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## EVIDENCE BASED COMMUNITY ALTERNATIVES TO INSTITUTIONAL PSYCHIATRIC CARE: towards recovery-oriented services. Alan Rosen<sup>1</sup>, Liz Newton <sup>2</sup>and Karen Barfoot<sup>3</sup>

#### Abstract and Introduction

Policies of deinstitutionalisation in Australia and overseas, have resulted in the majority of people with a mental illness now living in the community. As in many clinical conditions from day surgery and renal dialysis to coronary rehabilitation, the emphasis in psychiatric treatment is shifting to community based care, with briefer hospital admissions only if necessary.

International and Australian research evidence consistently shows that community-based treatment is superior to hospital-centred care for the vast majority of people with acute and long term mental illness.

Effective community-based treatment entails: ready access to 24 hour crisis intervention and ongoing care, assertive and intensive community case management, professionally supervised residential treatment in the community as an alternative to confining people to psychiatric institutions and real recovery-oriented vocational opportunities for individuals with mental illnesses.

The evidence that consistent assertive community care stabilizes homeless individuals with mental illness and prevents re-offending in the small minority of individuals with a mental illness who have been criminal offenders, is considered to be one of the best advertisements for community psychiatry, if it is well organised and properly resourced.

#### What are "Recovery Oriented" Services?

The past decade has seen the development of an individualised 'recovery' philosophy in mental health services. Curtis(1) points out that "... recovery means that a person with a psychiatric disorder lives a satisfying, productive and meaningful life irrespective of the disorder or consequent disability".

Recovery is the "ability to live well irrespective of an individuals experience of mental illness"(2) and to regain full membership of the community. Recovery orientation of is now growing in many community mental health services in Australia. Components of recovery models include collaborative symptom management, individual bed problem solving, individual decision-making and forming your own life direction. It is about creating hope and holding respected roles in our communities. It is about minimising the impact of mental illness on the quality of a person's life. 'It entails doing differently (as both service users and providers) what we do every day'(1).

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Services need to develop a culture to "stimulate, enhance, and support individual recovery by promoting hope, healing, empowerment, and connection in the lives of each individual served"(1). Staff need to believe that some form of recovery is possible for each and every mental health There should be no more psychiatric "maintenance" or consumer(3). "warehousing" programmes. The most important process in recovery oriented services is for consumers to be actively involved in all components of their own care and treatment. This involves increasingly making their own choices and taking risks. It also requires service providers to step back from doing things to service users and to increasingly doing things with them as collaborative partners. It also requires therapeutic optimism, hope and faith that whatever has occurred, there is someone who believes in them and their To become Recovery oriented often requires a potential abilities. transformation of existing mental health services.

### The place of Crisis Intervention in Psychiatric Services

The evidence now clearly indicates that 24 hour home-visiting crisis response services should be integrated into local comprehensive services for people seriously affected by mental illnesses and their families(4,5,6). The superiority of 24 hour mobile Crisis Intervention and Continuity of Care in the Community as an alternative to hospital-based care and after-care for severe mental illness was established in evidence by a seminal randomised control trial in Madison, Wisconsin(4) which was replicated in Sydney, Australia(5), and later elsewhere.

The potential for new learning and personal growth in this population and their families has probably been vastly underestimated, often by the clinicians involved(6). Systematic interventions to promote such new learning of "using the crisis" of acute psychiatric episodes are being developed to reverse the potentially erosive effects of early psychosis on self-esteem, identity and related maturational tasks(7). Family problem-solving techniques aimed at acquiring new coping techniques in crisis have been shown to prevent relapses(8).

The principles of effective crisis intervention are consistent with current good practice in mental health services, regardless of the phase of care(7). There is evidence that people severely affected by psychiatric illnesses are much more likely to cooperate with interventions which are tailored to their individual needs, when they feel listened to, and are consulted and offered choices regarding types of proposed interventions(7). Cooperation is further enhanced when they and their families are provided with sufficient information and explanation, when time is taken to negotiate intervention goals, when low-key and low-dose interventions are offered (at home on their own "turf", if possible, rather than ours) and when the traumatising effects of involuntary hospital admission and heavy sedation are avoided.

Inpatient psychiatric care is sometimes essential but should be arranged on a voluntary basis if possible.

