



MENZIES SCHOOL OF HEALTH RESEARCH

Northern Territory Australia

**Community Resource Base Project
Alice Springs**

Ann O'Kane
Eva Briscoe
Matthew Fowler
Members and Staff of Heritage Clubhouse

November 1999

DARWIN :
PO Box 41096
CASUARINA NT 0811
Ph : 08.8922 8196
Fax: 08.8927 5187

<p>ALICE SPRINGS : PO Box 8569 ALICE SPRINGS NT 0871 Ph : 08.8951 7757 Fax: 08.8951 7590</p>

**Community Resource Base Project
Alice Springs**

Ann O’Kane
Eva Briscoe
Matthew Fowler
Members and Staff of Heritage Clubhouse

Menzies School of Health Research
November 1999

Contents

- Acknowledgments..... 1**
- Foreword..... 2**
- Executive Summary 3**
- Introduction 5**
- Section One : Background Information..... 6**
 - 1.1 *The knowledge resource base* 7
 - 1.2 *Recovery* 8
 - 1.3 *Community resource base* 9
 - 1.3.1 *Partnerships in support*.....9
 - 1.3.2 *Human rights*.....10
 - 1.4 *Second National Mental Health Plan - 'Partnerships in service reform and delivery'* 11
 - Conclusion 12
- Section Two : Methodology for the *Community Resource Base* Project..... 14**
 - 2.1 *Mapping the community resource base* 14
 - 2.2 *Accessing the community resource base*..... 15
 - 2.3 *Survey target group* 16
 - Conclusion 17
- Section Three : Results from the *Community Resource Base* Mapping Exercise and Survey 18**
 - 3.1 *Background information - survey target group*..... 18
 - 3.1.1 *Demographic information*..... 18
 - 3.1.2 *Length of residence in Central Australia*..... 20
 - 3.1.3 *Gender, age and family status*..... 20
 - 3.1.4 *A profile of Australian mental health service consumers* 21
 - 3.2 *Accommodation*..... 22
 - 3.2.1 *Private/ public accommodation*..... 22
 - 3.2.2 *Who are you living with?* 22
 - 3.2.3 *Satisfaction with accommodation*..... 23
 - 3.2.4 *Accommodation difficulties*..... 23
 - 3.3 *Accommodation issues*..... 23
 - 3.3.1 *Public housing* 23
 - 3.3.2 *Supported accommodation* 24
 - 3.3.3 *Emergency accommodation* 24
 - 3.4 *Income* 25
 - 3.4.1 *Income Source* 25
 - 3.4.2 *Satisfaction with income* 26
 - 3.4.3 *Expenditure patterns*..... 27
 - 3.5 *Employment* 27
 - 3.5.1 *Employment status*..... 27
 - 3.5.2 *Preferences for employment*..... 28
 - 3.5.3 *Discrimination*..... 28

3.5.4	<i>Employment support</i>	29
3.5.5	<i>Employment issues</i>	30
3.5.6	<i>Employment support services</i>	31
3.6	Education/ training	32
3.6.1	<i>Educational levels</i>	32
3.6.2	<i>Further training</i>	33
3.6.3	<i>Preferred training institutions</i>	33
3.6.4	<i>Types of training support</i>	34
3.6.5	<i>Educational/ training issues</i>	34
3.7	Living situation support	35
3.7.1	<i>Access to living situation support</i>	35
3.7.3	<i>Transport</i>	36
3.7.4	<i>Issues</i>	37
3.8	Leisure and recreation.....	37
3.8.1	<i>Individual and group activities</i>	37
3.8.2	<i>Vacations</i>	38
3.8.3	<i>Barriers</i>	39
3.8.4	<i>Issues</i>	39
3.9	Social life/ friendships	39
3.9.1	<i>Social networks</i>	39
3.9.2	<i>Supports for social networks</i>	40
3.9.3	<i>Family relationships</i>	40
3.10	Mental health services.....	41
3.10.1	<i>Illness onset</i>	41
3.10.2	<i>Acute care</i>	42
3.10.3	<i>Alternative acute care preferences</i>	42
3.10.4	<i>Medication</i>	43
3.10.5	<i>Satisfaction with medication information</i>	43
3.10.7	<i>Culture and language</i>	45
3.10.8	<i>Case management services</i>	45
3.10.9	<i>Issues</i>	46
3.11	Consumer involvement.....	46
3.11.1	<i>Self help group</i>	47
3.11.2	<i>Consumer rights</i>	47
3.11.3	<i>Issues</i>	48
3.12	Barriers and opportunities for recovery	48
3.12.1	<i>Community support for the recovery process</i>	48
3.12.2	<i>Challenges to recovery</i>	48
3.12.3	<i>Assistance to recovery</i>	49
3.12.4	<i>Issues</i>	49
	Summary.....	49
Section Four : Discussion.....		51
4.1	Results	51
4.1.2	<i>Accommodation</i>	52
4.1.3	<i>Income</i>	53
4.1.4	<i>Employment and training</i>	53
4.1.6	<i>Daily living support</i>	55
4.1.7	<i>Clinical support</i>	55
4.1.8	<i>Intersectoral linkages</i>	56
4.2	Methodology	57
4.4	Implications.....	59

Summary.....	59
Conclusion.....	61
References	62
Appendix A	64
Appendix B	66
Appendix C	67

Acknowledgments

We would like to acknowledge with thanks the many people and groups who provided information, contributions and feedback for this research project. We wish to thank the Commonwealth Government Research and Development Grants Advisory Committee for funding the project (via the National Health and Medical Research Council).

Ann O’Kane was employed as the Senior Research Officer from Menzies School of Health Research. Eva Briscoe and Matthew Fowler were employed as consumer research assistants by Menzies School of Health Research to undertake the *community resource base* survey section of the project. Robyn Cruickshank (Chairperson of the Mental Health Association of Central Australia) also worked as a consumer research assistant. Robyn led a small team of consumer research assistants who were members of Heritage Clubhouse to undertake a contract to map the *community resource base* section of the project. Members of this team included Steve Ames, Lachlan Ross, and Paul Mann. Paul Hills (the Heritage Clubhouse Work Crew Supervisor, employed by the Mental Health Association of Central Australia) supervised the consumer research assistants and the contract between Menzies and the Clubhouse.

We wish to thank the following people who directly contributed to the project:

- Residents who completed the *Community Resource Base* survey;
- Members of the Heritage Clubhouse who supported the development of the project;
- Central Australian Mental Health Program staff - the Management Executive team, the Community Mental Health staff from Alice Springs Urban and the Barkly, Ward One clerks;
- Service providers in a range of agencies in Alice Springs;
- Members of the Mental Health Association of Central Australia;
- Komla Tsey, Chief Investigator for the project;
- Catherine Hume, Canadian Mental Health Association (British Columbia Branch) for providing survey examples;
- Sally Rogers; Centre for Psychiatric Rehabilitation, Boston University (USA) for providing survey examples.

Foreword

Accurate mapping of mental health services and sensitive interpretation of surveys of consumer's real needs are essential, if the future is to offer consumers services that will really meet their mental health requirements. It is only with this accuracy and sensitivity that individuals affected by mental health problems will be better enabled to realise their full potential within the community in the future.

There is a whole science to the surveying of populations for their health needs. In the mental health field this science is being challenged along with the professional practices and means of service delivery, by the consumers of these services. Consumers are increasingly seeking to influence the construction of the paradigms that describe their experiences. In surveys and questionnaires that try to grasp the reality of consumer's lives it is increasingly becoming apparent that to get a good map and survey we need reliable guides. Consumers experienced in the needs, lifestyle issues and lived experience of their peers, who have shared experiences of services are increasingly serving as those reliable guides, revealing knowledge that would otherwise fail to appear in those maps.

In involving consumers in the development and application of this survey I am sure a more detailed map of existing services, their strengths and deficiencies has been achieved. In particular, it helps to highlight certain aspects of the complex issues of what actually makes for recovery and the barriers and bridges to consumer's re-entry into the wider community. A highly individual process that is not always well understood or facilitated by health services.

Central Australia is unique in many ways. Its remoteness is just one element that creates particular challenges in the delivery of quality mental health care. However, consumers have universal needs and these are now protected by rights mechanisms and national standards. With this survey we have a good map of how things stand at the end of the millennium. Hopefully it will stand as a good guide for future development of services that respond to the unique challenges of Centralian mental health needs, in keeping with developments elsewhere in Australia that are creating better opportunities for consumers as we enter the new millennium.

Simon Champ
National Consumer Advocate
Sane Australia
November 1999

Executive Summary

Menzies School of Health Research was requested by the Central Australian Mental Health Program to evaluate mental health service provision in Central Australia. An initial assessment was undertaken to identify the parameters of the evaluation. From this assessment two key issues were prioritised (Tsey, 1998). One priority was to assess whether Central Australians received a fair share of financial resources to provide specialist mental health programs in the region. The other priority was to assess whether Central Australia had the right mix of services available for people experiencing mental illness. The results of the overall project are contained in a report titled, 'Shifting the balance - services for people with mental illness in central Australia. A framework for resource allocation and planning' (O'Kane and Tsey, 1999). In this report we included only a very brief overview of the investigation into the service mix question. We decided to publish a separate report, the Community Resource Base Project, Alice Springs, to provide a more detailed description regarding the mix of services that are required by people experiencing mental illness.

