

Submission to the Senate Inquiry

1. Introduction

The Queensland Alliance is the State-wide peak body for non-profit, non-government organisations and groups which serve the needs of Queenslanders living with mental illness & psychiatric disability. The Alliance represents 147 members including consumer groups, carer groups and non-government community based service providers. The mission of the Alliance is to promote, strengthen and develop the growth of non-government community managed responses to mental illness and psychiatric disability in Queensland.

This submission presents the key issues from our perspective, and responds mainly to your terms of reference a – e, h and j. Attachment One specifically addresses the issue of over-representation of people with mental illness in the criminal justice system – your terms of reference j.

2. Key Issues

The *National Mental Health Strategy* successfully placed issues of prevention, promotion, and early intervention and issues of carer and consumer participation on the agenda of the mental health system. A population health approach to mental health was articulated. Social health issues like access to housing, psycho-social rehabilitation, disability support, employment and training were acknowledged as part of an effective system to support people with mental illness.

This approach was exemplified in Queensland with an institutional reform policy and program known as Project 300. The program provided housing, clinical and support services for people leaving long-stay psychiatric institutions and gave birth to a vibrant non-government mental health sector in Queensland.

Project 300 and the outcomes for people have been independently evaluated and the cost benefits demonstrated. Unfortunately the results have not been published, but the initial evaluation is included for your information at Attachment Two. A follow up evaluation seven years later is currently near completion. The contribution of non-government organisations to the wellbeing and recovery of people with mental illness is acknowledged in the evaluation, as is their role in contributing to the coordination of housing, clinical and other services.

Unfortunately Project 300 remains an isolated example of how services to people with mental illness and psychiatric disabilities can be coordinated to enable people to live productive lives in the community. Similar programs could provide targeted benefits to people with mental illness who are inappropriately institutionalised in prisons, private proprietary homes, public hospitals or homeless.

Queensland Health has implemented a system of consumer and carer participation in public mental health services. Consumer/carers consultant positions now exist in approximately 17 of 39 districts across the state. Consumer participation is a requirement of national standards and demonstrates how a strong national policy framework linked to accountability mechanisms (such as standards and service audits) can influence service cultures. The Queensland Alliance congratulates Queensland Health on providing resources for consumer/carers participation in the system. While the commitment to consumer participation across districts varies significantly, the Queensland Alliance supports expansion of this initiative.

Apart from these initiatives, however, development of the mental health system in Queensland has not significantly shifted in the direction of the priorities articulated in the

National Mental Health Strategy. Modern public mental health services developed over centuries and for most of this time existed as institutions. The institutional culture is one of control, containment, and medication, which still exists in various areas of the public mental health system. This culture conflicts with a commitment to recovery as articulated in the current *National Mental Health Plan*.

In particular, Queensland's public mental health system has yet to devise recovery-focused alternatives to the medical model of intervention. Public mental health services are based in medical models which tend to approach the person's illness in isolation from other factors in their lives and their environment, focusing on medication as the central treatment modality. Queensland's public mental health services – both hospital and “community”-based – are managed by hospital executives at a district level. Public “community” mental health services increasingly resemble outpatient and outreach services of hospitals.

There is no direct accountability from public mental health services to any over-arching policy framework or model of practice. Mental health is generally not given high status within health, and there has been an absence of senior leadership on mental health within Queensland Health. This results in a wide variation in practice across Queensland, with some public mental health services applying a deficit model (ie illness focused) rather than a community focus on well-being and recovery.

The public mental health service is also faced with severe resource restrictions. Mental illness accounts for nearly 30% of the non-fatal burden of disease in Australia, yet mental health funding is only around 7% of the total health budget. In Queensland there is even less resources, as we experience the lowest per capita funding in mental health of any state/territory. The Queensland Alliance supports the call from the Mental Health Council of Australia for an increase of \$10 billion in mental health spending over ten years.

In this environment there is no universal access to mental health care – only those facing the most severe crises can access public psychiatric services and many are turned away. In Queensland the very limited resources are mainly allocated to clinical services. The lack of an effective community support system means people must reach a crisis point to get any service. Many are then stuck in hospital services because they cannot be discharged to a safe, supportive environment.

Queensland has a very long history of under-investment in social infrastructure, often appearing at the bottom of expenditure tables on social services. This also means access to public and community housing is extremely limited, and funding of disability support services remains well below the national average. The down side of Queensland's low tax policy is lower spending on social services across the board in Queensland. The difficulty of accessing affordable housing and psychiatric disability support services has a significant impact on the capacity of people to live successfully in the community.

Queensland's non-government organisations (NGO's) are focused on supporting consumers' recovery and well-being through community education, community capacity building, psycho-social rehabilitation and psychiatric disability support services. Some of these organisations are consumer operated and some are based in models of peer support – all are focused on recovery. The evaluation of Project 300 provides evidence of the efficiency and effectiveness of non-government service delivery. The development of a strong non-government mental health sector may reduce some people's need to access high-cost hospital services, and enable people to be discharged with support from such services when they no longer need them.

While Queensland's non-government mental health sector produces positive and innovative results for people with mental illness, the sector remains under-developed in relation to the

needs. There are also special needs in Queensland relating to rural and remote communities, including Aboriginal and Torres Strait Islander communities, which have not been addressed. Queensland Health allocates \$6.9 million or 1.6% of its \$430 million mental health budget to non-government mental health services. This contrasts with other countries such as New Zealand where 33% of the national mental health budget is allocated to non-government services. A significant community capacity building effort will be required to enable the NGO mental health sector to develop to a similar level as New Zealand.

It is our view that investing in the non-government mental health sector will produce the best results for the greatest number of people with mental illness or psychiatric disability. Medical care is important, but it is only one part of the solution, and should not be the focus of new investment. Queensland has focused on investment in bricks and mortar solutions and clinical care, while not investing sufficiently in community-based, NGO supports.

In other areas of health, the non-government sector has a significant role in the delivery of clinical services (e.g. Aboriginal and Torres Strait Islander health, youth health home and community care, etc). The success of Aboriginal Medical Services provides a clear example of the value of locating clinical services in non-government agencies. The Australian Government program Innovative Health Services for Homeless Youth (IHSY) demonstrates how effective primary health care and early intervention medical services are well placed in community-managed, non-government organisations. Location of clinical services in community settings provides much greater access for specific, disadvantaged populations groups, who are reluctant to access mainstream, hospital services.

