accessing public housing. In a worse case scenario the stress can precipitate a further episode of illness.

Importance and Difficulty

For a person with a mental illness, applying to be a tenant in the public housing system is not one of a list of options, it is often the only option. To achieve a priority listing is critically important. The importance of this process and the anxiety that this places on people with a mental illness cannot be stressed too highly.

The complexity and amount of paperwork needed to be placed on the priority housing list can be daunting to a well person. Because of the importance of 'getting it right', panic and stress can be the unwitting side effects of this process for someone who already has the burden of mental illness.

Extra Costs to Mental Health Consumers

The process of applying for accommodation with Housing ACT is not without financial cost. Accessing a doctor, psychologist or psychiatrist to request a letter of support can in itself be costly, as can photocopying, bus fares and postage. People with a serious mental illness are often on low budgets and this is a significant burden.

Letters of support from doctors and psychiatrist are sometimes inadequate and thus unsupportive. One doctor was reported as writing:

> *'I support this person's application for priority housing'.*

The doctor may have been unaware of the important of his input and the distress caused to the consumer because of the inadequacy.

Itinerancy as a Barrier to Accessing Housing

Mental health consumers who have a priority listing with Housing ACT can be difficult to trace when housing becomes available for them. Countless changes of address can occur from the time of application to Housing ACT to the offer of accommodation.

> *'One young woman was offered housing but didn't find out until much later because she had changed address so many times since she'd first applied for priority housing'. Service Provider ACT*

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[2]Reynolds, A. Inglis, S. O'Brien, A. 2002, *'Linkages between housing and support - what is important from the perspective of people living with a mental illness'* Australian Housing and Urban Research Institute

Required: Adequate linkages between service providers to alleviate this type of problem

Perceived and Real Stigma

Some consumers choose not disclose a mental illness when applying for housing for fear of discrimination. Whether their anxiety is perceived or real it exists and can be a bar to accessing housing as readily as it is required.

> *'Some individuals may not have an awareness of their illness or be unwilling to disclose their illness to others for fear of repercussions, however the ability of housing and support providers to respond effectively can depend on having such information'*[3]

Service Staff

Concerns were raised about the level of understanding and knowledge of mental illness by direct service staff and managers. In the ACT many service providers have commented on the lack of knowledge and understanding of front desk staff when dealing with someone with a mental illness. Consumers who may be rude and demanding as a side-effect of their illness can be treated in a discriminatory manner.

> *'There was a lovely woman in one office. She heard the fuss X was making came out and started talking to her normally. X settled down did what she came in to do. That women left though and no one since has had the skills to help X.' Service Provider ACT*

The community sector acknowledges that significant training and up-skilling along with appropriate behavioural responses when dealing with mental health consumers would assist both the service deliverer and the consumer.

Housing ACT employ specialised staff who address the needs of people with complex problems. One consumer commented that the specialist staff allocated to her had little or no knowledge of mental illness. She commented that the brief of the staff member was too diverse to allow specialisation in any one area.

The statement below, reportedly spoken by a manager to a mental health consumer after a community meeting discussing the issues of mental health and housing, highlights the need for training and understanding of basic issues around mental health.

> *'…but you look too normal [to be a mental health consumer]' Housing ACT Official speaker to a mental health consumer.*

Required: Up-skilling of knowledge of mental illness is needed by Housing ACT staff at all levels

Access to Housing Denied - Slipping Through

[A case study was provided but not authorised for publication by the Committee due its potentially identifying details.]

Transfer in Housing Denied – Falling Through

[A case study was provided but not authorised for publication by the Committee due its potentially identifying details.]

Required: Flexibility and response to serious need from Housing ACT

Housing Stock

The most direct cause of a person seeking and not accessing public housing in the ACT is the decline in the quantity of housing stock.

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[3] Ainsworth, E. 2000, '*Housing Clients with Psychiatric Disabilities: Enhancing Service Responsiveness*,' OT820 Supervised Project, OT, University of Queensland

'… in 1998 or thereabouts a young person with a dual diagnosis [mental illness and drug and alcohol use] returned to the ACT. This person slept on people's floors for less than 3 weeks before being offered public housing accommodation' Service Provider ACT

At the 'Raising the Roof' forum provided by the Mental Health Community Coalition in May 2005 the representative from Housing ACT stated that as a priority one applicant a person would be on a waiting list for 8 months (service providers say this is more likely to be 12 months). Whatever the difference the effect is the same, homelessness, decreasing capacity for maintaining stable mental health and disdain for the Human Rights Act of the ACT. See section1 for more information on availability of public housing.

Required: Adequate and appropriate choice in housing and accommodation with support provided for people with a mental illness.

2. Support mechanisms for people who currently live in public housing

Choice

> *'For people living with a mental illness, the ability to choose, access and maintain secure, appropriate and affordable housing is often the cornerstone to stabilising their illness and improving their quality of life.'*[4]

Little has changed since the above statement was made in 1990.