The Community Resource Base Project was a collaborative effort between a research organisation (Menzies School of Health Research) and a consumer self help organisation (Heritage Clubhouse, Mental Health Association of Central Australia). The research team included a part time senior research officer, two part time consumer research assistants and a small team of casual consumer research assistants, plus the Work Crew supervisor from the Clubhouse. The project was undertaken over a period of six months (October 1998 - March 1999).

Consumers and researchers worked together to establish a method that would be able to accomplish two objectives. Firstly, to work out what services people experiencing mental illness required. Secondly, to establish whether this group of people in Alice Springs and Tennant Creek were accessing these services. We used a number of influential concepts to guide our thinking. We were interested in the work undertaken by the Canadian Mental Health Association that promoted the concepts of the *community resource base* and the *knowledge resource base*. These ideas assisted us to broaden our horizons when thinking about the range of resources needed and who could provide the resources. We decided that the goal of service provision should be to facilitate a wellness and recovery approach to mental illness. We became interested in the current work being undertaken in New Zealand which pinpointed stigma and discrimination as the largest stumbling block to recovery from the consequences of mental illness.

We found these sorts of concepts to be compatible with current Australian policy frameworks and directions. In fact we believe we have established a methodology which will enable service providers and service users to work together to implement the 'partnership' reform of the Second National Mental Health Plan (1998). This reform essentially calls for the establishment of partnerships between specialist mental health providers and a very broad range of other services, to ensure that the requirements and needs of people with mental illness are met appropriately.

The method devised for this project consisted of a mapping exercise and a survey. Consumer research assistants identified and mapped out what they believed were the most important resources needed to get on with their lives. This included a great deal more than the specialist mental health programs. It started with accommodation options, income support, education/ training options, employment services and continued into the supports available through churches, transport options, sporting clubs etc. The officers/

professionals working in these agencies in Alice Springs were then interviewed to find out what they did or did not provide for people with mental illness.

The next step involved developing a survey to find out if people experiencing mental illness were actually accessing these resources. The survey targeted people who were currently using the case management services provided by the urban teams of the Central Australian Mental Health Program in Alice Springs and Tennant Creek. It requested information about accommodation, income, training, transport, daily living, employment, experiences with the clinical services, acute care, medication, understanding of rights, other health problems, recreation, hobbies, social networks, self help, ideas for recovery.

Overall we found that consumers in Alice Springs and Tennant Creek are poor and appear to have restricted their life style to accommodate poverty and stigma. They spend most of their income on food and rent and are generally renting from the public housing authority. Many have experienced difficulty with accommodation. One of the reasons people are so poor is that they are unemployed and rely on income support from Centrelink. Almost all the unemployed group indicated they would like some form of paid work, but needed assistance in this area. The majority also wanted to undertake further training to improve their employment options. However consumers are not accessing support services for either employment or training. This is for a variety of reasons, ranging from inappropriate services, financial barriers, a lack of information about what is available and a lack of confidence to pursue what is available.

Consumers in this region rely almost entirely on their family and friends and the mental health staff to assist with their daily living needs and other challenges in their lives. Nearly half have a very narrow social network. There is a belief that consumer self help options would be useful, particularly for pursuing social activities and support. Only one quarter of respondents believed that people in the general community had a good understanding of mental illness. Overall, we believe that the data discovered in this process provide mental health stakeholders in this region with clear directions for developing partnerships, overcoming barriers, changing attitudes, and facilitating appropriate service and program responses for people experiencing mental illness.

Investigating the question of service mix, through the *community resource base* framework, was significant in a number of ways:

- Consumers were employed not only have input and direction into the research effort, but also to carry out the research.
- There is potential to commence a shift in attitudes. The consumers involved started to think more broadly about what resources they actually used, and wished to use, to take control of their lives. Mental health professionals and other service providers in the community were also challenged to take into account this concept of people with mental illness needing a much broader level of access to resources.
- The methods used in this project can be used by other service providers and service users around Australia who wish to work together to assess which partnerships and networks need to be established and strengthened in their region for people experiencing mental illness. Therefore others can also use the process to commence shifting attitudes about mental illness and the needs of people experiencing mental illness.

Introduction

This is a report outlining an innovative project which investigated the mix of services required by people experiencing mental illness. The results of the project are a reflection of a partnership between a research organisation and a consumer self help organisation. The project was undertaken as a collaborative effort between staff at Menzies School of Health Research (Central Australian Unit) and members of the Heritage Clubhouse (Mental Health Association of Central Australia). This report will outline the following:

- The ideas and principles guiding the project;
- The methods developed for the investigation;
- The results of the investigations.

Section One presents the ideas and principles that guided the project. These were essentially centred on the concepts of the *community resource base* and the *knowledge resource base* (Canadian Mental Health Association). These ideas promote the need for a broad understanding of:

- what services people with mental illness required to get on with their lives?
- who can provide these services?
- who has expertise regarding the experience and treatment of mental illness?

Section Two reports on the methods used to gather the data. This consisted of a mapping exercise to find out:

- what was available in the Alice Springs community?
- who was providing what services/ supports?
- how services/ supports were being provided?

The other major component of the methodology was a survey to investigate whether people experiencing serious mental illness were accessing these resources. Residents using the case management services from the Central Australian Mental Health Program were invited to participate in the survey.

Section Three provides a detailed exploration of the results of the research work. The data collected indicates that there is a substantial amount of work to be undertaken in establishing partnerships, linkages and networks to ensure that people with mental illness can actually access essential resources in the community. This work has to be undertaken collaboratively between service providers and service users, as well as between policy makers and decision-makers.

The final section of this report is the Discussion. The strengths and weaknesses of the methodology are reviewed and a summary of the key trends that emerged in this work is provided.

Section One

Background Information

The Central Australian Mental Health Program requested Menzies School of Health Research to evaluate mental health service provision in the Central Australian region. The *Community Resource Base* project was undertaken as part of this larger evaluation of mental health service provision in the region (O’Kane and Tsey, 1999). An assessment of the key issues concerning local mental health stakeholders was initially undertaken by Menzies School of Health Research (Tsey et al, 1998). Two key concerns emerged. These were:

1. Firstly that key stakeholders in central Australia wanted to know what a reasonable level of resource allocation would be to provide specialist mental health programs for this region.
2. Secondly, they also wanted to know what mix of services were required by people with mental illness and whether these services were available in this region.

This report is a documentation of the results from our investigations into the second concern, regarding the mix of services required for people experiencing mental illness.

When we commenced our investigations three recurring themes emerged from the literature review. These were that:

- the range and types of service and supports required by people experiencing mental illness went way beyond what is generally available in a specialist mental health program. (This theme is now a central platform of the Second National Mental Health Plan, 1998);
- recovery from mental illness was both a desirable and possible objective for both the individual and the broader community;
- discrimination and stigma were major impediments to focussing on wellness and facilitating a recovery process.

Over the past decade these themes have been documented through a growing body of literature authored by people who experience serious mental illness (Deegan, 1988; Deegan, 1996; Chamberlain, 1998). These previously unheard voices have spoken about discrimination, coercion, loss of rights, lives of poverty, unemployment, homelessness, isolation, incarceration. This is quite different to the knowledge of service providers, who speak about prevalence rates, symptoms, medications, treatment, disruptive behaviours and psychiatric services. There is an increasing acknowledgment that consumer knowledge about mental illness is legitimate. Taking account of consumer expertise definitely expands the boundaries for the question concerning the appropriate mix of service.

These types of shifts have also been promoted through the directions in the Second National Mental Health Plan (1998). The Plan is attempting to shift the Australian mental health sector away from focussing only on a specialist tertiary role, to encompassing a broader public health role.

Other planners and policy makers who have tried to answer these questions also influenced our approach. We were particularly interested in what had been happening in Canada over the last decade and what was

commencing in New Zealand. Both of these policy environments promoted the goal of facilitating 'recovery' as central to the role of mental health service provision. Within this type of approach mental health services are no longer confined to the objectives of 'keeping people out of hospital' or 'helping people to live as independently as possible in the community'. Recovery objectives are couched more in terms of ensuring access to appropriate types of support and actively limiting discriminatory environments, attitudes and practices. The New Zealanders argue that mental health services have historically failed to use a recovery approach, as people with mental illness were expected never to get better and interventions were often coercive.

Virtually everything the mental health sector does can either assist or impede recovery. Some people have experienced recovery without using the mental health services. Others have experienced recovery in spite of them. (New Zealand Mental Health Commission, 1998).