Given the limited access to public mental health services, a similar program in mental health which located medical care in community and/or consumer-operated services would be beneficial. These services would complement the public system, provide a source of innovation in the provision of primary mental health care, and provide access to specific populations who are unlikely or unable to access public mental health services.

A similar investment in psycho-social rehabilitation, peer support and psychiatric disability support services would enable people to move from crisis into recovery, with sufficient support to develop an ordinary life in the community.

The Queensland Alliance Recommends -

1. the strengthening of the national focus on prevention, early intervention, health promotion, and psycho-social rehabilitation;
2. the strengthening of the national focus on consumer and carer participation in the service and policy systems;
3. a significant increase in funding to mental health to reflect the burden of disease of mental illness within the community. The Queensland Alliance supports the call by the Mental Health Council of Australia for an increase of \$1.1 Billion annually in mental health over ten years;
4. the Australian Government establish an Australian Mental Health Commission to establish clear national leadership and accountability on mental health. One function of the Commission is to fund non-government organisations to provide a range of health promotion, early intervention/prevention services and psycho-social rehabilitation services;
5. the proposed Australian Mental Health Commission also have a role to fund development of non-government organisations that provide clinical services similar to youth health (IHSY) and Aboriginal and Torres Strait Islander health services.

Growth funding of such services should be linked to evaluation of innovative modes of clinical service delivery and access to specific, disadvantaged populations;

6. a significant increased investment in non-government, community owned and managed mental health services, resulting in 30% of the total mental health budget in Queensland allocated to non-government organisations within ten years;
7. the Australian Mental Health Commission evaluate some of the benefits of the Queensland Project 300 model in relation to people who are institutionalised in government or private systems of control or care or are at risk of institutionalisation as a result of homelessness or other socially vulnerable circumstances;
8. the Australian Mental Health Commission, along with other funding and research bodies, ensure that research spending in mental health is not exclusively focused on clinical trials and medical research. The research agenda in mental health needs to focus on social and environmental supports and their impact. Research and evaluation can then guide which interventions (including psychiatric disability support services, peer based support and psycho-social rehabilitation services) best support people's recovery in the community. This research will ensure a significant increased investment in mental health is directed to where it can achieve greatest outcomes;
9. the Queensland Alliance recommends an investment in a range of strategies to ensure people with mental illness are diverted from the criminal justice system to appropriate health and support services (see Attachment 1).

Attachment One
CRIMINALISING ILLNESS?
SENATE INQUIRY TERMS OF REFERENCE J
Over-representation of People with Mental Illness in
the Criminal Justice System

SUMMARY

There is a significant over-representation of people with mental illness in the criminal justice system. Most of these people have not committed serious crimes, and many have been arrested, charged and/or sentenced without appropriate reference to their health, and the role of mental illness in the commission of the offence. The criminal justice system – police, lawyers, courts, corrective services – is not sufficiently sensitive to the specific needs of this population, resulting in bad outcomes for people with mental illness. The solution is to invest in a range of early intervention and diversionary practices to ensure this population is diverted away from the criminal justice system.

Introduction

There is now considerable evidence demonstrating that people with mental illness are coming to the attention of Police when they should be receiving treatment, are arrested inappropriately (often because police believe it is safer to arrest them than to leave them on the streets) and are inappropriately sentenced through the court system. The evidence referred to in this submission demonstrates the over-representation of people with mental illness in the prison system.

The Queensland Alliance believes it is important for there to be a place of consequence for those who commit serious crimes. The culture and purpose of prison, however, should be about rehabilitation and addressing the underlying causes of offending. Correctional cultures – based on the experiences of people from the system – appear focused on punishment, control and the breaking of spirit. This approach to prisons produces brutalised, dehumanised individuals and so reduces community safety.

The Queensland Alliance suggests most people with mental illness should not be in jail, because

- there are viable alternatives to prison which produce better outcomes for individuals and safer communities;
- prison produces negative outcomes for individuals – incarceration worsens mental health;
- people with mental illness need health care and social support, not punishment – the therapeutic environment required to deal with mental illness is in direct conflict with a prison environment focused on punishment;
- prison can produce frustrated or brutalised individuals who are released to the community with little preparation or support - this reduces community safety;
- incarceration does not operate in practice as a deterrent and has a centuries long history of failure in reducing crime.

The submission presents two key policy areas contributing to the over-representation of people with mental illness in prison. ‘Whole-of-government’ solutions to diverting people with mental illness from the criminal justice system are presented, and some specific recommendations made in response to the discussion papers. The Queensland Alliance

submits that most people with mental illness in corrective services are there due to a lack of health and social supports, and not because of any intentional wrong-doing.

This submission uses the term “people with mental illness” to refer to people with mental illness as well as people with psychiatric disability. Psychiatric disability refers to people who have ongoing social limitations as a result of a mental illness and its treatment, while they may or may not continue to be clinically treated as mentally ill. The term mental illness includes the full range of illnesses described in the American Psychiatric Association DSMIV-TR, principally Axis 1 conditions (eg schizophrenia, bipolar, etc) and the personality disorders described in Axis 2. While intellectual disability and substance mis-use disorder are listed in the DSMIV-TR, we do not include these conditions in our definition of mental illness.

2. About this Attachment One

This submission has been developed by:

- Brief review of the literature – including reports and submissions by government departments and independent community-managed organisations - on people with mental illness and the criminal justice system;
- Consulting with the Queensland Alliance membership by distributing an earlier draft of this document to 147 non-government organisations across Queensland
- Individual consultations with key informants in the departments of health, disability services and corrective services, and non-government workers across a range of human services (homelessness, women, youth and community legal services);
- group discussions and workshops with staff of prison support groups and mental health organisations;
- incorporating written feedback from members and key informants on an earlier draft.