# Assertive Community Treatment

Assertive Community Treatment(9) is an intensive mobile community case management system for delivering treatment and support to individuals with severe and prolonged mental illness. It has been extensively researched in randomised studies, demonstrating that it is one of the most efficacious and cost effective intervention modalities in contemporary psychiatry(9). It works best for individuals identified as being high users of mental health services and/or those experiencing the greatest levels of symptoms or disability, whether continually or intermittently. Services of this type originated when services tried to prevent repeated "revolving door" hospitalisations and to help people live more stable lives in the community.

### <u>Table 1:</u> From Rosen and Teesson, 2001(9) <u>Principles of ACT: (Assertive Community Treatment)</u> Structure:

- A usual maximum staff ratio of 1:10 service users
- Services are available 24 hours, seven days a week
- Services are mobile and provided "in-vivo" in the person's own home and local environment

Content:

- Services include specific counselling and behavioural interventions, medication administration, and monitoring, attending to all clinical (psychiatric and other medical) needs and practical assistance with all functional needs, including self-care, social, vocational, finance, accommodation etc needs
- Plans are tailored and interventions adjusted to meet changing needs of service users.
- Support, education and practical skills training is provided to both service users and their families or confidantes.
- Services are individualised and diverse and include anything that promotes the service user's integration into the community. The team is assertive in engaging individuals in treatment and monitoring their progress, and to maintaining contact no matter what. Training:
- Multi-disciplinary teams include psychiatrists, nurses, social workers, occupational therapists and psychologists. Within this group there would be specialists in substance abuse issues and vocational rehabilitation.
- Team members are cross-trained in their areas of expertise and assistance and consultation is assisted by daily meeting to plan and review daily activities.

Timeframe:

• There is no arbitrary time limit on receiving services such intensive services are ongoing for as long as they are needed.

# Day and Evening Programmes

Just as more sedentary mental health services have shifted towards mobile assertive community treatment the role of day treatment centres, which may have traditionally involved various activities ranging from recreation to vocation, has drastically changed. Many Australian services have shifted to programs being "consumer run". These include drop in centres and the internationally recognised "club-house model", where members are integral in managing as well as participating in the centres' work-related activities(3). The "Consumer Movement" is gaining momentum with Mental Health Services turning to service-users as partners in service planning and delivery. Service users are increasingly gaining paid employment within mental health services for roles ranging from advocacy; practical service provision such as peer support, service user transport and social program coordination; to representing consumer interests on management committees; and promotion and education of mental health issues within the wider community.

#### Vocational Rehabilitation Initiatives

Community mental health facilities historically provided rehabilitation programs focused on living skills, activities and leisure opportunities. More recently training and work programs have developed in collaboration with mental health consumers and access to mainstream agencies. The value of work cannot be underestimated in a person's recovery. Many service users actively seek work and training opportunities. At present in Australia, many rehabilitation services either create work opportunities or encourage access to outside agencies for vocational pathways(3). Types of employment available include 'open' employment on the competitive market. With support this is an achievable goal for some. Apprenticeships and Traineeships are also available and specially funded for people with a range of disabilities. Particularly, but not solely, young people with mental illness should be encouraged to pursue these opportunities. Supported employment is regarded as one of the successes of vocational rehabilitation and is an "attempt to increase the percentage of persons with psychiatric disabilities who are able to get and keep jobs"(10). Supported employment should be at award wages and conditions offering on the job training and ongoing support. Supported employment is a pathway to open employment. Businesses set up by mental health services should focus on "mainstream" contracts and customers to encourage integration for workers with a mental illness. For example, the CREATE team of Ryde and Lower North Shore in Sydney works in partnership with a not-for-profit business, MARS Incorporated. This commercial enterprise includes an up-market café, an organic nursery and site specific seedling supply, bush regeneration contracts with local councils and a garden maintenance business. Transitional Employment is another type of employment offered by services such as "Clubhouses". This enables clients to have short term jobs (eg three- six months], in local businesses with support, which provide work experience, confidence and skills. Sheltered work opportunities are also available and have traditionally included production and piecework at productivity based wage levels. Again, this type of work can be a pathway for other opportunities. More recently mental health services have created paid work as "consumer consultants" for service users from within the mental health service budget. This recognises the true value that consumers have in providing services and as partners in decision-making processes. Work opportunities within the health arena has included "consumer" Team Leaders, Individual Care Assistants, leisure coordinators, support people and drivers. Mirroring mainstream practices has shown that volunteering for consumers is not only a valuable asset to the service offering peer support, but also a pathway to job readiness, training and work. Successful community mental health rehabilitation requires exploring all the above options for creative solutions to turn dreams into realities for consumers. The evidence from high quality studies clearly supports the provision of and connection with "real work for real pay" for individuals with a severe mental illness, demonstrating a strong correlation with positive outcomes, and has been reviewed by Rosen and Barfoot(3).