The concept of recovery from mental illness has emerged as a critical process. While medical professionals and scientists have continued to work on trying to uncover the secrets of the brain to cure and prevent mental illness, people with mental illness have started to work on the processes of getting on with their lives. This is quite a paradigm shift in our society's attitudes and understanding of mental illness. For people with a mental illness the consequences of the illness can be as challenging as the symptoms of the illness. Anthony (1993) argues that the most critical component of recovering from the '*catastrophic effects of mental illness*' at the personal level is regaining the belief that there are options to choose from. These options start to emerge through the type of personal support available to individuals experiencing mental illness. Through accessing a range of effective types of personal support, people with mental illness develop new meaning and purpose in their life. Support comes in many forms - family/ relatives, friends, health professionals, and other people with mental illness, books, and films, support groups, community resources, employment and training opportunities, participation community activities and services. One way of viewing the elements of recovery is to map out the types of resources that people with mental illness require to get on with their lives. The Canadian Mental Health Association has provided a comprehensive way of understanding this through the concept of the *community resource base*. We have used these concepts as a central idea in this research project.

In this Background Information section we provide a brief overview of the core ideas that have influenced this project, such as the:

- *knowledge resource base*
- recovery
- *community resource base framework*
- Second National Health Plan (1998)

1.1 The *knowledge resource base*

The way that mental illness is understood plays a crucial role in shaping the options available to people deemed to be experiencing a mental illness. Trainor *et al* (1993, 1997) have used a range of theories from sociological and anthropological schools of thought regarding knowledge and power, to develop the concept of a *knowledge resource base*. There are four categories of 'expert' knowledge identified in the *knowledge resource base*. These are: medical/clinical knowledge, experiential knowledge, customary/ traditional knowledge and social science knowledge.

This idea is an attempt to go beyond the notion that ‘real’ knowledge is only in the hands of clinical experts (service providers) and that others such as consumers, families and the public have little to contribute (Trainor *et al*, 1993). These authors argue that the many attempts over the decades to reform mental health service provision have always looked towards psychiatry to provide guidance. By attempting to make use of the full range of rich information available in the *knowledge resource base* concept, previously devalued knowledge can contribute to the debates about mental health service reform.

This concept of the *knowledge resource base* became a central guide within this research project. It resulted in a number of decisions that influenced the methodologies and therefore the outcomes of the project. People who experienced mental illness were viewed as having ‘expert knowledge’ and played a significant role in investigating the question posed for this project. Menzies collaborated with a consumer self help organisation and employed consumer research assistants. We believe that consumer expertise has strengthened the capacity of this research project to contribute to a wellness/ recovery approach to service provision

1.2 Recovery

At a personal level the concept of recovery does not mean that the symptoms of illness disappear. As with physical conditions such as stroke, paraplegia, arthritis, the problem does not disappear. Tooth *et al* (1997) likened the concept of recovery to being in a continuing state, rather than an end state – the problem is always there, however the meaning one attaches to it changes. There can be more to one’s life than just the problem.

The goal of the recovery process is not to become normal. Recovery does not mean cure. Rather recovery is an attitude, a stance and a way of approaching the day’s challenges. It is not a perfectly linear journey. There are times of rapid gains and disappointing relapse. There are times of just living, just staying quiet, resting and regrouping. (Deegan, 1996: 96)

Through accessing a range of effective types of support, people with mental illness develop new meaning and purpose in their lives. Tooth *et al* (1997) completed one of the first major studies in Australia regarding how people experiencing the illness of schizophrenia recovered. A significant number of participants in this study reported that the illness was a crisis in their lives and they had learnt how to take control of their lives, rather than be dominated completely by the illness. All reported that they had found their own way to manage their symptoms, without the help of professionals. Professionals were helpful only when they were able to build a positive relationship with the person, a relationship often described as friendship. This appears to be an uncommon phenomenon.

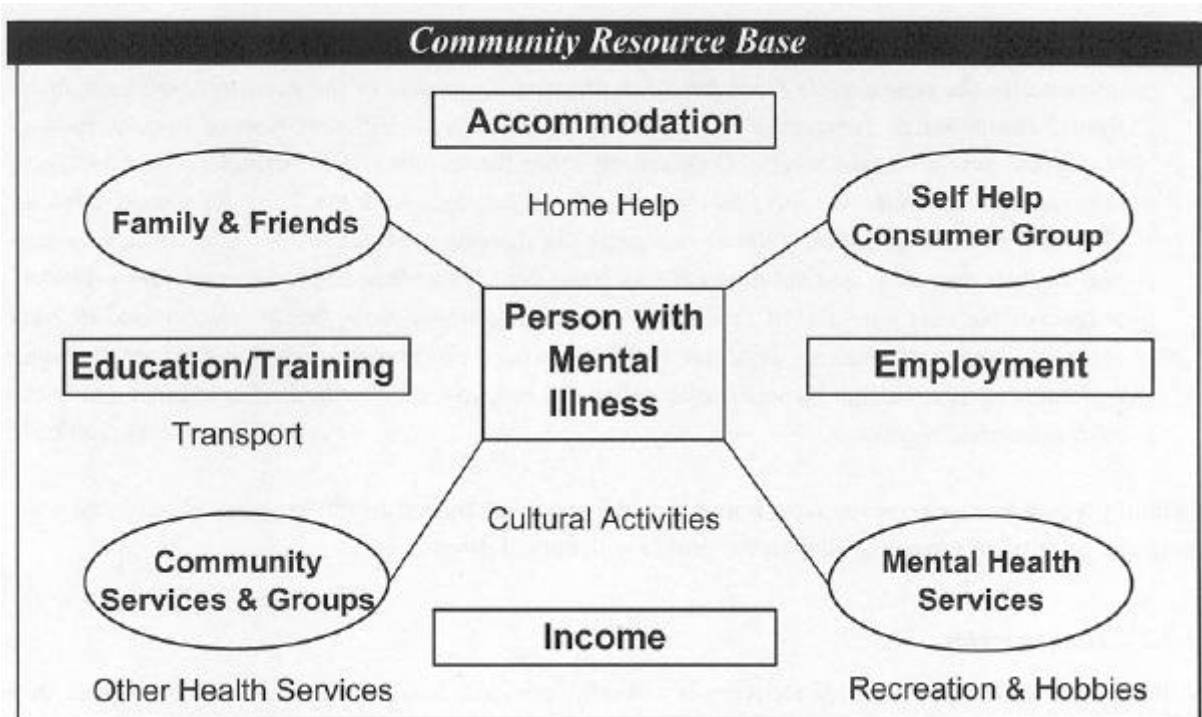
The most significant barrier to recovery is stigma and discrimination, which is not caused by the clinical symptoms of mental illness, but rather by beliefs and attitudes about mental illness.

Recovery from mental illness involves much more than recovery from the illness itself. People with mental illness may have to recover from the stigma that they have incorporated into their very being, from the iatrogenic effects of treatment settings, from the lack of recent opportunities for self-determination, from the negative side effects of unemployment and from crushed dreams. Recovery is often a complex and time-consuming process. (Anthony, 1993: 15)

1.3 Community resource base

We found the concept of the *community resource base* (Trainor et al, 1993) to be useful in providing an overall framework for following through with our investigation. There are two central features of the *community resource base*:

- One is the idea that people with mental illness utilise a range of resources to form a support system/ support networks (the idea of '*Partnerships in Support*').
- The second is that society must ensure that basic human rights are met through the provision of essential resources, such as income, housing, employment and education (accessing *Basic Human Rights*).



1.3.1 Partnerships in support

The '*Partnerships in Support*' proposal asserts that the most useful and efficient way of providing what people with mental illness require is through developing partnerships between four key sectors of support: These are:

- consumers themselves and facilitation of their self help organisations/ networks;
- family/ carers and facilitation of their self help organisations/ networks;
- generic community services/ agencies/ clubs etc;
- specialist mental health services.

The presence of four 'balanced' sectors means that all sectors can be involved in mental health resource planning and delivery. The person who experiences mental illness makes choices about which support/ resource to use.

The *community resource base* concept goes one step further and promotes an idea called '*community reinvestment*'. This idea asserts that resources for mental health should be available to the other sectors of

the partnership and not just the specialist mental health programs. This is a fundamental shift in terms of the usual priority given to the specialist mental health program. The specialist sector almost always receives all the funding resources that may be available to provide supports for people experiencing mental illness. This idea is significant in shifting the focus away from the needs of the specialist mental health service, towards the needs of the person with mental illness¹.

Trainor et al (1997) argue that the central priority for any mental health service provision is to work out whether it is effective in supporting people with mental illness.

The message is simple: services, whether in hospital or the community, are not the centre of the universe. In the past decade there has been growing awareness of the need to re-allocate funds from institutional to community based services. However, a different type of re-allocation of resources must also take place. Even setting aside the resources for institutions and focussing only on the community, we still find that virtually all-mental health funds are for formal services. This kind of funding pattern fails to recognise the dynamic and active role that consumers now play in their own care, and the extent to which this could be enhanced if resources were provided. It ignores the vast potential of families to provide support to their family member and to each other if given resources to organise. By assuming that professional services are the only legitimate option, current mental health policy has confined itself to limited, and incidentally the most expensive, responses. (Trainor et al, 1997:61)

Within the *community resource base* framework the specialist mental health program is only one way, only one priority, of providing support for people with mental illness.