3. SUMMARY OF LITERATURE

A range of articles is included at the end of this attachment, but in essence the literature identifies:

- People with mental illness are significantly over-represented in the prison population. Conservative estimates are that severe illnesses such as schizophrenia are at least three to four times more prevalent in prison than in the general community. Estimates and survey results vary considerably in the research, and as always there are issues of defining mental illness and approaches based on clinical observation versus self-reporting. While the numbers vary, anywhere between 70% - 90% of prisoners have a mental health problem;
- People with mental illness are inappropriately arrested, sentenced and refused parole – most recently highlighted by the plight of Cornelia Rau and Sylvia Young;
- Incarceration worsens people’s mental health, and the therapeutic environment required to improve mental health is directly at odds with the control and punishment culture of corrective services.

4. OVER-ARCHING ISSUES AND SOLUTIONS

The rate of incarceration of people with mental illness reflects the stigma and discrimination so many people experience as a consequence of their health status: this is unfair. The Queensland Alliance identifies two main reasons why people with mental illness are over-represented in the corrective services system.

One contributor is the inadequacy of community-based and non-government health and human services in Queensland. This lack of support results in many people remaining

untreated, homeless and at great risk of offending or coming to the attention of Police. Increased funding to human services generally, and increased funding to support services for people with mental illness specifically, is likely to reduce the numbers of people in jail.

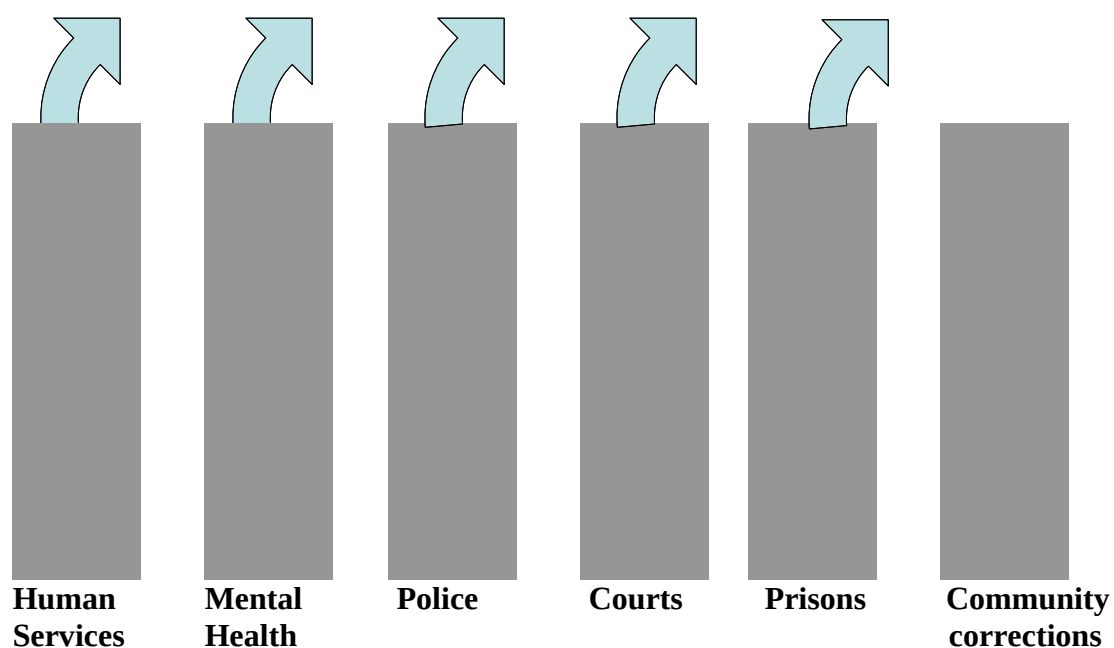
The second contributor is a law and order debate focused on punishment and criminalisation, rather than concepts of rehabilitation and community safety. Incarceration brutalises individuals and increases their likelihood of offending in the future. Many leave the corrective services system with limited experience of rehabilitation, and no support or preparation for a new life on release. If people with mental illness can receive appropriate support in community settings that is focused on rehabilitation and not punishment, community safety will be increased. Unfortunately the populist “lock ‘em up” response from media and politicians stifles debate and produces significant harm for people with mental illness.

Solutions to the over-representation of people with mental illness in prison must include an expansion of community-based and non-government human and health services. Also required is a public policy debate which focuses on rehabilitation, health and community safety, rather than punishment and control, as a response to mental illness.

One step in this direction is to invest in diversionary activities for people with mental illness – both preventing people being arrested, sentenced and imprisoned, and supporting people out of prison to community corrections, and smoother release programs. The next section provides details on these diversionary solutions.

5. SOLUTIONS: IMPROVING LINKAGES AND DIVERTING PEOPLE WITH MENTAL ILLNESS

People with mental illness are being arrested, sentenced and imprisoned when they should be diverted for treatment. There are many points in the system where diversion can occur – through inter-departmental collaboration. Following member consultation and stakeholder interviews, the following framework has been developed:



The diagram represents the various points in the system where diversion can occur.

Human services - Insufficient investment in community based, non-government mental health and mainstream human services results in people with mental illness in prison or homeless. More than 60% of people with mental illness do not access mental health services. Mainstream public health services often do not adequately meet the needs of marginalised people with mental illness: homeless people, Aboriginal and Torres Strait Islander people, people from non-English speaking backgrounds and young people. Non-government services have a track record of working well with these populations, and strong investment in mainstream social services (housing, counselling, support, employment, training, etc.) will ensure people do not need crisis mental health services, and will not proceed to criminal justice systems.

Project 300 is an independently evaluated, successful, cross-government initiative which could serve as a model for a prison diversion programme. Project 300 provided funds for housing, health and support services to enable people to leave institutions and live in the community. This initiative was backed by a Memorandum of Understanding signed by the Directors-General of Health, Housing and (then) Family Services, and remains the sole exemplar of such strong coordination in the Queensland Government. The participation of non-government organisations in this model assured its success. This model could be directly replicated to reduce the over-representation of people with mental illness in prisons or homeless.

Community Mental Health— funding in the public system needs to be re-oriented to meet the needs of people in the community, to prevent them entering acute wards. A prevention and early-intervention framework is more cost effective than simply waiting until people are so unwell they need hospitalisation, become homeless or simply offend. Unfortunately the mental health system is focused on clinical care and medication issues, at the acute end.

Police diversion – Queensland Health has formalised a Memorandum of Understanding at a central office level with Queensland Police, and rolled out local agreements that are signed off by District Commissioners and District Mental Health Service Directors. These arrangements include education and training of Police by mental health services, the development of protocols, and district operational forums in which operational issues between these two departments can be raised.