The ability to choose where to live is one of the freedoms most of the population enjoy. This is sometimes not the case for people with a mental illness but can be the decider between healthy living and the 'revolving door syndrome' (frequent trips to the PSU). Much of the single accommodation in the ACT is in large, noisy, multi-storey complexes where many single people live. Many people with mental illness are housed in these complexes. They are not the place where a person with confusion, frequent delusions or profound depression would choose to live for their health's sake, yet there is often no choice.

> *'There are all-night parties, people get very drunk, the police are here often, and fire hydrants regularly let off.' Mental Health Consumer*

Other comments about living in unsuitable accommodation range from:

> *'I've had window broken by a bullet.' Mental Health Consumer*

To:

> *'I was broken into by a drunken man and woken up in the middle of the night.' Mental Health Consumer*

This situation is not conducive for people with good mental health but even less so for people with mental illness.

Choice not to live in such circumstances is not an option (see 'Transfer Denied'). The need for choice between *acceptable alternatives* of housing and accommodation will be addressed in statement 3.

Co-ordination of Service Response

Accommodation alone will not lead to successful and sustainable tenancies or lives for someone with a mental illness unless adequate and appropriate services are set up at the outset as an integral component.

> *'Giving people a roof and nothing else is setting them up to fail and they'll just end up back in the PSU'. Service Provider ACT*

One of the effective approaches to prevent people being set up to fail is detailed below.

> *'…developing service responses that allow for assertive outreach, time to build relationships, responses to unpredictable fluctuations in needs and capacities, consistent support, cross service coordination, planning for crises and addressing interagency confidentiality issues'*[5]

ACT documents from the Social Plan to the Mental Health Strategic Plan stress the importance of integrated service provision, coordinated services and a seamless service response. In reality this rarely exists. Significant improvement in service coordination and response would enhance

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[4] Keck, J. 1990, 'Responding to Consumer housing preferences: The Toledo experience' *Psychosocial Rehabilitation Journal*, 13(4) pp51-58

[5] Reynolds, A. Inglis, S. O'Brien, A. 2001, *'Effective program linkages: An examination of Current Knowledge with a Particular Emphasis on People with a Mental Illness: Position Paper.'* Australian Housing and Urban Research Institute

the capacity of mental health consumers to retain tenancies and be set up *to succeed and not to fail*.

An example of lack of service co-ordination, or lack of service availability is identified when a person leaves the Psychiatric Services Unit. While resident in the PSU a discharge plan is constructed with the discharge planner. This can assure the consumer that a MHACT worker will access them within a week of discharge. However on exit from the PSU consumers are still seriously unwell. Consumers can and do go home to a cold, unwelcoming environment with no food and an escalation of bills. Frequently the result is a return to the PSU within a short time period.

Adequate, appropriate and respectful information sharing with suitable organisations including timely communication could turn this and similar instances into a positive experience with no 'revolving door syndrome'. Appropriate resoucing would be necessary.

Cooperation with MHACT and Housing ACT

Partnerships exist between the community sector and government agencies. The partnerships are important but of concern to the community sector. Where partnerships exist they need to be based on goodwill and mutual respect. Currently it is perceived by the community organisations that this does not exist or, if it does, it does so in an inadequate manner. Recognition by government agencies of the unique role community organisations provide in service provision would lead to an appropriate sharing of information which in turn is vital to good outcomes for consumers. Currently this does not happen. The reasons put forward include the different focus in service provision. The psychosocial model of care (provided primarily by the community sector) differs from the medical model. The psychosocial model sees the consumer within their environment and addresses the issues relevant to the consumer. The medical model is the main tool of MHACT and is different but not incompatible with the psychosocial rehabilitation model used by community organisations.

A lack of respect for the professionalism of the community sector was also commented upon by the community organisations and information relevant to both services is not shared resulting in fragmented and sometimes counterproductive service delivery to shared clients. There is an MOU but it is perceived to be inadequate or not adhered to by all MHACT staff.

Required: Mutual respect and appropriate information sharing between agencies

Cooperation between service providers

Problems were reported between service providers within the community sector. The competitive climate created by the previous funding model (purchaser provider) has had an adverse impact on relationships between providers. This will take time to heal. The competitive tendering model encouraged a large number of small projects. While choice is essential for the consumer, so are sustainable and long term projects to provide that service.

There is no clear mapping of mental health community services in the ACT available to the community and other service providers. Mapping was identified as a great need within the community sector. Mapping would inform the community of service provision and identify significant gaps. An annual update would also be important. This piece of work would be of immense benefit to the sector.

Required: A mapping process showing what services exist, how the service is provided, the philosophy underpinning service delivery and linkages between service providers.