1.3.2 Human rights

Although the concept of personal recovery is powerful, personal recovery also needs to be viewed in a broader social context. As mentioned above, much of what gets labelled as mental illness may have little to do with a medical condition, but may have a great deal to do with social status, opportunities and discrimination.

A useful framework for picking through the personal and political aspects of mental illness can be found in the World Health Organisation (1980) classification of the consequences of disease. This classification breaks down into four categories – impairment, dysfunction, disability and disadvantage. Anthony *et al* (1993) have summarised the implications of this classification system for serious mental illness as follows:

- Impairment, which includes any loss or abnormality of function (for example, hallucinations, depression).
- Dysfunction, which includes any restrictions or inability to perform activities/tasks (for example, lack of work skills, social skills).
- Disability, which encompasses any restriction or inability to undertake a role which is considered 'normal' (for example, unemployment, homelessness).

1 In fact in Canada these ideas have been used to re-allocate mental health resources. For example, in 1993 the Ontario Ministry of Health re-directed a proportion of mental health funding to a 'Consumer/ Survivor Development Initiative' to fund a range of organisations undertaking consumer focussed projects. For an evaluation of these sorts of resource allocation strategies see Trainor, et al, 1996.

- Disadvantage, which encompasses a lack of opportunity that limits the performance of an activity or role (for example, discrimination, poverty).

This conceptualisation helps to make it clear that mental illness not only encompasses clinical symptoms (such as hallucinations), but also a range of experiences resulting in dysfunction, disability and disadvantage. People with major mental illness can experience a significant level of handicap and this can be experienced on and off over a long period. Delusions, hallucinations, thought disorder, loss of concentration, incoherent speech, apathy, distractibility, anxiety and depression are impairments that can have a major impact on an individual's cognitive and interpersonal capabilities and lead to a psychiatric disability. This group of people experience high levels of stigma and discrimination. A consequence of psychiatric disability in western countries is that people with mental illness have exceptionally high levels of unemployment, ill health, poverty, homelessness and social isolation, to name a few disabilities and disadvantages.

The experience of mental illness may be fundamentally different to physical illness. People with mental illness may not reach a stable equilibrium. They may be acutely sick and then recover or they may need intensive support for long periods of time.

There are important differences between mental and physical illness, which have implications for service delivery. Mental illness impairs the cognitive, affective and relational abilities. Impairment of these abilities results in considerable difficulties for people trying to get the various services they require and in complying with treatment. Mental illness often results in functional disabilities, which may be static and long term or which, unlike many chronic physical disabilities, are unpredictable and fluctuate significantly in intensity and duration. The manifestations of mental illness are diverse, range in severity and are inextricably linked with quality of life issues, employment opportunities, social and family relationships, general health, economic factors and community participation. Disability should therefore be seen as a function of both the illness process and the context within which the individual functions.

(National Mental Health Strategy, 1993)

In the early 1990's a major human rights investigation was undertaken by the Australian Human Rights and Equal Opportunity Commission (HREOC, 1993) to make recommendations on remedying this situation for Australia. The Review investigated many of the areas that were covered in our *community resource base* survey. Unfortunately the results of our survey work in 1999 were not dissimilar to the results of the results of the 1993 HREOC Review. The implication is that in terms of access to essential resources not great deal has changed for people experiencing psychiatric disability during this decade.

1.4 Second National Mental Health Plan - 'Partnerships in service reform and delivery'

This project is compatible with one of the key reform agendas for the Australian mental health sector, which have been outlined in the Second National Mental Health Plan (1998). The Plan has three major areas that will be the priority for reform and development, at both a national and local level, over the next five years. The area of activity that this project has progressed is the partnerships between the mental health services, consumers, carers and key service sectors in the community. This reform aims:

To encourage the provision of a mix of health and welfare, employment and income support services. This Plan places major emphasis on the need to forge linkages and partnerships in collaboration with stakeholders and agencies providing health and community support.

(DHFS, 1998)

People with mental illness have the same needs as other people for general health care, stable housing, home supports, recreation, employment, education and friendship. However, as has been documented, people with mental illness often have extremely limited opportunities to access these resources. Specialist mental health services can only meet some of the needs of people with mental illness.

The need to formally entrench partnership arrangements is expected to occur through developing collaborative policies, procedures, and protocols. Part of this process will also require clarifying the roles and responsibilities of service providers, removing barriers to funding and eligibility for services, developing referral strategies and agreeing about reporting mechanisms. The Second National Mental Health Plan recommends that the specialist mental health programs form strategic alliances with:

- consumers, families and carers. These groups will require resources to participate in decision making and support activities;
- general practitioners, RFDS, Aboriginal health workers and nurses in remote areas;
- private psychiatrists and the private mental health sector;
- emergency services such as police, ambulance officers, emergency hospital staff;
- the wider health sector (maternal and child health, paediatrics, geriatric services, public health and health promotion);
- other government services (criminal justice, welfare, drug and alcohol);
- non government disability agencies who provide disability support such as advocacy, housing, rehabilitation;
- community support services including housing, home help, family support, recreation, employment and education;
- the broader community including employers, service organisations, churches.

This project attempted to map what resources people with mental illness need to use and whether they were able to access these services. This process was viewed as the essential preliminary step needed to implement this partnership reform of the Second National Mental Health Plan (1998).

Conclusion

There have been a number of influences over the past few decades that have led to these shifts in ideas about the service mix required by people experiencing mental illness. These are:

- the development of consumer self help organisations, from the 1950's/60's onwards which commenced a process of encouraging consumers to speak out about what life was like and what was really needed to get on with life. This movement also offered social networks and friendships, which has potential to address the social isolation experienced by people with mental illness. This has been found to be a key ingredient in the recovery process. This critical component to health is rarely available from the specialist services;
- a growing recognition that the single largest stumbling block to the recovery process is discriminatory policies, practises, attitudes which block access to resources such as employment,

education, accommodation, social networks, recreation and choices about what is most useful for recovery;

- on a broader horizon there has been an influence from the mounting evidence from the public health arena that specialist services are not the most influential factor in maintaining health. In the physical health sector there is a great deal of data showing that there are many other important factors in maintaining health, for example decisions about lifestyle, alleviation of poverty, limiting discriminatory social practices, prevention activities;
- for the mental health sector specifically, a major international study on schizophrenia, which was undertaken by the World Health Organisation (1980), published paradoxical findings. Basically the outcomes amongst people living in villages in developing countries were substantially better than for people in western countries who could access hospitals and specialist services.

This study clearly demonstrated that the sophisticated treatment approaches of western nations are no match for the dramatically marginalised positions to which these nations relegate the person with schizophrenia. (Trainor, et al, 1992:26)

The evidence mounting within these arenas influenced the approach we took in this project. In the next section we detail the steps used in the methodology.

Section Two

Methodology for the *Community Resource Base* Project

The *community resource base* project aimed to map the resources that people with mental illness in Alice Springs needed to get on with their lives. We then followed up this mapping exercise and tried to assess whether this group of people were actually accessing what they required. The mapping and assessment tasks relied on a collaborative effort from personal from Menzies and the Heritage Clubhouse. Menzies employed the Senior Research Officer (part time) and two consumer research assistants (part time). Six members of Heritage Clubhouse, plus the Work Crew supervisor were also involved on a casual basis with the project. Mental health professionals and mental health service users, as well as workers in community agencies were also invited to participate in the process.

2.1 Mapping the *community resource base*

Menzies contracted the “Work Program’ of the Heritage Clubhouse to map the *community resource base* for the Alice Springs area ². \$5000 was made available for this section of the project. Heritage Clubhouse is an Alice Springs based consumer run psychosocial rehabilitation program. It is auspiced by the Mental Health Association of Central Australia, a community based advocacy group for mental health issues in this region. Four consumers were employed on a casual basis on this part of the research project.

Consumers nominated which services and supports they believed to be most useful for people with a mental illness. They used the *community resource base* framework as a starting point, both in terms of prioritising which services to investigate and also to affirm the importance of the task. This prioritising process was undertaken through a series of discussions groups. Consumer research assistants then interviewed workers from the various local agencies that were identified as important. A list of questions was developed which were used to guide these interviews with service providers. A copy of the interview format is in the Appendix. The Menzies Research Officer, along with the Clubhouse Work Crew Supervisor, assisted consumer research assistants in the process of interviewing staff and then transcribing the information. There was an attempt to have the one research assistant follow through with all the identified agencies within a sector. For example one consumer research assistant interviewed all the service providers in the accommodation sector. This was partly to get an overview of what was available in that

2 Mapping a *community resource base* was not undertaken in the non-urban areas of Tennant Creek region or in the Apatula region. This was partly because there are no consumer organisations currently functioning in this part of the Central Australian region. It was also partly because of the perceived appropriateness of a survey instrument for remote area indigenous residents. The language and concepts in the survey were not appropriate for people who do not have English as a first language (which includes the majority of remote area Indigenous residents). The logistics and costs associated with re-designing the survey and engaging the consumer research assistants to travel to remote communities to assist in completing a survey were beyond this project. A consumer research assistant was employed for the Tennant Creek town area.