Similar protocols between community based service providers and Police occur on an ad hoc level.

The experience of our members is often that when a person is identified as having a mental illness, and has the support of a community organisation, the Police respond in flexible and appropriate ways. In developing this submission Alliance members reported that Police would often contact them if they apprehended someone who they knew to be a client. The difficulties arise when the Police are simply not aware the person has a mental illness, or the person with a mental illness has no connection to family, friends or service providers.

The Queensland Alliance recognises the Police face a difficult task in many of these situations, and – because of the insufficient resources to community-based mental health services – are often forced to take on roles that far exceed their training and official role. Additionally, police may arrest someone with a mental illness and keep them in the watch house, not because they have committed serious crime, but because there is simply no other safe place for them.

Court diversion – a pilot project is currently occurring in Toowoomba which employs a legal advocate to represent people with mental illness (and intellectual disability) in court systems. The volume of people presenting at courts means there is limited time for duty lawyer or Magistrate to know the defendant has an illness which mitigates their circumstances. This

project is exposing the significant numbers of people with mental illness who inappropriately are facing trial and often are sentenced. The attitudes of those within the legal profession (eg duty lawyers) indicate a limited knowledge of mental illness and a lack of empathy for the plight of those inappropriately charged.

There is one mental health worker in Brisbane and one in Townsville Magistrates court trying to identify defendants with mental illness. The Queensland Government's 2002 Forensic Policy recommended this service be expanded to all busy magistrates courts in Queensland.

The Mental Health Court – unique to Queensland - is a key aspect of the Mental Health Act 2000 which was passed by Parliament on 30 May 2000 with some amendments included in the Health Legislation Amendment Act 2001. The ACT is considering a similar court. The legislation was introduced to offer a more effective and accountable system of involuntary treatment and care for persons with mental illnesses and designed to provide for the unique features of mental illness that are not catered for in other mainstream legislation.

The Mental Health Court is constituted by a Supreme Court judge who is assisted by 2 experienced psychiatrists who advise the Court on medical or psychiatric matters. Advice given by the assisting psychiatrists is provided in a way that is accessible to all parties. In each case, the decision is that of the judge. The Court has inquisitorial powers that enable the Judge to investigate the issues fully, and to accept material that may otherwise be inadmissible in other court proceedings. Hearings are generally open to the public.

The Mental Health Court and accompanying legislation and forensic policy allows someone with mental illness in the criminal justice system to be diverted to treatment at any point. This court is strongly supported by the Queensland Alliance. Many of our members have identified that legal and health professionals do not seem aware of the mental health court and how to access it.

Unfortunately this court is under-resourced and some people incarcerated on remand spend more time in prison awaiting a determination of the mental health court, than if they had simply pleaded guilty through a mainstream court and served their sentence in prison. Additional resources must be allocated to improve access to this court. The court is also only available to those charged with indictable offences.

Prison diversion – Most people with mental illness in prison are not a danger to other individuals or the community at large – they have mainly committed minor offences, and not crimes against the person. For this majority of prisoners with mental illness referral to community corrections or community-based forensic treatment would seem the best solution.

There are currently limited mental health services available in prisons in south-east Queensland. In general the Queensland Alliance believes it is better to divert people with mental illness from prison, rather than spend scarce resources on increasing mental health services in prison.

There is a need to provide information, training and support to prison officers on mental health. The Queensland Alliance does not suggest prison officers become de facto mental health workers, but given the huge percentage of prisoners with mental health disorders, some base level of training in mental health is required (eg the Mental Health First Aid training course may be appropriate for all prison officers).

There is also substantial untapped potential for peer-based prisoner support. For example, GROW is an organisation which develops peer or mutual support groups in the community. They have also supported the development of groups within the prison, but due to limited resources and the difficulties of outside organisations accessing prisoners, they have not been

able to continue to support these groups. Similarly, members of one consumer advisory group provide information and support to prisoners, so that they in turn assist and support prisoners with mental illness inside. We believe these types of peer-based support initiatives are very cost-effective and may improve health outcomes for prisoners with mental illness.

Diversion to secure (forensic) treatment is another alternative. A small number of people with mental illness that we spoke to who had been incarcerated in both settings expressed a preference for prison over secure forensic services. This is a sad indictment on our mental health services. The reasons given for this preference varied, and include:

- in prison people know when they will get out (whereas forensic unit release is based on medical assessment, not a time limit);
- in prison people have access to work and study;
- friends and family report that forensic units are not very accessible for visits; and
- in prison people find a more normalised environment (ie some people don't have mental illness).

The Queensland Alliance cannot confirm that these views represent the perspective of all such people with mental illness, but they seem to indicate a need for greater accountability within secure forensic services. Additionally it is important to remember that most of the population we are speaking about have not committed serious crimes and so secure forensic services are not relevant for the vast majority of people with mental illness currently in prison.

For these reasons we believe referral of prisoners with mental illness who have not committed violent crimes against the person, to community based mental health services and/or community corrections - rather than prison or forensic facilities - is better for the individual and safer for the community.

The Queensland Alliance does not support the concept of developing prisons exclusively for people with mental illness. Indeed this model was first developed in the nineteenth century and was the precursor to asylums and psychiatric hospitals. While there may be a small percentage of people with mental illness for whom prison or secure care is the best response, the overwhelming majority of people would be better served through community based treatment and support services. This is where resources are best directed.

Lack of Planning Pre-Release and Lack of Support Post-Release

There are no systems in place for graduated release, or special consideration of people with mental illness when considering community corrections orders. The Queensland Alliance endorses the report "Incorrections" (2004) by Tamara Walsh and commends this document to the Senate Inquiry. For people with mental illness the consequences of not planning release are even more significant – not only are people released without transport, housing, food, income support, etc. but also without medication or referral to mental health services.

We believe these practices reduce community safety. We heard many stories from ex-prisoners and their supporters during the development of this submission about the impacts on community safety of poor release procedures.

We believe Corrective Services is at least in part responsible for what happens to prisoners after release, particularly for vulnerable prisoners such as those with mental illness and other disabilities. In addition to ensuring all prisoners have pre-release preparation and post-release follow up from Corrective Services, we recommend that community-managed support services have access to people while in prison so that links can be made prior to release.