Housing ACT - Urgency

Housing ACT could achieve greater consumer satisfaction and improve the sustainability of tenancies for people with mental illness by increasing the responsiveness of maintenance work. Issues which appear non-urgent can be of major need to a mental health consumer. Issues of safety as perceived by the consumer need to be addressed with the same urgency as they are requested. For example, Post Traumatic Stress Disorder (PTSD) is debilitating by itself but can also accompany other mental dysfunction. People with PTSD often need added security, secure back yards, window locks and other additional inexpensive features which enhance the quality of life and feelings of safety and security. It is estimated that up to 80% of women with serious

mental illness were sexually abused as children. A request for window locks is an urgent need and an urgent response is required.

Required: Understanding the need for an urgent response by front line and maintenance staff.

Stigma Impact, Tenants and the Community

The knowledge and awareness of mental illness by other tenants in public housing can be of great assistance to a person with a mental illness. The absence of stigma and discrimination in neighbours is of the utmost benefit.

> *'Lack of community awareness, education and therefore understanding of mental illness can lead to discrimination, stigma, fear, compounding the difficulty of living in the community with an illness'*[6]

Unfortunately this situation is all too rare and people with a mental illness can at best be given 'the cold shoulder' and at worst be victimised by other tenants.

Some public housing tenants are concerned about the developing mental illness of their neighbours but there is no service to contact when a consumer becomes unwell. MHACT Crisis Assessment and Treatment Team (CATT) will respond when someone is suicidal or endangering another persons life. The Police are the only option and there is little they can do to help the consumer. The Police Federation's submission to the recent Senate Inquiry expressed concerns about the frequency with which the police are dealing with mentally ill people who have committed no crime. This service deficit has been noted many times by consumers, carers and community organisations. When consumers are becoming unwell there is no service provision. The only option is to wait until a life threatening situation eventuates, then they may or may not be admitted to the PSU. This is a serious service deficit.

Required: Provision of and access to appropriate services when consumers are becoming unwell

[6] Reynolds, A. Inglis, S. O'Brien, A. 2002, *'Linkages between housing and support-what is important from the perspective of people living with a mental illness'* Australian Housing and Urban Research Institute

3. Opportunities to involve Non-Government stakeholders in the provision of appropriate housing

This section looks at permanent and temporary housing and supports needed by people with a mental illness that are not provided in ACT service providers. Linkages and identified responsibility between Mental Health ACT, Housing ACT and community service providers are paramount to the success of adequate housing.

Adequate housing and appropriate service provision is a health promoting exercise and can prevent further episodes of mental illness. The need for personal choice has been highlighted in the previous statement. The variety of existing choice is listed in part one of this document. Highlighted below are specific 'other accommodation facilities' needed at times by mental health consumers.

PSU

The PSU provides accommodation when a consumer is in danger to himself or others. This is usually short term and the consumer is discharged while still unwell but no longer a danger. This service is provided by MHACT and information is given here to place the services below in context.

Step Up Facility

This type of facility operates successfully as a place where mental health consumers can *choose* to go when they are becoming unwell. Here they are cared for in some circumstances by trained peer support workers with visiting medical workers. The atmosphere is conducive to regaining wellness without reaching a critical situation. The aim is to avoid a crisis and admittance to the acute service. The length of stay in a successful UK model is a maximum of three weeks. Step up facilities are situated in the community in ordinary suburban houses needing no special or expensive facilities. Currently this type of service does not exist in the ACT. *See Appendix 1 'Crisis Housing'*

Step Down Facility

As mentioned earlier, on exit from the acute service, mental health consumers are still unwell and a return to their normal accommodation can be a start of the 'revolving door syndrome'. A step down facility serves a similar purpose to the step up facility but admittance is after an acute episode of illness, on exit from the PSU, while the consumer is still unwell but no longer a danger to himself or others. The step down facility enables the consumer to become well in a safe, caring and non-medical environment. Trained peer support workers are often the choice of consumers for their care workers. After a short period of time consumers leave the step down facility and return to their normal place of residence well and able to continue normal life. Currently there is no facility in the ACT which offers these services. *See Appendix 1*

Implementation

The options of step up and step down facilities rely on a series of conditions; that suitable housing is available; that suitable staff are trained and available; that community organisations are sufficiently resourced to supply the service and foster linkages with Mental Health ACT; that workers from the community and MHACT are sufficiently flexible to support the consumers in the chosen option. Joint training of MHACT staff and the staff of the facility would assist in mutual respect and common goals, a deficit noted earlier in the document.

Required: Resourcing step up and down facilities in the ACT

Housing Options - Choice

The type of accommodation offered in *Group Housing* is often viewed as appropriate accommodation for people living with serious mental illness and in some cases it is both appropriate and preferred. However many people living with a mental illness prefer to have

their own accommodation. With appropriate supports the type of accommodation people chose for themselves is often the most successful.

Supported *Cluster Housing* is appropriate and preferred by some consumers, others have no desire to live in an 'enclave' of mental health consumers. Listening to the consumer preference and trying to provide the type of accommodation preferred can be best for the consumer and their mental health and the permanency of their tenancy.