A short investigation was undertaken in remote Aboriginal communities. This was a collaborative effort between Menzies School of Health Research and the Central Australian Mental Health Program Remote Nurses to investigate what was considered important in getting well. Results from this investigation are reported in O’Kane and Tsey (1999). An example of the guidelines used for this investigation is included in the Appendix.

sector and also to build up confidence. It also assisted consumer research assistants to become quite informed about the sector they were specialising in investigating.

2.2 Accessing the *community resource base*

After this mapping process commenced we also wished to investigate whether people experiencing mental illness were able to access the services and supports identified in the *community resource base*.

Through literature searches and contacts with various organisations we tried to locate a process/ assessment/ survey tool that would suit this assessment. Unfortunately we could not find a ready-made instrument. What we did find were surveys which investigated parts of the concepts contained in the *community resource base* framework. From these surveys we constructed a survey which would suit the purpose of this project.

To construct our survey we primarily used the themes and questions from two different survey tools. We located these surveys through e-mail contact with a range of national and international organisations. We found two to be most suitable, one from America and one from Canada.

1. The Centre for Psychiatric Rehabilitation, Boston University (USA) developed one of the survey examples we used. This is an institution well known for undertaking research regarding recovery from mental illness. This survey investigated issues around employment, education, accommodation, recovery, social life, support networks.
2. The other survey example was obtained from the Canadian Mental Health Association (the British Columbia division). It was basically a survey investigating some similar issues, but also included a range of questions regarding clinical options, community involvement, self help options, crisis planning.

Locating this previous work saved an extraordinary amount of time. Having said that consumer research assistants still had to spend a great deal of time working out what to put in the survey and what to leave out. This process involved negotiation and lengthy discussions. Members from the Heritage Clubhouse were employed to work on ensuring that questions were relevant, appropriate and understandable. The survey ended up containing ten sections with questions in the areas of:

Income	Social networks
Employment	Clinical care
Education/ training	Recovery
Accommodation	Living situation support
Recreation/ social activities	Background information

The survey was piloted on members from the Clubhouse and adjustments were made according to feedback. The survey was designed to be analysed with the Microsoft Access package. A copy of the survey is included in the Appendix..

2.3 Survey target group

We wanted to target residents who had a serious mental illness. The most pragmatic way of approaching this group was through the Central Australian Mental Health Program.³ It has now been well established that there are numerous 'filters' in place, within the general community and the health sector, which provide access to specialist mental health services for people most disabled by a mental illness (Goldberg and Huxley, 1980, 1992). The most significant 'filter' are GPs in the primary health care sector. These authors comment that,

The findings for schizophrenia are particularly striking, and appear to indicate that many cases of schizophrenia are in contact with the specialist services, but are either not in contact with their family doctor or not recognised as schizophrenics when they are in contact. We may conclude that the severity of the disorder is an important determinant of passage through the filter.

(Goldberg and Huxley, 1992: 47)

Therefore targeting residents who used the case management services of the Central Australian Mental Health Program ensured that the survey would target residents with serious mental illness, particularly those residents who experience psychiatric disability.

Case managers in the Central Australian Mental Health Program Urban Community Teams (Alice Springs and Tennant Creek) were requested to assist in this part of the project. The Ward Clerk for the Outpatients Unit of Alice Springs Hospital also participated. The case managers were asked to inform clients about this survey⁴. People who were willing to complete the survey could either do it themselves or seek assistance. Menzies School of Health Research employed two consumer research assistants (one non-Indigenous male and one Indigenous female) to assist people to complete the survey. Case managers were specifically requested not to assist people to complete the survey. This was to ensure that:

- service users felt that they could answer the questions freely;
- survey participants felt confident that their answers were confidential.

3 Approaches were also made to the Central Australian Division of General Practitioners, as well as the Central Australian Aboriginal Congress Social and Emotional Well being Unit to investigate whether there was interest or capacity for clients using these services to participate in the survey. Neither program was in a position to participate. This was reported to be because there were:

- major difficulties in identifying clients who had mental illness within these services;
- perceived restrictions on the time available to participate in this project;
- challenges in viewing this type of project as a priority for agencies that do not perceive their charter as providing services for people experiencing mental illness;
- Agreed definitions of mental illness.
-

4 This was challenging condition for some casemanagers who felt that they were in the best position to assist 'their' clients.

Conclusion

The mapping and survey section of the evaluation commenced in October 1998. The survey was completed by March 1999. It is not possible to establish a precise amount of time that was required by this type of project. The mapping contract with Heritage Clubhouse was not completed. A further goal of this project was to produce a '*Resource Directory of the Service and Supports Available for People with Psychiatric Disability in the Alice Springs Region*'. This directory has also not been completed.

There were significant challenges in using this innovative methodology which are presented in the Discussion section of this report. However, we believe that our methods can be refined and used by service providers and consumer groups in other parts of Australia. These methods particularly favour approaches which aim to inform and empower consumers. We invite service providers and consumer groups to contact the Mental Health Association of Central Australia (phone 08 89523311) to obtain a disc copy of the survey and the data package for analysing the survey

Section Three

Results from the *Community Resource Base Mapping Exercise and Survey*

The *community resource base* survey results presented in Section Three are divided into the headings associated with the two concepts outlined in the *community resource base*. These are the:

1. 'partnerships in support' concept which encompasses the support provided by the four sectors of:
 - specialist mental health services
 - family/friends
 - consumers
 - community services;
2. basic human rights which encompasses access to:
 - employment
 - accommodation
 - income
 - education/ training resources.

3.1 Background information - survey target group

The potential target group for the *community resource base* survey was approximately 140 people. The majority of these residents have case managers from either:

- Alice Springs Community Mental Health team (it is estimated that 90 residents at any one time are case managed);
- Barkly Community Mental Health team (it is estimated that 20 urban residents are case managed at any one time).

There were approximately a further 30 residents using the Outpatients service (at any one time) of Alice Springs Hospital, who were also included in the target group. These residents did not concurrently use a case management service.

There were 64 completed surveys which were returned and accepted. There were a further 9 surveys returned, but not completed. These were not accepted. This represents a response rate of approximately 50% of the residents using the Central Australian Mental Health Program case management services.

3.1.1 Demographic information

The overall profile of service users responding to this survey revealed that the majority lived in Alice Springs and have been residents in central Australia for ten years or more. Well over half were non-Aboriginal males in the age range of 25 - 44 years. This survey profile is almost identical to the actual profile of service users of the Central Australian Mental Health Program, in terms of ethnicity and gender. There was however a difference in age groups (**Table 1**). There were more respondents from the 35 -54

age groups and less in the under 35 year age groups in the survey sample, than in the whole population of residents using case management services.

Table 1: Profile of survey respondents and services users

Demographic Information	Survey Respondents	Mental Health Service Users
Females	38%	39%
Indigenous	30%	29%
Age Groups- under 35 years	39%	53%
- 35 -54 years	50%	41%
- over 55 years	11%	8%

Due to this close matching of profiles, along with the reasonably high level of response, the results are considered to be valid for the urban population using the specialist mental health services. Therefore the responses and patterns revealed in this survey can be considered to reflect the experiences, lifestyles and opportunities for residents in Alice Springs and Tennant Creek who experience significant mental health problems.

The ethnic breakdown is generally representative of the background of the urban-based Central Australian adult population (Figure 1).

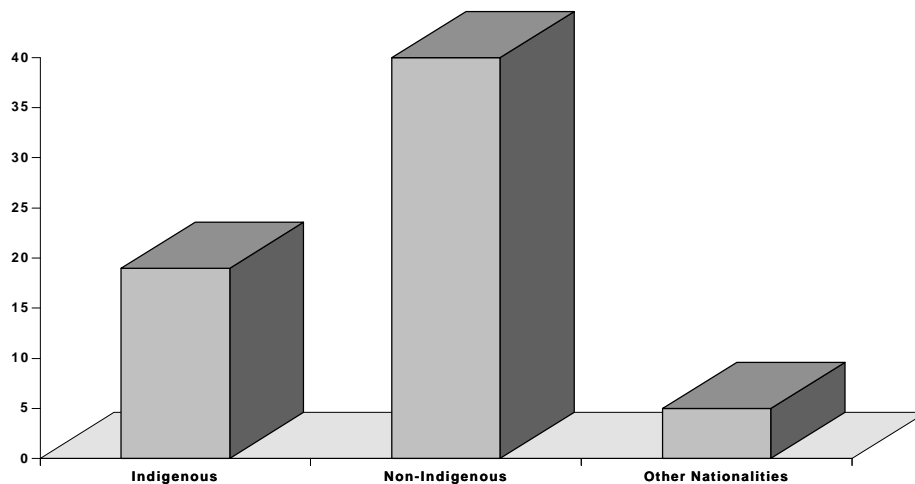


Figure 1: Ethnic background of survey respondents

However, this is an over representation of Indigenous residents. The ABS (1998) census records that just under 20% of the population in the Alice Springs region were Indigenous. The reasons cited for this over representation (by members of the community mental health team) were that:

- remote area Indigenous residents often reside in town when they are unwell and require services;
- Indigenous residents are highly mobile around the region. Census records may not be an accurate reflection of where people live during other times of the year or other years.