Community Corrections – there is scope to link mental health services – both public and NGO – into community corrections reporting systems. Currently the reporting system is high volume (ie often only 5 – 10 minute periods of contact weekly) and so an opportunity to engage a needy population group in support and treatment services is lost.

Some people with mental illness, however, advised us that they had developed a positive relationship with their community corrections officer, and that their community corrections officer had been supportive and on a number of occasions “saved” them from re-imprisonment.

There are clearly many ways of diverting people with mental illness from the criminal justice system. These solutions can be implemented if the policy objective is rehabilitation and community safety, and there is coordinated effort across government portfolios.

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ATTACHMENT TWO

First Evaluation of Project 300

QUEENSLAND UNIVERSITY OF TECHNOLOGY

IN COLLABORATION WITH

THE UNIVERSITY OF QUEENSLAND

EVALUATION OF ‘PROJECT 300’

RESULTS AT 6 MONTHS AND 18 MONTHS

January 2001

EXECUTIVE SUMMARY

Evaluation funded by Mental Health Branch, Queensland Health

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Tom Meehan (for the Evaluation Team)

FOREWORD

***Professor Harvey Whiteford
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By the early 1990's Queensland had greatly reduced the size of its three stand-alone psychiatric hospitals. Individuals with a primary diagnosis of intellectual disability had been transferred to separate facilities as those who had a primary diagnosis of alcohol abuse. Patients requiring short-term hospitalisation were largely cared for in general hospital psychiatric units. Individuals with lower levels of acuity and disability had been discharged into the community with clinical care provided by general practitioners, psychiatric outpatient departments and fledgling community mental health services.

These developments mirrored what had been occurring throughout the rest of Australia and in fact throughout much of the Western world. The census of stand-alone psychiatric hospitals in Australia had peaked in the early 1960's at 281 beds per 100,000. This had decreased to 40 beds per 100,000 by 1990 [1].

Institutional reform in the mental health field was becoming increasingly challenging. Those people remaining in stand-alone psychiatric hospitals had higher levels of disability and lower levels of family or other social supports. It had become apparent to many clinicians that the provision of good clinical psychiatric care in the community was only one of three crucial elements necessary to ensure optimal outcomes for patients discharged from psychiatric hospitals. The other two elements were the provision of adequate housing and the provision of adequate disability support services. This was recognised by the Commonwealth in its report on intersectoral linkages [2]. It was also apparent that the failure of any one of these three "legs" could see the patient relapse and require readmission to hospital [3].

In Queensland, as in some other Australian states, clinical mental health services, disability-housing and disability support services were provided by three separate departments. Coordination of services provided by different government departments has long been problematic. The challenge for Project 300 was to provide sufficient resources in the same budget to all three departments, targeted on the same 300 individuals. If successful it could serve as a model for the provision of the necessary level and mix of services for people with significant psychiatric disability living in the community.

This report is the evaluation of Project 300. The service model demonstrated improved well being for people with significant disability. It showed that clinical, housing and disability support services can be brought together to meet the needs of this population. Eighteen months after discharge, individuals continued to demonstrate improvements in symptoms, clinical functioning and quality of life. Remarkably few disadvantages for the clients were identified. Only 3 of the 218 clients discharged returned to long-term care.

Many lessons are learnt from a project such as this. The report makes several important recommendations which should inform care planning in the future. The

recommendations apply to Disability Services Queensland as well as to Queensland Health. The level of skill development and training, especially for disability support staff, is one area that needs to be addressed.urgently This is not necessarily a criticism of those disability services staff involved in Project 300. Most disability service agencies and the Department of Families, Youth and Community Care only began to seriously consider the provision of disability support services for people with psychiatric disability when Project 300 was being planned. Finally eighteen months is a relatively short period of time and it is too early to claim a long term victory for the model. Ongoing monitoring of the Project 300 group is essential.

The Second National Mental Health Plan has a strong focus on promotion, illness prevention and early intervention. It attempts to get “up stream”, to prevent psychiatric disability. This is admirable. However in the enthusiasm to introduce such programs, those individuals with established significant mental illness and disability must never be neglected. We have not yet achieved adequate care for these people in Australia (4). The lessons from Project 300 are that community care, even for those with severe disability, is possible in a way which is cost effective, clinically appropriate and satisfies the aspirations of consumers and carers. I commend those involved in carrying through the original mission of Project 300 and those who have been involved in the evaluation and the preparation of this report. I believe their work deserves wide recognition not only within Queensland but also in other states of Australia and internationally.

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EXECUTIVE SUMMARY

Institutional reform in Queensland is occurring in the context of initiatives outlined in the National Mental Health Policy (1992) and the Planning Framework for Institutional Reform in Queensland (1996). A significant component of the reform process involves the decentralisation of services provided by the three stand-alone psychiatric hospitals in Queensland. A number of initiatives have been developed to promote the resettlement of people with long-term disabilities into the community. One of these initiatives, Project 300, was established in 1995 to assist 300 people with psychiatric disabilities to move from institutional to community accommodation in their region of origin or choice.

Project 300 brought together the Government Departments of Housing, Disability Services and Health to ensure that each individual returning to the community had the supports and infrastructure necessary to maximise participation and integration in their chosen community. Each individual accessing Project 300 was provided with a support 'package' consisting of mental health services, disability support services, and normal community housing in keeping with their needs. Clinical supports were provided by local Mental Health Services while lifestyle support services were provided by Community Support Agencies.

Clients Involved

The clients accessing Project 300 were selected from the three stand-alone psychiatric hospitals in Queensland (Wolston Park, Baillie Henderson & Mosman Hall). Emphasis was placed on long-stay patients, many of whom had been in hospital for a number of years. Eligibility criteria included:

- the person chooses to leave hospital and agrees to participate in the Project;
- the person is assessed as being able to leave hospital as they no longer require a 24 hour extended treatment or rehabilitation environment; and
- the person's ongoing clinical, support and housing needs can be met within the parameters of the Project; (ie. Mental Health Act, budget allocation, etc).