A very small group of mental health consumers need the safety and security of *long term safe accommodation*. This has been noted in the Promotion, Prevention and Early Intervention document of the ACT (draft form on the MH website) as a need for 'sanctuary'. A very small number of consumers need the support and security of the long term safe accommodation.

Currently *rehabilitation accommodation* is available in the ACT. This varies in length of stay and intensity of support. The length of stay in this type of accommodation is often an issue. Because of pressure on resources the consumer can be discharged too early.

> *'He was doing so well in Hennessey they thought he would be OK in his own place. They didn't realise he was doing so well* because *he was in Hennessy.' Mental Health Carer*

The young person mentioned above was discharged back into the community and within a very short time was again in the PSU. The length of time of stay and the quantity of rehabilitation accommodation in the ACT is in short supply.

Required: An increase in the variety and quantity of short and long term housing options for mental health consumers.

Leasing to Community Organisations

Housing ACT provides housing to a range of community organisation who use the facilities to provide accommodation and support to people with a mental illness. The services provided and the length of stay differs from service to service. There are many different types of service provided with many different names: Rehabilitation; Planned Respite; SAAP. SAAP housing covers many of the refuges and emergency accommodation options. However all combine the elements of housing/accommodation (both long and short term) and support.

Being both landlord and therapeutic service provider creates a conflict of interest and complicates and confuses relationships with the consumer.

However this causes a dilemma. If the community provider decides that service delivery in these circumstances is too difficult and return the housing stock is to Housing ACT there is a consequential loss of accommodation choice for the consumer.

Barriers - 'The Measurement of Outputs'

Funding requirements deal in 'outputs' which is an inaccurate and inappropriate measurement when providing responsive psychosocial care.

Mental health consumers vary greatly in their need for service provision. Adherence to prescribed hours and lengths of time is plainly inappropriate. Meeting 'outputs' is appropriate to a business setting but not in a setting with mental health consumers who have chronic relapsing conditions and need services to respond to their illness and life conditions. One community service provider stated that some consumers after initial contact may need a phone call once a week for an extended length of time while other consumers need intensive contact over a much longer time frame.

Measurements and evaluations are essential for all service provision both to measure quality and to assess future need and service provision but a more realistic tool is required to accurately gauge the service provided and future service needed.

Required: A realistic and appropriate method of evaluation

4. The feasibility of alternate support based housing models

The first three items below describe specific accommodation and services for people with a mental illness.

The fourth item gives examples of carer involvement and the barriers to that support.

The fifth and final item describes areas of research into innovative financing of social housing.

'Crisis Housing'

This is a UK project which offers mental health consumers a choice when becoming unwell. Currently no similar service provision is available in the ACT. Some community organisations offer respite accommodation but it is not designed or staffed for the purpose of preventing or diverting from a critical situation of unwellness.

In the ACT the consumer must reach the crisis stage before the situation is addressed. At crisis stage the consumer loses all control over where they live. Added trauma includes of change of residence to the PSU, CATT, Tribunal and orders. 'Crisis Housing' offers a place where self-identified consumers who are becoming unwell can choose to go to regain wellness in a place where they are looked after by other mental health consumers (with backup) and stay for a designated period of time before regaining health and returning to the community. The ramifications of such a service provision would reduce the need and associated expense of the PSU, CATT and more importantly increase the consumers well being and sense of control over their illness.

> *'There's no care for us unless we are in crisis. Nobody even mentions recovery anymore. I want to recover'*[7]

See Appendix 1 'Crisis Housing'

'Consumer Operated Services'

A discussion paper written by Helen Connor and presented to the National Mental Health Working Group in March 2005 identifies services operating in the USA which are peer led and cover many of the issues involved in the scope of this submission from housing through to supports to enable people to stay successfully in that housing. *See appendix 1*

PARC

Prevention and Recovery Care (PARC) is a step down facility and highlights the success of systems working together. Comparable practice in the ACT would be staff of MHACT and those of community organisations sharing the care of consumers in a defined way. PARC has been running successfully in Shepparton since March 2004. The model is being replicated in other areas of Victoria.

PARC provides clinical and psychosocial rehabilitation services to prevent relapse and expedite recovery within an established mental health system. Goulburn Valley Area Mental Health provides intensive assessment, treatment planning and specialist mental health care, and Mental Illness Fellowship provides general supervision, psychosocial rehabilitation and therapeutic group activities. The intention of the PARC programs is to avoid hospitalisation and promote recovery following an in-patient admission.

Required: Research into existing models of accommodation and support for people with a mental illness successfully working elsewhere and establish facilities in the ACT

Carer Resourced

A number of carers who have adult children with a mental illness have established suitable independent accommodation for their children. The following are examples of current practice.