Sixty (94%) survey respondents listed English as their preferred language.

Over 80% (52) of respondents lived in the town of Alice Springs and a further 10 (16%) lived in the town of Tennant Creek. This breakdown is generally representative of the users of the Mental Health Program that were requested to participate in the survey (Tennant Creek is slightly under represented).

3.1.2 Length of residence in Central Australia

Fifteen (23%) respondents have been living in Central Australia for less than 2 years. At the other end of the spectrum 26 (40%) had been living here for more than 20 years. This profile is somewhat surprising for the urban locations of a remote region. There is an extraordinarily high transient population, particularly among the non-Aboriginal residents in these regions. The Northern Territory as a whole experiences nearly 40% turnover between census years. There may be two trends indicated in this data reflecting the higher than expected length of residence in central Australia. One trend may be that people in the more transient part of the population do not choose to stay in Central Australia when they become mentally unwell. Another trend may be associated with the number of Indigenous people responding to the survey. Over 75% of Indigenous respondents had been residing in the region for ten years or more. In fact, Indigenous residents tend to be born in the region and to stay in the region.

Slightly more than half of the respondents had been using the mental health services for less than 2 years and only 25% had used the service for more than 5 years.

3.1.3 Gender, age and family status

Men outnumbered women at a ratio of nearly 1:2. Forty (62%) men and 24 (38%) women responded to the survey. This is the same as the gender ratio using the case management programs within the Central Australian Mental Health Program. However, for some other parts of the service, such as acute in-patient care, rehabilitation services and the forensic service, males outnumber females at much higher ratios.

Over 60% of survey respondents were between 25 - 44 years (Figure 2).

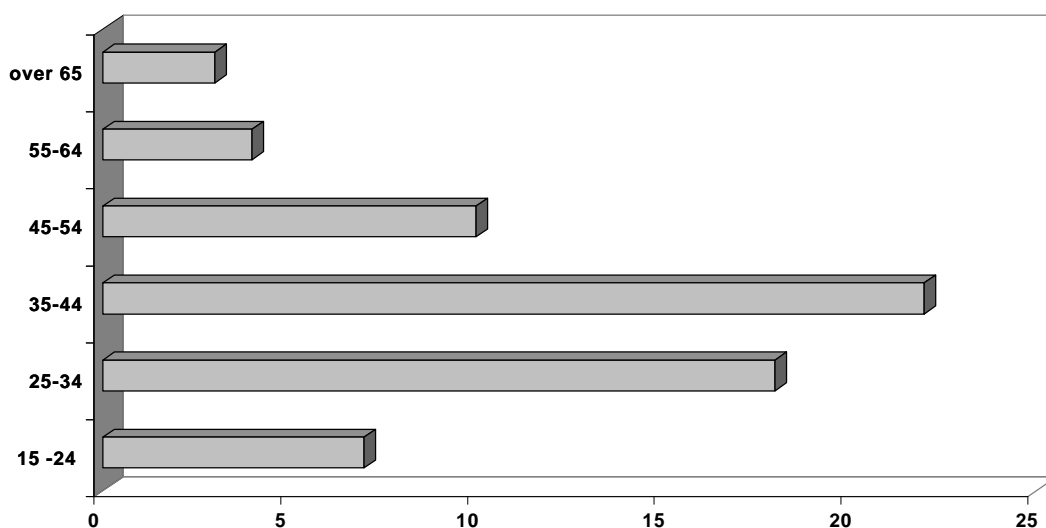


Figure 2: Age groups

Only one third of survey respondents indicated that they had dependants - either children or other family member. Of this group 9 (14%) had one dependant and 13 (21%) had more than one dependant. Forty-one

(65%) indicated that they had no dependants. Sixty percent of respondents reported that they were single (Figure 3).

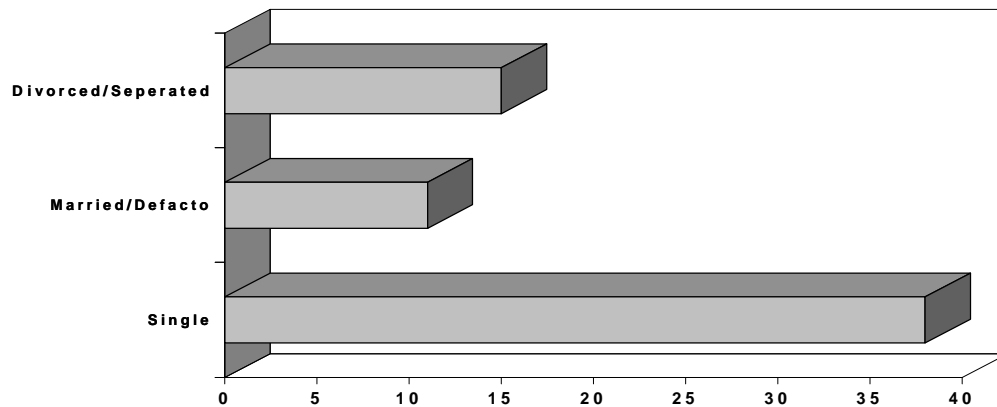


Figure 3: Marriage status

3.1.4 A profile of Australian mental health service consumers

During 1997 a national survey of the users of specialist mental health services in Australia was undertaken. This was part of the Mental Health Classification Service and Costs Project (DHFS, 1998) which investigated the viability of introducing a casemix model for mental disorders. This project-investigated data from 25% of Australia's specialist mental health services and included information from 18,000 consumers⁵. The following is an outline of the profile of the consumers of Australia's specialised mental health services.

Males and females in the adult categories were evenly represented. As mentioned above this is different to the Central Australian profile. In the child and adolescent group males outnumber females by 50%, but the reverse occurs in the over 65 years group. In Central Australia the target groups at either end of the age spectrum are not well represented as clients of the service, so it is difficult to indicate trends. There are currently minimal levels of specialist program resources allocated to either the very young or the elderly (O'Kane and Tsey, 1999). Eighty percent of service users were born in Australia and 2% were Aboriginal/ Torres Strait Islander. This level of Aboriginal people using specialist mental health services reflects the level of Australia's Aboriginal population (2.1%).

Just over 20% were married, 20% divorced/widowed/separated and nearly 60% never married. Seventy percent have no dependant children. This is a very similar profile to the information reported by survey respondents in central Australia. Schizophrenia/ related psychotic disorders and mood disorders account for 67% of in-patient service and 60% of community mental health service. Accessible data for community mental health service is currently not available in the Northern Territory. However, in the Northern Territory, in-patient treatment featured schizophrenia, adjustment reaction and drug and alcohol psychoses as the three most common conditions.

⁵ In the Northern Territory the Darwin Urban Mental Health Service participated in this project.

3.2 Accommodation

Accommodation is one of the most critical resources for people experiencing mental illness. Without affordable, appropriate and accessible accommodation there is a high risk of homelessness (HREOC, 1993). We were interested in finding out what types of accommodation people were using and how satisfied they were with their current situation. The data revealed that the majority of people were satisfied with being a tenant, sharing either a flat or house from the Northern Territory Department of Lands and Housing.

3.2.1 Private/public accommodation

Twenty-seven (42%) survey respondents were in the public rental market and 18 (28%) indicated that they were renting privately. This is substantially different to the national survey of consumers, where 80% were in the private rental market. It is however reflective of the type of accommodation options that are available in this region. Central Australian patterns of accommodation are generally a reversal of national trends. Private rental properties in remote locations are hard to find and more expensive than other regions of Australia. In Alice Springs the rental for one and two bedroom units ranges from \$120 - \$220 per week. The rental for houses ranges between \$220 - \$300 per week. Approximately 75% of the residents who use the mental health program receive a fixed income in the form of a pension/ benefit from Centrelink. Private rental options are therefore often too expensive to be a viable option.

- The most popular type of accommodation was a house, followed by a flat/ unit (Figure 4).
- Nearly three quarters of respondents (72%) were renting their accommodation and only 7 (11%) survey respondents were buying.
- Eleven (17%) were boarding, camping etc.