## Table 2: From: Rosen A and Barfoot K, 2000(3)

# Types of Work Appropriate for People with Severe Mental Illness

- Open competitive work (full or part-time)
- Apprenticeships and Traineeships (especially if relatively young)
- Supported employment (social enterprises)
- Transitional employment (short term supported jobs)
- "Consumer as mental health service provider employment"
- Sheltered employment

<u>Community Residential Alternatives to Psychiatric Institutions</u> <u>Factors Affecting Community tenure Study for Northern Sydney Mental Health</u> <u>Services.</u>

The FACTS project involved pre [6 months], and post [2 years] discharge follow up of 47 long stay residents as they moved from a psychiatric hospital to the community. The project triangulated three research approaches: quantitative, -qualitative, - and health economic. (11, 12, 13).

A brief 6-year follow up was undertaken in 2000-01(14). With a one off injection of Commonwealth Transitional Funding, the initial study enabled forty long-term hospital residents who had been in the institution continuously for 2-43 years, to resettle to the community. These were residents who would <u>not</u> normally have been considered for discharge at that point in time. The discharges accompanied the amalgamation of two psychiatric hospital campuses in Sydney, with the eventual closure of one. The forty-seven residents were resettled to four sets of households community mental health sub-areas where they had 24 hour supervision by familiar staff wherever possible. Three sub-areas utilised 10 bed group home facilities and one sub-area utilised a block of flats. The original study followed the residents for two years post discharge. In that period seven residents returned to hospital for long term care, and one male resident died of medical causes. Subsequently their community places were filled by other long-term residents.

## a) Quantitative clinical evaluation

This component of the study used a quasi-experimental longitudinal pre-post design(11). Evaluation of clinical indicators took place pre discharge and at intervals for the ensuing two years of community tenure. Instruments used were the Brief Psychiatric Rating Scale, Life Skills Profile, Social Behaviour Scale, Montgomery Asberg Depression Rating Scale and a Quality of Life measure, along with recordings of

demographics, readmissions, case history and medication data. Of those residents who achieved two years community tenure [n=35], there was a significant improvement in psychotic symptoms without a significant change in the level of neuroleptic medication. There was no statistically significant changes in resident's living skills, depressive symptoms or social behaviour problems over two years. Importantly there was a significant increase in residents' life satisfaction.

## b) Qualitative Ethnographic study

The qualitative component of the study involved two and a half years ethnographic fieldwork pre and post discharge, along with semi-structured and open-ended interviews(12), life history taking and perusal of written records. Rich descriptive subjective material enhanced and complemented other aspects of the study. The study showed slow but positive change for this group of people. Quality of life was improved with 'freedom' cited as a major aspect of community living. The initial study showed that for change/recovery to take place for people that have spent the major portion of their adult life in an institution, there needs to be planned and resourced commitment from Government. A range of supported accommodation and care with 24 hour staffing prior to semi-independent living is desirable. Transition to the community requires intensive individual case management to assist in relearning life skills required to maintain successful community tenure and enhance quality of life. This usually takes about two years. Once this is achieved, staff can be redeployed for the next stage of rehabilitation. A range of accommodation options is desirable. This project resettled residents initially into larger style group homes [10 in each] and a block of four, three bedroom flats. Learning skills en masse is not a normalising experience. Those who relocated to the flats developed skills much more readily within their individualised spaces. Residents in the larger households subsequently took up opportunities to move to smaller households with less supervision. A range of respite/inpatient accommodation is also useful in the early days for residents who have an exacerbation of symptoms or require commencement on new medications [eg, clozapine].

c) Economic Evaluation

The economic evaluation involved a cost analysis of the psychiatric hospital care compared to community care for people with long-term mental illness(13). Expenditure and income data in both settings were collected and costs were analysed on an occupied bed-day basis. Community care was shown to be one third to one-half of the comparable hospital costs. Factors which possibly contribute to hospital care being \* nearly twice as expensive as community care may have related to 'organisational inefficiency'.

Generally the study showed that given adequate support and resources, people who have been deinstitutionalised after many years can manage in the community with no clinical or functional deterioration. Over time people gradually integrate into the community and move on in their lives. The cost

savings for community care are significant and should remain within mental health budgets to increase the range of services and opportunities for mental health clients.