Aims of the Evaluation

The evaluation was designed to assess changes in functioning and quality of life of those people supported by Project 300 following their discharge to the community. The evaluation had two main objectives:

- (i) To evaluate the quality of life for the individuals following the move to the community and to identify whether this conforms to acceptable standards in the community.
- (ii) To evaluate the contributions of housing, disability support services, informal support networks and access to mental health services, to the person's quality of life and the process of change in which they are engaged.

Evaluation Framework

Employing a combination of both qualitative and quantitative research approaches, attempts were made to collect outcome data on all 218 people who had accessed the Project 300 program by the 30 June 2000. The *qualitative* component of the

evaluation was designed to capture the personal experiences of the people discharged to the community. Over the four years of the evaluation, a convenience sample of 53 people (ie. 15 people from each year for the first three years of the Project, and eight people from year four) were invited to participate in one-to-one interviews. These 53 people were interviewed in hospital six weeks prior to their discharge and again at six weeks and six months post-discharge. This interview data provides valuable insights from the consumers' perspective into the challenges of resettlement for people with long-term mental illness.

The framework for the *quantitative* component was derived from previous evaluation studies conducted in Australia (Andrews et al., 1990; Meehan, 1993; Robson, 1995; Farhall et al, 1996) and overseas (Goering et al., 1984; McClary et al, 1989; Burns et al., 1991; Leff, 1993). All people accessing the Program over the four-year period were assessed on a number of recognised scales to monitor changes in quality of life, functioning, life skills, symptoms, medication utilisation, and general satisfaction with living situation. While the initial assessments were carried out six weeks prior to discharge, it should be noted that subsequent follow-up assessments were carried out at six months and 18 months post-discharge. The use of both qualitative and quantitative assessment techniques provided a complementary and comprehensive analysis of the Program.

Findings:

When the discharge process ended in June 2000, some 218 of the 300 clients had been discharged. The increasing cost of support packages for those clients remaining in hospital and a shortfall in funding made it impossible to discharge all 300 clients. Of the 218 discharged, 181 were followed up by the evaluation team. A small number had been discharged prior to the commencement of the evaluation and others refused to participate.

Changes in Client Functioning Over Time

Overall, approximately 41% of clients improved, 38% remained the same and 21% showed some deterioration in their general functioning during their first 18 months in the community. In the area of general functioning (ADLs), there was significant improvement in the clients as a group between six weeks pre-move (ie. baseline) and 18 months post-move ($p=.04$). However, we found no significant improvement in clinical functioning and symptoms for the same period. However, when we examined the data by gender we found that female clients demonstrated significant improvement in clinical functioning between baseline and 18 months post-move.

Having classified the overall sample into groups based on their clinical or demographic profile, we found that the clients from Wolston Park Hospital produced significantly less improvement in general functioning between baseline and 18 months. This reduced functioning may be related to symptoms, in that the group from Wolston Park Hospital had higher levels of 'positive' symptoms at all three assessment points (ie. baseline, 6 months and 18 months post-move).

Client Perceptions of their Quality of Life

While all clients were in receipt of disability support at the commencement of the project, by 18 months 5 clients had relinquished their support as they felt they did not require it. The mean number of support hours provided had decreased from an

average of 25 at discharge to 21 at 18 months. When the total sample was divided into two groups based on the number of support hours provided (ie. 0-21 hours versus more than 21 hours) significant differences were observed in the domain, 'Activities of Daily Living'. Those clients with more than 21 hours of support per week rated themselves as being significantly less involved in Activities of Daily Living when compared to their colleagues who were receiving less than 21 hours of support per week. This finding seems to validate the allocation of support hours, in that those who rate themselves as having less ability in the area of Activities of Daily Living were receiving higher levels of direct support.

Changes in Quality of Life

While quality of life for the clients in our study improved between six months and 18 months, the changes in improvement did not reach statistical significance. In fact, the clients rated their satisfaction with Occupational Activities and Physical Health lower at 18 months (than at 6 months post-discharge). However, little or no improvement in the domain of Occupational Activities is not unexpected. It is somewhat unrealistic to expect that any improvements, significant or otherwise, could have been obtained during their initial 18 months of community tenure.

Client versus Case Manager Perceptions of Client Quality of Life.

It would appear from the results that there are very few similarities between client and case manager ratings of client quality of life. In five of the seven domains assessed, case managers rated the quality of life of their clients lower than the clients did themselves. However, in two domains (ie. Activities of Daily Living and Physical Health) the case managers rated the clients higher than the clients did. This incongruity in ratings is likely to arise from the fact that case managers and clients use a different yardstick when making judgements about quality of life (Sainfort et al, 1996).

Client Perceptions of Project 300

We selected a convenient sub-group of 53 clients and interviewed them prior to leaving hospital and again at six weeks and six months post-discharge. The interviews enabled clients to tell us, in their own words, how they felt about different aspects of the Project. As a result of the disability associated with mental illness, the clients in our group had lost most of the material comforts and emotional support that many of us take for granted. During their time in hospital there was little in their lives over which they had a sense of control. However, despite the severe dislocation and the losses that many had experienced, they continued to have a sense of hope and spoke positively about a future in the community. In contrast to commonly held misconceptions for this group (Watts et al, 1973), their dreams and plans for the future were not unrealistic. They wanted to have friends, get a job, get married, and have something useful to do with their time.

All expressed a strong preference for community living. Of the 181 enrolled in the evaluation only 3 had returned to long-term care by 18 months. It is evident from the interviews that their quality of life had been improved in important respects by their move into the community. A comment from one client reflects the optimism of this relocation:

“Well the outside world is a good place. You wake up in the morning and the outside world is there, you’re always free. You can do what you want as long as you don’t break the law.”

They were very positive about their new homes in the community and the support provided to them, especially by support workers. While they missed the company of staff and the other patients in hospital, they felt that the freedom, autonomy, dignity, and the sense of hope that community living has to offer more than compensated for this. The majority recognised that while moving to their chosen community was relatively easy, becoming part of that community was going to be much more difficult to achieve. They recognised that lack of money, social venues, and meaningful activities such as work presented the greatest barriers to community integration.

Admission to Acute Care

Despite the provision of stable housing, good case management and support services, 30% of clients were admitted to ‘acute’ care by 6 months post-discharge and some 49% by 18 months post-discharge. Although the number of readmissions ranged from 1 to 10, most clients had only one readmission. Those who required acute inpatient care had significantly lower functioning and higher levels of positive symptoms at the time of relocation to the community when compared to those who did not require readmission. Only three (1.4%) of the 218 people discharged had returned to long-term care and were withdrawn from the Project. These clients are currently enrolled in rehabilitation programs and may enter the community via other schemes at sometime in the future.