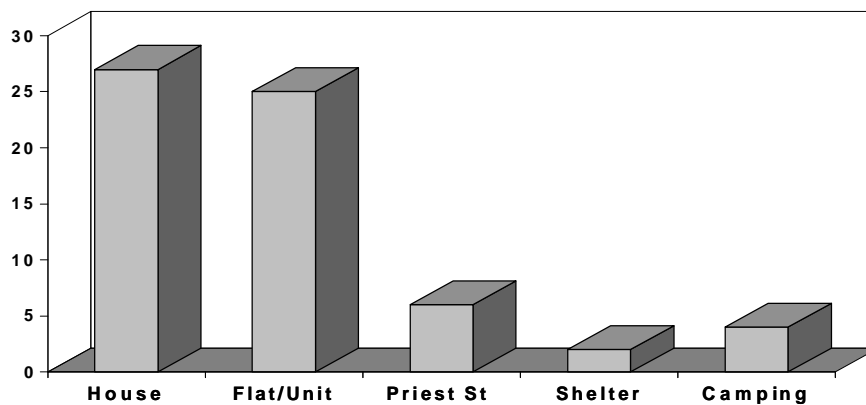


Figure 4: Accommodation type

3.2.2 Who are you living with?

A third of all survey respondents lived by themselves, while two thirds (66%) lived with other people, the most popular being a friend/ roommate (Figure 5). There was a difference between Aboriginal and non-Aboriginal respondents. Eighty percent of Aboriginal survey respondents lived with someone else, primarily a family member/ relative, while 60% of non-Aboriginal respondents lived with someone else, primarily a roommate. There was a higher percentage of Aboriginal service users sharing houses and a higher percentage of non-Aboriginal people living in flats.

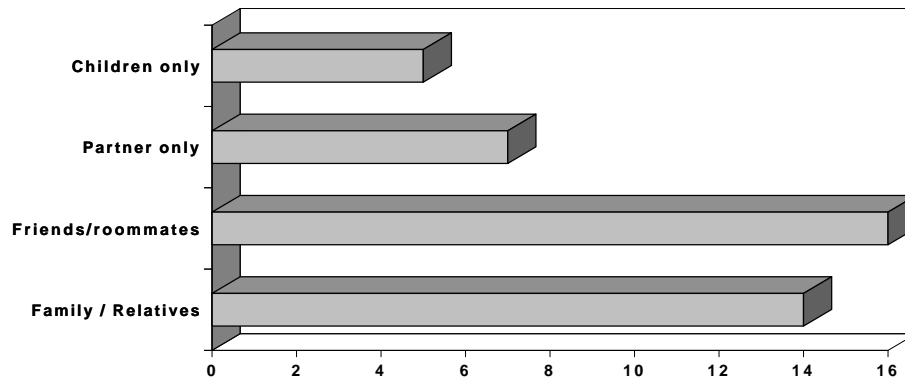


Figure 5: Who are you living with?

3.2.3 Satisfaction with accommodation

Overall, survey respondents reported that they were content with their accommodation. It appears that once people find somewhere to live they are generally happy, with nearly 80% indicating they were satisfied with their current accommodation. Thirty six (56%) respondents indicated that they were given choices about their accommodation. There was no difference in levels of satisfaction between Indigenous and non-Indigenous residents. A high number of respondents (74%) believed they could stay where they were, for as long as they wanted. In answer to a question about any changes they would like to make, the only trend emerging was that more people wanted to move into houses. Nearly 60% of respondents indicated that their ideal accommodation would be a house.

3.2.4 Accommodation difficulties

Before people settle and become satisfied with their accommodation the picture is more challenging. Seventeen (27%) reported that they had experienced personal difficulty in last year or two in finding accommodation. A further 24 (37%) knew someone else with a mental illness who had experienced difficulty finding accommodation. Twenty-one (33%) respondents reported that they had to go on a waiting list to find a place to live. Eight (13%) respondents believed they had been discriminated against in getting accommodation due to mental health problems and 11 (17%) had experienced homelessness in the past two years.

Given the high costs of private rental, combined with the waiting lists for public housing, it may be that people who experience accommodation difficulties and who may not necessarily be overly attached to the region, move back to their home state. Therefore people who are not satisfied leave the region.

3.3 Accommodation issues

The following information was provided through the work undertaken by consumers at Heritage Clubhouse to map the accommodation section of the 'community resource base' for Alice Springs. They investigated supported accommodation options, public housing, private housing and emergency accommodation.

3.3.1 Public housing

The Department of Housing and Local Government provide public housing rental options for one and two bedroom units and three and four bedroom houses. Rents are fixed between 14 - 28% of weekly income.

However, there is often a substantial waiting list for public housing. For example, for one-bedroom units there is a waiting list of between 15 -30 months. The Department does provide priority housing to eligible residents ⁶. It was reported that the Department receives approximately 300 requests per annum for priority housing and a third are successful. In the last financial year only 4 of the successful applications were for people with a psychiatric disability. The main stumbling block appears to be that residents with a mental illness requiring priority housing either:

- do not satisfactorily complete the application process; or
- do not satisfactorily complete the assessment process.

The Department of Housing officer indicated that a handicap in overcoming these problems for both current and potential tenants is that there is minimal follow through with applications. It was reported that residents with mental illness may lose their accommodation due to inadequate levels of support in times of crisis. There are no formal agreements or protocols in place between the Department of Housing and Local Government and Territory Health Services (Mental Health/ Disability Support Programs) to overcome these issues. The Department of Housing and Local Government currently do not have support mechanism or policies in place for people with psychiatric disability.

3.3.2 Supported accommodation

Currently in Alice Springs the only dedicated accommodation service for residents with a psychiatric disability are the Priest Flats and the Gap Road Respite House. The Transitional Living Program at Priest Street can accommodate 8 adult residents (without dependants) in shared accommodation on a medium term basis. The respite house can accommodate 3 adult residents on a very short-term basis ⁷. This style of accommodation is a 'tenants in common' arrangement. Neither of these accommodation options provides 24-hour support. In fact there are no 24 hour supported accommodation services available for people with mental illness in the Northern Territory (DHFS, 1998). This is a fundamentally different pattern to all other states in Australia. The recommended basic level of supported accommodation for a population of 50,000 is fifteen places (for the under 65 year group) (O'Kane and Tsey, 1999). Extra resources taking account of the remoteness of the region and the large Indigenous population would also have to be factored into this resource allocation.

3.3.3 Emergency accommodation

The HREOC (1993) found that access to appropriate accommodation is regarded as the most important determinant in the success or failure of people with chronic mental illness living in the community.

One of the biggest obstacles in the lives of people with a mental illness is the absence of adequate, affordable and secure accommodation. Living with a mental illness – or recovering from it – is difficult even in the best circumstances. Without a decent place to live it is virtually impossible.

(HREOC, 1993: 337)

6 To be eligible a person must have a medical condition / serious social situation verified by a professional and to have tried all other accommodation options. They must also complete an application and assessment process.

7 Anglicare manages these accommodation services employing one full time and one part time officer. These officers also provide 'flat support/living skills support'. People wishing to use these options require a referral from the Central Australian Mental Health Program.

Homeless people are defined as individuals living without shelter or staying in hostels or emergency accommodation. Homeless people have very high rates of both mental health problems and physical health problems, with extremely high levels of co-morbidity, particularly of mental illness and substance misuse. The most common mental illness experienced by homeless people is schizophrenia. This is the most disaffiliated group of people in the community. Surveys of homeless people suggest that between one-quarter and one-half of homeless adults have experienced severe and/or chronic mental disorder (Hermann, 1991; HREOC, 1993). The Supported Accommodation Assistance Program (SAAP) is the primary response in Australia to assist people who are homeless or at risk of being homeless. It is a 'safety net' program targeting some of the most disadvantaged people in Australia. The SAAP Strategic Directions report (1998) estimated that across Australia between 13 -30% of all SAAP clients have a mental disorder.

Alice Springs Youth Accommodation and Support Services (ASYASS), the Red Shield Hostel (Salvation Army) and the Alice Springs Women's Shelter (ASWS) receive funding under SAAP. The SAAP funded services in Alice Springs provide accommodation for over 1000 people per annum. However, agencies such as the Red Shield Hostel have actually put in place a policy whereby they will only provide a service to a maximum of two residents who are experiencing mental health/ behavioural/ substance misuse problems at any one time. The ASWS also experiences difficulty in providing services for women experiencing these problems, due to the communal living arrangement, (which also accommodates a large proportion of children). At the moment there are no formal agreements or protocols in place between the Territory health Services (Mental Health/ Disability Support Programs) and the SAAP funded accommodation services.

Clearly, the Mental Health Services and SAAP services have a joint responsibility to provide relevant, flexible and coordinated responses to meet the needs of homeless people with a mental illness. The development of useful linkages requires on-going liaison and coordination and begins with staff at Mental Health Services and SAAP Services identifying their respective responsibilities to clients and may involve the development of appropriate inter-agency protocols and agreements.