This study fairly closely replicates the outcomes of the much larger "TAPS" study in the UK (see 11) except that the costs of community living in the UK were a much greater proportion of the costs of hospital living. The reasons for this difference is the subject of a current joint study between these projects.

<u>Deinstitutionalization and community mental health care are not synonyms</u> Many concerns have emerged from advocates of psychiatric hospitals about the aftermath of deinstitutionalization in terms of neglect of the homelessness among the mentally ill and the burden placed on their families and the community, including the prison system.

Studies(15) show that many of the homeless mentally ill, rather than being among the deinstitutionalized, have actually spent very little time in mental hospitals. They are often independently minded, out of reach services, and certainly not inclined to ever go anywhere near a hospital.

Teesson et al(16) in their 5 year follow-up of schizophrenia in homeless men, dispel the myth that there is a linear causal between deinstitutionalisation and the growth in the homeless mentally ill population. Teesson et al (see 9) and Mullens(17) have shown how strategies such as Assertive Community Treatment style case management consistently stabilize homeless mentally ill individuals and mentally ill offenders, who would otherwise be prison recidivists.

#### Setting Standards

The United Nations Principles for the Protection of Persons with Mental Illness (final draft, December 11<sup>th</sup>, 1990) include the proposition that "Every person with a mental illness shall have the right to live and work, as far as possible in the community".

Unless rigorous standards are set for the essential components of community mental health services, 'community care' could merely become a meaningless cliche, a generic expression labelling a diverse range of facilities and services, from the excellent to the gestural, to the non-existent. At worst, it becomes a cynical euphemism to gloss over communal neglect and intolerance, and a withdrawal of resources as patients are transferred to the community.

The Australian National Mental Health Standards(18) and its associated accreditation process, involving trained and expert "consumer surveyors" (as well as professional surveyors) as part of the ACHS "Equip" programme help to ensure that the required components of service are in place. Wing(19) defends the continuing need for some individuals for 'Asylum' in the best sense: a 'haven of needed refuge but also a harbour from which to set out again'. He considers that many of the functions of asylum can be served by a variety of geographically separated agencies, as long as their operations are

well managed and coordinated, securely resourced and supervised to ensure high standards of care. To do otherwise or to ignore these needs, he warns, will court disaster.

In the light of international reforms in mental health care, Tansella(20) more rigorously defines community-based psychiatry as 'a system of care devoted to a defined (local) population and based on a comprehensive and integrated mental health service'. This should include a 'wide spectrum' of outreach, day patient, drop-in, community based care continuity of, and in-patient, staffed and unstaffed residential facilities. It relies on multi-disciplinary team work to ensure early diagnosis, prompt treatment, continuity of care, social support and close liaison with other community medical and social services, in particular with G.P's. It also entails encouraging service users and their families to become empowered, to be actively involved in monitoring and developing their local mental health services as well as their own recovery.

## **Conclusion**

Among recently renewed calls to return to psychiatric institutional, care was a recent front page headline in the Australian(21) reading "Community care fails mentally ill". This article, its accompanying feature and editorial misrepresented the truth depending on hearsay from traditional proinstitutional sources, while omitting the crucial evidence. Community care clearly works, but only where it really has been tried – that is where it has been implemented in accordance with the evidence. It is the Australian Government's failure to systematically transfer and maintain adequate resources for community care that has sometimes failed people with mental illness and their families. International and Australian research evidence consistently shows that community-based treatment is superior to hospital-centred care for the vast majority of people with acute and long term mental illness.

The Australian feature article The Forgotten Ones(21), mistakenly equated short admissions with system failure. Rather, briefer admissions are less lifedisruptive and both clinically and socially advantageous to the majority, as long as sound 24 hour community care is available. Ongoing hospitalisation is then only required for a significant but small minority. This trend is similar to the shift to briefer admissions and community based care for a wide range of potentially long term medical and surgical conditions, from coronary care to renal dialysis.

The main problem is that core community-based psychiatric services have been resource-starved, putting even more pressure on the remaining inpatient beds. Australian Governments have left mental health services severely under-funded, in comparison to the large proportion of communal disability it accounts for, and compared with New Zealand and Europe. In terms of funding, mental health always loses out to more appealing areas of medicine and surgery, and community care is always eclipsed by the black hole of spiralling hospital costs. Good mental health care involves both balancing and integrating community and hospital care, and properly resourcing both.

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