Medication Use

The amount of antipsychotic medication (converted to chlorpromazine equivalents) prescribed over the study decreased slightly from an average of 419 mgs/day per client prior to leaving hospital to 400 mgs/day at 18 months post-discharge. The levels described here are considerably less than those described in previous studies. In a Melbourne study, Farhall et al (2000) report that the mean chlorpromazine equivalent for patients who moved to independent living was 545 mgs/daily while those who remained behind in the CCU was 882 mgs/day.

Employment

The fact that 14.9% of the clients in our sample had secured some form of paid employment by 18 months demonstrates the determination of the group to carve out a life for themselves in the community. However, it is still early days and while only three (3) clients were working in paid employment 38-hours per week, the majority of ‘working’ clients were employed for less than eight hours per week. It was encouraging to note that at 18 months post-discharge, 43% wanted to have paid employment as their main activity. The challenge in the future will be to provide an opportunity for these clients to fulfil their wish to secure some form of paid employment.

Housing

It is clear that the effort made by the Department of Housing to meet the needs of each individual was a significant factor in contributing to the success of the Project. The overwhelming majority of clients (95%) were satisfied with the accommodation provided to them. Indeed, of the 181 clients enrolled in the evaluation, only 22 of

these (12.1%) were relocated to alternative accommodation in the initial 18 months of community living. It is likely that these low levels of dissatisfaction with accommodation arose from having consumers involved in the selection of the accommodation prior to moving to the community.

It is clear that institutional living lacks privacy and imposes limitations on choice and the personal freedom of individuals. Having enough space was considered an important factor in the overall satisfaction of accommodation. While 98% of those who moved decided to live on their own, most of their housing options had at least two bedrooms. Having a spare bedroom was useful when family and friends visited. Others, with a flair for art and hobbies used the second bedroom as a studio. The provision of an outside area was also considered important, however it is clear that such an area should have adequate privacy. As a consequence of their illness, many consumers felt restless and wished to walk about in their yard but were mindful of neighbours looking at them.

Disability Support Services

There is no doubt that the disability support sector has been instrumental in the success of Project 300. Support workers, in particular, are to be commended for their motivation and commitment to improving the quality of life of the clients they work with. Our assessment of the work carried out by the 19 disability support agencies involved with Project 300 indicates that support workers are involved in providing practical help with financial matters, home making and community access. They also provide friendship, emotional support and advocacy. The findings confirm the multi-dimensional nature of support and the range of skills required by support staff.

The majority of support workers who replied to our survey were younger than 40 years, 54% were female, and they had been working for Project 300 for an average of 14 months. They supported an average of three clients each for an average of 23 hours per week. Although the support workers were not trained mental health professionals, many (54%) had previous exposure to people with mental illness. In relation to the training provided for their role in Project 300, 65% were satisfied with the training provided while 10% claimed to have received no training. Some 78% felt they required more training in areas such as clinical issues, crisis intervention, anger management and counselling.

From the free-hand comments provided by support workers, it was clear that *“the role was over valued by the clients and under valued by the professional staff”*. However, there was a general impression that support workers were gaining more respect for the work they did with clients. They felt that they played an important role on the team and outlined that *“to be the person at the coal face in helping a consumer was a great responsibility”*.

The support workers felt their relationship with their clients was based on friendship rather than one of paid employee. The issue of friendship between support workers and clients can be viewed in different ways. If support workers become too successful in building relationships with clients, the long-term goal of reducing contact with clients as independence increases could be undermined. On the other hand, clients making friends with those people with whom they have most contact is not only a good survival strategy, but also exercises a capacity for friendship which can be used

outside the home environment to build a support network. In any case, the provision of support services should be based on some assessment of client need, and as Strauss (1996) outlines, disability services should be on *tap* not on *top*.

How does functioning relate to the provision of support services? The strongest association found on all of the scales used was between cognitive impairment and support hours. As cognitive impairment increased, so too did the number of support hours provided. However, while the association was significant it was relatively weak. Indeed, readmission trends provide strong support for the way in which disability support services have been allocated. The more disabled clients (ie. those clients receiving more than 21 hours of support per week) were almost three times more likely to be readmitted to acute care than those who were receiving 21 hours or less per week.

Social Integration

In this study, support workers perceived isolation and loneliness to be the greatest difficulty faced by clients in the community. Loss of long-standing friendships at the hospital, lack of money to engage in community activities, and lack of meaningful activities were also seen by the clients themselves as contributing to their state of loneliness. It suggests that the barriers to social integration are more likely to exist in the environment rather than the individual. Indeed, in some areas, clients with severe disabilities were more integrated into their community than higher functioning clients in other areas.

There was a steady increase in clients' reports of socialising with friends and visiting family during the post-discharge period. Only 12% clients reported contact with friends and family during their time in hospital while 23% did so at six weeks, and 41% did so at six months post-discharge. This hopefully indicates the development of a social support network outside the formal system. This activity, in conjunction with talking to and going out with the support worker, replaced the social interaction which took place between patients in hospital. It was encouraging to note that 52% of clients at six months and 66% of clients at 18 months claimed to have five or more people in their lives that they called 'friends'. This suggests that as community tenure increases, the size of the social networks also increases. However, as many clients included their support workers in their pool of friends, the actual number of 'unpaid' friends in the lives of the clients is difficult to estimate.

Cost Implications

It was not the aim of this study to carry out an economic evaluation of the project. A comprehensive evaluation of the Project 300 funding model has already been conducted (Johnson & Leahy, 1999). However, our data expands on the findings presented by Johnson & Leahy and makes it possible to draw some tentative conclusions about the cost of hospital and community care. The cost distribution of disability support packages (support hours) for Project 300 clients are shown below.