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[7] Mental Health Council of Australia, 2003, *'Out of Hospital Out of Mind' p20, 4.2.1.2 Spectrum of Care Settings*

One family have built a unit onto their house which is self-contained and successfully houses their adult child who lives a productive life in this semi-supported environment. The expense of the capital works have been met by the carers (who are retirees) with no grant or support available from government sources. Any rent is a peppercorn rent and does not cover the ongoing maintenance and expenses (eg water, lighting and heating expenses). The carers cover these costs. The carers will receive no profit from the 'improvement' to the site. This will be accessed by their heirs after their deaths. Some carers need a small amount of encouragement (eg modest capital funding or negating some building fees/ongoing taxes) to create independent, secure housing for the person they care for. The gain for the ACT would be less people on the housing list and more people with a mental illness housed in safe, secure and appropriate housing.

Other carers have bought a unit for the young person they care for. Again they rent it to the consumer at a peppercorn rent. The capital costs have been borne by the parents. The parents have not had access to the first time mortgage grant and are charged a higher rate of mortgage interest because the property is seen to be a rental property. Some carers are willing and able to support their mentally ill children in this way. With encouragement (eg reduction in taxes/mortgage rate or access to first time buyers grant) more parents could take this option and provide the consumer with safe, secure and appropriate accommodation.

Required: Innovative ways to reduce the financial burden on carers who support the consumer by providing independent accommodation

New Ways of Financing Social Housing

It is not within the scope of this document or the abilities of the writer to think creatively about funding housing stock for mental health consumers. However a few ideas follow.

The Australian Housing and Urban Research Institute (AHURI) website has a plethora of research papers and reports in this area. A few of the relevant one's are highlighted below with the direct web address.

1. *'A practical framework for expanding affordable housing services in Australia: learning from experience authored by Vivienne Milligan, Peter Phibbs, Kate Fagan and Nicole Gurran Australian Housing and Urban Research Institute*

   http://www.ahuri.edu.au/general/project/display/dspProject.cfm?projectId=89

2. *'Financing affordable housing: A critical comparative review of the United Kingdom and Australia' Mike Berry* Short Description - Critically compares the debates, research findings and policy developments directed towards attracting private investment into affordable housing provision in Australia and the UK.

   http://www.ahuri.edu.au/general/project/display/dspProject.cfm?projectId=92

3. *'New approaches to expanding the supply of affordable housing in Australia: an increasing role for the private sector' authored by Mike Berry(with the assistance of Jon Hall)*

   http://www.ahuri.edu.au/global/docs/final_affordable.pdf?CFID=236614&CFTOKEN=11945107

4. *'A private retail investment vehicle for the community housing sector' authored by Sean McNelis, David Hayward, Hal Bisset, Australian Housing and Urban Research Institute*

   http://www.ahuri.edu.au/global/docs/final_retailinvestmentvehicle.pdf?CFID=236614&CFTOKEN=11945107

Required Research into new ways of financing affordable housing and accommodation options for people with a mental illness

5. Any other related matter

Co-morbidity

The co-morbidity of people who have a mental illness and drug and alcohol use is high. The Stepping Stones report of 1999 stated that between 60% and 80% of people with mental illness also have drug and alcohol use. This document has focussed specifically on the issues of mental illness as the inquiry required however, in reality, the two issues of mental illness and drug and alcohol use are regularly interwoven. The issues and problems which emerge for consumers with co-morbidity are of greater magnitude and with wider ramifications than this document indicates. Judicial implications, loss of housing, unsupported returning prisoners and ever present debt are a few of the issues common in this population.

'Pathways to Housing' is an innovative programme started in the 1990's. Pathways' mission is to move people who are homeless and have psychiatric disabilities directly from the streets, shelters, psychiatric hospitals, and jails into permanent homes in order to provide immediate and independent housing, to begin the process of recovery and promote integration into the community and work life. 'Pathways to Housing' is one of a number of projects addressing the issues of co-morbidity and housing needs.

Overview at: http://www.pathwaystohousing.org/html/overview.html

CALD and Indigenous People

Culturally and Linguistically Diverse Communities and Indigenous people with mental illness have added difficulties both in accessing housing and in maintaining that housing. Issues of language, culture and stigma can be added problems for consumers from these population groups. Some cultures suffer from internal stigma and guilt concerning mental illness as well as the external discrimination endured by the mental health community a large.

The Aged

There is an increase in depression in the aged population. Isolation, bereavement and loss of physical health are all contributing factors. The needs of the aged population may differ from the needs of a younger group, but accommodation and support are needed by both. This group of mental health consumers are increasing in quantity and will continue to do so.

Borderline Personality Disorder

BPD is very difficult to treat in a climate where no consistent approach by all agencies government and community sector has been decided on. The Richmond Fellowship have successfully used the Everest program with individuals with BPD since 1994. However consumers with BPD will 'go shopping' to service providers, and without adequate linkages between all service providers, many case managers can be managing the same consumer. This is a great waste of resources and highlights the need for adequate and appropriate information sharing. Working with people with BPD is labour intensive and expensive. A lack of effective and consistent models of treatment used throughout service provision by MHACT and community services was identified as detrimental to the consumers and a drain on resources. More staff training is needed on principles of relationship with BPD clients

Required: An overarching vision to address the serious and complex issues detailed above, and resources to implement the vision

Solutions yet to be happen

> '*Support services will focus on individual needs and will have the capacity to bring together services such as mental health, alcohol and drug, emergency assistance, advocacy, tenancy management and financial advice and support to provide assistance as and when it is required.'* Breaking the Cycle - the ACT Homelessness Strategy, 2.4.2 For people at risk of homelessness

Appendix 1

Crisis housing

A home away from home

Contributed article written for Mental Health Today By Alison Faulkner, Head of Service User Initiatives, Mental Health Foundation Sophie Petit-Zeman, Medical writer Joanne Sherlock, Researcher, Sainsbury Centre for Mental Health Jan Wallcraft, Senior researcher, Sainsbury Centre for Mental Health

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Pioneering voluntary sector initiatives are complementing traditional inpatient psychiatric services with more flexible, accessible options. Crisis houses offers one such alternative.

Service users have been calling for alternatives to hospital for people in crisis for many years, but mental health policy and services have lagged some way behind. The Audit Commission's report 'Finding a Place' revealed consistently strong support among service users for community-based services, especially those offering 24 hour response and aiming to prevent hospital admission.

The needs and demands of mental health service users, the priorities of professionals and government policy do at last appear to be converging, with mental health practitioners and policy makers now calling for there to be a variety of responses to people in crisis. The NHS Plan for England and the National Service Framework for mental health recognise the need for improved crisis care, highlighting out of hours services and rapid responses to emergencies.

A Mental Health Foundation survey asked over 400 people who had experienced mental health problems what they wanted when in distress. Overwhelmingly, they answered 'someone to talk to'. The survey also revealed preferences for places of safety that can be accessed quickly and at any time, enabling people to avoid being admitted to hospital. In other studies, people reported that they preferred to use services which are flexible and responsive to their individual needs, allowing them to remain as independent as possible, and to retain the right to exercise choice over their treatment and care.

A recent Mind survey on conditions in psychiatric units brought together the accounts of 340 people with recent experience of hospital admission, and describes the experience as untherapeutic, depressing, and frequently unsafe. 57% of patients said they did not get enough time with staff.

Out-of-hours care is also vitally needed. Many community mental health teams operate between 9am and 5pm, although crises rarely fit obligingly into working hours. Many crisis services do not operate a 24 hour staffed service and it is clear that insufficient resources frequently prevent even these from providing adequate cover.

Last, research suggests that some service users want more control over their crises, for personal coping strategies to be recognised and respected, and for their strengths and skills to be acknowledged. By learning from crisis, people are then able to understand them within the context of the rest of their lives. This reflects the theoretical basis of crisis intervention as outlined by Caplan in which a crisis can be seen as an opportunity for change. In addition people are often frustrated by the solely medical response they receive from mainstream services.

The closure of large asylums and a system based on community care and short term treatment in general hospitals has had general support from the public, professionals, users and carers. However research suggests the lack of alternatives to hospital has led to increasing numbers of people with severe psychiatric problems living mainly in the community, and increased the

number of crises which these people experience. It has been estimated that the shift to community-based care has led to a 30% increase in referrals to the acute psychiatric sector.

The Crisis Programme

In 1996, the Mental Health Foundation took up the challenge of identifying and establishing models of good practice and launched a Crisis Service Development Programme to assist the establishment and assess the success of 'user-led' voluntary sector crisis services. The programme was underpinned by the recognition that the voluntary sector, in particular groups representing service users or minority ethnic communities, has a vital role to play in their development, and will require support. The funded projects were two residential crisis houses, one of which also operated a 'crisis sponsor home' programme in which local people took someone in crisis into their own home; two 'safe houses' providing weekend and evening support, and three telephone helplines.

Each project provided a different model of crisis care that had been developed to meet local need. This article looks in detail at the role and services provided by the residential crisis houses, Anam Care in Birmingham and the Nile Centre in north London, and a further north London residential crisis house not funded in the programme, Highbury Grove.

The crisis houses

Anam Cara opened in 1997 and currently occupies a four bedroom house in a residential area. Referrals are through home treatment teams (HTTs) or self-referrals from previous users of the service. It is intended for people who are in crisis and unable to stay in their own homes. The maximum stay is three weeks. The service is staffed by a team of people with "lived experience" of recovery from mental distress, who refer to themselves as 'recovery guides'. The main approach of staff is to 'be with' people, listening and giving advice if this is asked for. The crisis is seen as a potential turning point from which full recovery is possible, and this process is seen as one of personal growth. Where possible, staff work with people's families and social networks. A range of groups and activities are available, including numerous complementary therapies. The house is staffed from Monday to Friday 8.30am to 8pm and for four hours on Saturdays, with staff on call for four hours on Sundays. The service also runs crisis sponsor homes in which people agree to take people into their homes through difficult periods, with support from centre staff.