Cost of disability support packages by frequency

Cost of Disability Support Packages	Number of clients/packages
\$0 - \$9999	3
\$10,000 - \$19,000	12
\$20,000 - \$29,000	38
\$30,000 - \$39,000	27
\$40,000 - \$49,000	32
\$50,000 - \$59,000	40
\$60,000 - \$69,000	13
\$70,000 - \$79,000	16
\$80,000 - \$89,000	13
\$90,000 - \$99,000	7
\$100,000+	5
TOTAL	206

The average value of a community support package was \$47,437. However, when the administration cost of approximately \$10,000 per package is included, the average cost per package increases to \$57,400. While the 'brokerage' model has an operational split between the purchase and provision of services, it has an inherent managerial and administrative cost associated with it.

Health care costs must also be considered. The major costs in this category include those incurred by mental health services (case management and GP services). Given that the majority of clients receive a visit from their case manager every two weeks and visit a GP every month, the estimated average cost is \$11,500 pa. However, it must be pointed out that by 18 months post-discharge some 50% of clients had been readmitted to an acute care facility. The costs associated with re-admission to hospital during times of crisis are not included. Data related to readmissions was to be supplied directly to Qld Health by case managers. However, as this database remains incomplete, it is impossible at this stage to estimate the costs arising from readmission to hospital. The approximate total cost for the 'average' Project 300 client (who did not require readmission to acute care) in the community is \$68,900 per year (ie. \$57,400 + \$11,500) or approximately \$189 per day. From data supplied by Queensland Health it is possible to compare the cost for Project 300 clients with clients in other treatment options.

Cost of care - Project 300 and alternative options.

Facility Type	Annual/Daily Cost
26 Bed Acute Unit	\$159,500 (\$437 per day)
26 Bed Rehab/Dual Diagnosis Unit	\$90,880 (249 per day)
20 Bed Community Care Unit	\$85,770 (\$235 per day)
Project 300	\$68,900 (\$189 per day)

It is clear that the cost of approximately \$69,000 per year for a Project 300 client may appear excessive, it remains considerably less expensive than the alternative forms of treatment. On average, a Project 300 client costs approximately \$20,000 per year less than their colleagues in a Rehabilitation Unit and \$15,000 less per year than the cost of keeping a client in a Community Care Unit.

Conclusion

Given the focus on community care in national policy, the findings of this evaluation have a number of implications for service provision. Project 300 is an excellent example of how the Government Departments of Health, Housing, and Disability Services can work together to improve the wellbeing of people with psychiatric disabilities. Project 300 demonstrates that given adequate support and good case management, the accommodation needs of people with long-term psychiatric disabilities can be met through ordinary/normal housing in the community.

Assessed on any measure, our findings indicate that the Project 300 model has been as successful, if not more successful, than the majority of the resettlement programs reviewed. Community care within the Project 300 model appears to have an overall economic advantage over hospital care and no clear disadvantage for clients. Data from the objective measures used in the evaluation of Project 300 highlight major benefits and few disadvantages for the clients in the Program. After 18 months of community living, there were improvements in all of the domains assessed (symptoms, clinical functioning, and quality of life) with significant improvement in the ability of clients to perform life skills.

All of the clients in the evaluation demonstrated a strong preference for community living and only three of the 218 clients discharged returned to long-term care. The freedom and choice that community living offers appears to compensate for the increased responsibility associated with such living. Overall, it is clear that while some clients have made considerable advances in securing a future in the community, others have been less successful in taking advantage of the opportunities available to them. While service models continue to provide support, they must also allow for what Deegan (1992) calls the ‘dignity of risk and the right of failure’. Thus, the challenge for service providers is to find the right balance between the provision of planned interventions for clients and the freedom to be self-determining individuals.

While the majority of clients have now been relocated to the community, the next phase of the resettlement program needs to be more firmly grounded in the principles of psychosocial rehabilitation. In the absence of a common model of psychosocial rehabilitation, there is a danger that service provision reaches a plateau and becomes a form of ‘maintenance’ rather than ‘rehabilitation’. The implementation of a common model of psychosocial rehabilitation would provide a framework to guide service planning and ensure consistency of service delivery across providers. The principles could also be used as minimum standards against which service delivery could be assessed and monitored.

Recommendations:

- Those involved in the planning of future resettlement programs are encouraged to consider the Project 300 model. The policy of intersectoral collaboration (multi-agency involvement) fostered by Project 300 appears to have an overall economic advantage over hospital care and no clear disadvantage for clients. Indeed, the Project 300 model could be used to inform the development of mental health services in general.

- There are 19 different disability support agencies providing services to Project 300 clients and these tend to differ in respect to philosophy, models of service delivery and outcome expectations. The ongoing development of policies and service agreements should continue by Disability Services Queensland (DSQ) in collaboration with the support sector. Clearly operationalised policies and service agreements will help protect the rights of clients and the agencies involved.
- The current model of service delivery needs to be more closely aligned to the principles of psychosocial rehabilitation. A model grounded in such principles would provide a common framework to guide service planning and ensure consistency of service delivery across providers. The model employed by Psychiatric Disability Services Sector in Victoria (VICSERV) is one such model that could be considered.
- As to this last recommendation, the relationship between the provision of support services and client needs requires regular review. Given that funding is attached to the client and not to the agency, there is a structural disincentive to reduce support services. It is possible that some clients may be over-serviced in such a system and this may impact on their potential to become self-determining, responsible individuals.
- The ongoing role of Key Workers within the Project 300 model needs to be addressed. Since funding/support structures are now well established for the majority of clients, the future role of Key Workers needs to be clarified. The uncertainty surrounding the role of this group has a destabilising effect on other service providers and indeed, the clients themselves.
- Ongoing skill development and training for disability support staff needs to be addressed. Considerable variation exists in the duration and focus of training provided to disability support workers. The disability support sector in collaboration with TAFE (or some other educational body) should consider the establishment of an accredited course (perhaps at certificate level) for disability support workers. The number of disability support staff employed in the mental health field is likely to increase significantly over the next decade and the training needs of this group will need to be considered.
- A system of ongoing evaluation of the services provided and the outcome for clients needs to be established. Such a system should include a mechanism for obtaining feedback directly from the clients themselves.
- Although the evaluation highlighted the ability of the Project 300 model produced major benefits and few disadvantages for the clients in the Program, following-up clients at 18 months is too brief to serve as an adequate indication of adaptation to community living. We recommend that funding be made available to extend the evaluation for a period of five-years in keeping with overseas trends in the evaluation of resettlement programs.

Tom Meehan