The Nile Centre

was opened in July 1997 to provide an alternative to hospital admission for African and Caribbean adults living in the London Borough of Hackney who experience a mental health crisis. The Nile Centre offers three distinct but complementary services: an outreach crisis response service, a short stay (up to three weeks) residential crisis sanctuary with nine beds including two family rooms, and a range of traditional and complementary therapies. It is staffed round the clock. The centre also sponsors a user-led personal development training programme designed for African Caribbean people, 'A Better Way Ahead'. The model used in the centre is African Caribbean centred with a focus on learning about patterns of relapse and developing coping strategies. This aims to help users and families to understand the meaning of crisis and how the crisis occurred, thus developing crisis plans for the future. It offers a place of safety and wholeness for users, and response to needs is holistic.

Highbury Grove

opened in March 1996 and initially provided both crisis beds and a drop-in social facility. The house has 24 hour staffing, with three workers at the drop-in between 8-9.30pm, and then two until 6am, with an additional staff member in the residential service at all times. It offers a 'safe' environment and operates a care planning process in which users needs are assessed at the point of entry and reviewed during their stay, with ongoing multi-disciplinary support arranged when they leave. Staff seek to develop a wide range of responses to user needs and to test and review ways of working. The service is for people at risk of being admitted to hospital and also for planned respite care. Stay is limited to three weeks but with provision for negotiated extension up to six weeks. Users are offered a maximum of six "in-reach" sessions, once a week, after leaving. The service operates a policy of self-referral, but the majority now come from assertive

outreach, crisis resolution teams and community mental health teams. Information packs have been introduced in order to promote the benefits of planned referrals. None of the services accept people who are sectioned under the Mental Health Act and are not, as such, routinely caring for the small number of people in crisis who are thought to present a risk of harm to self or others. However a key point is the strong belief among many staff of alternative crisis services that violent behaviour is frequently as response to unacceptable circumstances and that when people are offered respectful care within calm environments the risk of violence diminishes significantly.

Users' views

As part of a wider evaluation of the three crisis houses, a sample of service users were asked about their satisfaction with the service offered by their crisis house. They were first interviewed approximately one week prior to discharge from the centre, and half were followed up around three weeks later, mostly by telephone. The questions sought information about their overall satisfaction with the house, their views about the physical and emotional environment, staff/quality of care, holistic/social approach, recovery/complementary therapies, their concerns about leaving and how they felt it compared with hospital in-patient care.

The physical environment at all three sites was highlighted by most clients as particularly pleasant and important:

'Very satisfied, the house is beautiful' (Anam Cara user)

'It is very homely.' (Nile Centre user)

In addition, staff felt providing a pleasant environment appeared to increase feelings of respect among clients and all three sites had very few violent or aggressive episodes. Many of the clients interviewed described their home living situation as unsatisfactory and in some cases believed it had contributed to their crisis.

Clients appeared to appreciate the informal approach and relaxed environment, particularly at Anam Cara. Positive environment appears to impact on the feelings and behaviour of clients in crisis:

'It is a totally informal approach, which I can see would be really attractive, if you had been caught up in the mental health system. They are there for people but it is a hands-off approach, a good atmosphere all around, which is really good, it gets people talking. There are no set times, even the gardening group usually gets going later.'

Over 50% of clients at the Nile Centre also commented on the relaxing environment:

'They let me be. There was no approval or disapproval, they provide the right environment for me to recover.'

Users of all three services were particularly impressed with staff:

'The people, staff are really supportive, make me laugh. I love it here, having lots of chats. I like the garden; people are looking out for you. It has been brilliant.' (Anam Cara user)

'I felt comfortable and able to talk if I wanted to, usually I find it very difficult to open up.' (Anam Cara user)

Clients at the Nile Centre highlighted the respect that they felt from staff, as did many at Highbury Grove, who also emphasised the value of having staff available at all times:

'It's a home away from home, lots of support - 24 hours, seven days a week. They listen to you and advise you and organise and get on with things.'

'Having two key workers who I could see regularly, 24-hour staffing so you can always see someone, I feel it is a safe place.'

All clients interviewed said they felt the particular service used had met their needs, including important practicalities:

'They have done practical things for me here, like write letters to the council for me about my accommodation.' (Highbury Grove client)

'The practical help I received, trying to resolve problems, domestic situations, the opportunity to rest and eat.' (Anam Cara client)

Counselling and/or advice were also highlighted as helpful on both sites:

'I came with a very special problem, they helped me move on.'

The primary way in which the services were perceived to be helpful by clients was through having staff available for clients to talk to throughout the day:

'I have been able to laugh, stimulate your mind, when you are at your lowest point you can go and talk and get back to the point where you were before.' (Anam Cara client)

'Could have a chat with staff about life and get advice. No need to drink, more relaxed now I have people to talk to. It's nice that someone knows where you are coming from.' (Anam Cara client)

Interestingly, clients in the sample did not express a desire for talking therapies or similar interventions. Simply having people available to chat to and interact with appeared to have a significantly positive impact: the key thing most enjoyed at Highbury Grove was having 'someone to talk to'.

Several clients at Anam Cara described their stay as having had quite a profound impact upon the future direction of their lives, particularly those using the complementary therapies:

'I am not being melodramatic, if I say it has changed my life, something really positive has come out of it - it is the whole thing, you are given love and acceptance.'

'I wish there were more. It is absolutely brilliant. I don't feel like a mental patient but a human being. It is not like hospital but like home with the security of other people.'

The permitted length of stay at all three evaluated crisis houses is three weeks, and this is generally not exceeded. All users of Anam Cara said they felt happy with the way their discharge had been planned and arrangements for after care; indeed staff there actively prepare clients for their leaving from the beginning. Despite this, about 40% said they felt apprehensive about leaving and would have liked their stay extended. Nile Centre users also appeared apprehensive about leaving, particularly those who had accommodation problems prior to their stay that had not been resolved. Some clients described the knowledge that they were leaving as the worst thing about their stay:

'I know I can't stay forever, but just a little while longer.'

Such feelings could raise concerns that these types of service create their own 'revolving door patients', or encourage repeated self-referrals, but readmission rates to the crisis houses proved in fact to be very similar to those on acute wards.Asked whether they felt that they could have got the kind of help they were receiving from any other service, users provided strikingly vigorous support for crisis houses:

'It is completely different compared to the hospital. I was in hospital for seven months, the staff sit and read newspapers and dish medication, you are not allowed out. It really does not compare, you get your own life back, people help to pick up pieces.' (Highbury Grove)

'There is freedom here, compassion, understanding it is different to hospital, the staff do anything within their power to make you happy. You are not forced to take medication and in other institutions you will be injected. I know it first hand.' (Anam Cara)

Conclusion

Crisis houses are but one of a range of models of crisis care that, as the Foundation's programme shows, can provide useful and acceptable alternatives to hospital admission. While there were many aspects of the crisis houses appreciated by service users, the key issue was the nature and level of interaction with staff. Having someone to talk to in times of crisis is a relatively simple need, and one that is not difficult to achieve through the development of small, local crisis services founded on an ethos of humanity, respect and care. These might be crisis houses, drop-ins, safe houses or crisis lines, depending on local circumstances and needs.

Another important element of the programme has been the demonstration of the value of user-led crisis services. While they are difficult and time-consuming to establish - against problems from NIMBY-ism to misgivings within some mainstream services - they can work well if set within a programme of support that enables them to withstand this frequently unsupportive and, indeed, sometimes hostile professional environment, particularly in the services' early stages.

The Foundation is calling on policymakers to promote and support the development of a range of alternative and complementary crisis services in all localities. Commissioners need to carry out an audit to identify the most appropriate models of crisis care to meet local needs and circumstances and ensure the new services integrate well with the statutory sector.

The full report, 'Being There in a Crisis' is available £27.50 plus p&p from the Mental Health Foundation Tel: + 44 (0) 20 7802 0300, Fax: + 44 (0) 20 7802 0301 or email: books@mhf.org.uk

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'Once I was staying at the crisis house I found many differences. I found that the staff had much greater face-to-face contact with residents and included us in the running of the house. I felt there was no sense of 'us and them'. I was treated with, and saw other residents being treated with, respect. Trust between staff and residents was good. There was a lot of time to talk with staff members. Each resident has two key workers but can speak to any other member of staff at any time. I was able to spend time talking to staff in private, which was just what I wanted but not what I had received in past hospital stays. In the hospital I had been faced with the medical approach which meant medication and little else. The approach at the crisis house was much more holistic and included help with practical problems - something that users frequently ask for. Being [in the crisis house] was a completely different experience from the hospital. In the hospital I feel somehow that I am being punished for my state of mind. In the crisis house I did not feel this sense of retribution.'

John Hart (Service user at Highbury Grove)

Appendix 2

Consultation

The Mental Health Community Coalition hosted a forum on this issue, 'Raising the Roof' Forum May 9th 2005. There were 63 participants including mental health consumers, cares and community organisations.

Speakers Included:

Kerry Tucker	ACT Shelter
Heide Seaman	Richmond Fellowship
Maureen Sheehan	Housing ACT
Chris Redmond	Woden Community Services

Individual Consultations with Representatives from:

Heira (Toora)

Innana

Members of MH Community Coalition

Members of MH Providers Network

MHCC Consumer and Carer Caucus

Mental Health Foundation

Mens Centre

Sails – Centacare

Youth Coalition