(Perceptions, 1999)

3.4 Income

Income support has been and still is a basic citizenship right for most Australians. This section of the survey requested information regarding the level of income and source of income that people using the specialist mental health program were receiving. We were also interested in how respondents were coping in matching their levels of income with the cost of living in remote area Australia. The survey found that nearly three quarters of mental health service users receive a fixed income from Centrelink, the majority receiving the Disability Support Pension (Figure 6). However, few people reported that they experienced difficulty coping on low incomes. Rent and food expenses were the two largest weekly items of expenditure.

3.4.1 Income Source

Nearly a third of all respondents received income from earnings. Employment ranged from full time positions to a few hours per fortnight through work contracts available at Heritage Clubhouse. There was a difference in the levels of paid employment between Indigenous and non-Indigenous respondents. Just over

a quarter of the Indigenous respondents (26%) reported that they had some form of paid employment. Over a third (35%) of non-Indigenous residents reported having some form of paid employment.

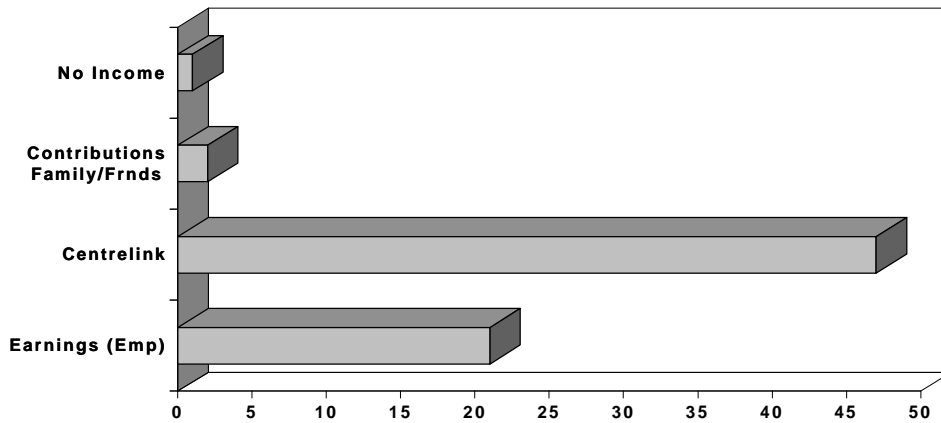


Figure 6: Income source

Of the survey respondents who receive Centrelink income support:

- 26 (55%) - received the Disability Support Pension;
- 8 (18%) - received Job Search;
- 13 (28%) - received an 'other benefit/ pension'.

3.4.2 Satisfaction with income

Even though just over 60% of respondents reported that they are earning \$250 or less per week (Figure 7). Over 80% indicated that they lived either 'OK' or 'well' on this level of income. This is a surprising result, as there are substantial additional costs associated with living in this region.

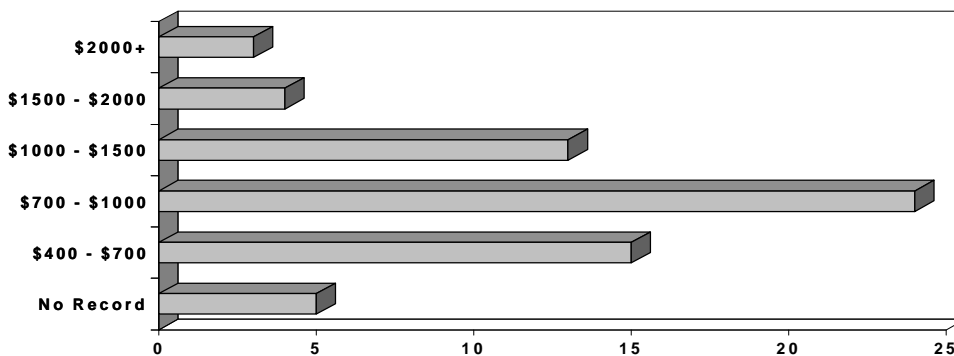


Figure 7: Monthly income

Thirty-five percent of the unemployed non-Indigenous respondents and 20% of the unemployed Indigenous respondents reported that their income level was not adequate. The higher level of satisfaction for Aboriginal respondents may be reflective of the overall numbers of Aboriginal residents in this region who receive income support from Centrelink and who already experience a substantial level of poverty (O'Kane and Tsey, 1999).

3.4.3 Expenditure patterns

Respondents were asked to rank items that took the largest share of weekly expenditure. As can be seen from the following data, expenditure on rent and food received the highest level of first and second ranking. Alcohol and cigarettes followed at a substantial distance in third place (Table 2).

Table 2: Weekly expenditure

Item	First	Second	Third
Rent	24	10	8
Food	18	26	5
Alcohol, Cigarettes, Drugs	3	3	12

Medical expenses, clothing, savings, recreation and expenditure on family members/ dependants barely rated amongst weekly expenditure items. Only 15 (23%) respondents indicated that they had been given financial/ budgeting advice.

Although Alice Springs is the administrative and business hub of Central Australia costs are still substantially higher than the more populated eastern seaboard. For example, a recent Committee was established by the Northern Territory government to specifically investigate the cost of fresh food items (vegetables, fruit, meat, dairy products). This Committee found that residents living in urban centres of the Northern Territory paid approximately 24% more for food compared to other parts of Australia. For people living in the more remote regions this jumped to an increase of 64% (Centralian Advocate, 2 May 1999).

3.5 Employment

The employment section of the survey aimed to gather information about the preferences of service users regarding their employment status. We were also interested in understanding more about the kinds of supports people thought they required in order to choose, get and keep employment. Over the last two years there have been major changes undertaken at the Commonwealth level in terms of employment programs for unemployed people, which particularly impacted on unemployed people with a disability. There are currently no specialised psychiatric disability employment services funded to operate in this region.

Three quarters of mental health service users indicated that they were unemployed. However, the majority of this group wanted to gain some form of employment. Over half wanted support with gaining and keeping employment. The question we posed asking whether people were satisfied with their level of employment support was not well answered. Only a third of respondents were in employment, and only a third accessed employment support. It is not clear which situation comes first, that is, whether people cannot access support and therefore do not access employment opportunities, or whether people do not access employment opportunities and therefore do not access support.

3.5.1 Employment status

Overall 21 (33%) respondents participated in some form of employment (Figure 8). Of this employed group of respondents:

- 20% worked less than 10 hours per week;
- nearly 50% worked in open employment without support from an employment agency;
- Nearly 30% did receive support from an employment agency;
- The majority of this group were satisfied with their current employment situation.

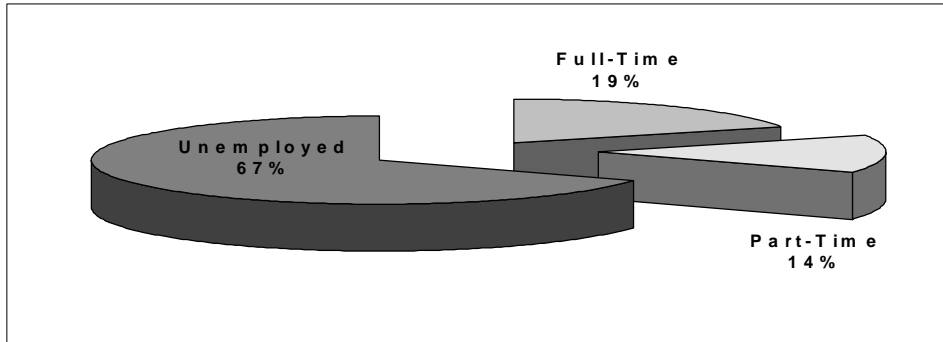


Figure 8: Employment status

3.5.2 Preferences for employment

Thirty-five of the 43 respondents (81%) who were unemployed wanted to get a paid job. There were already 14 (22%) who were currently undertaking some form of voluntary work. Most of the respondents who were not seeking employment opportunities were in the older age groups. There was a wide range of preferences expressed by unemployed respondents in terms of the number of hours they wished to work. The majority of this group wished to work 20 hours or more (Figure 9).

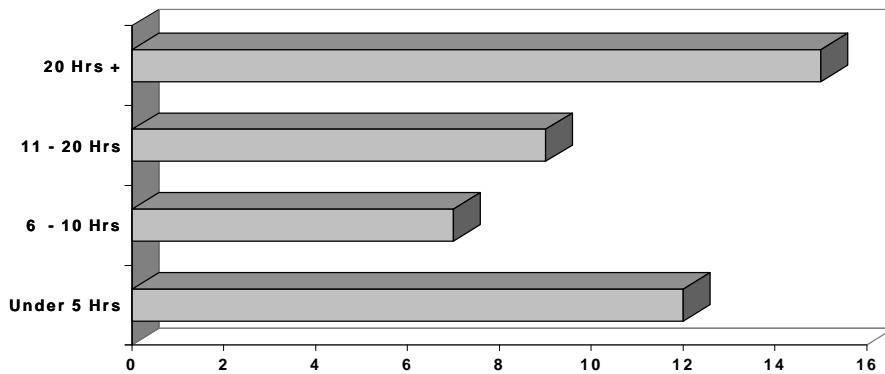


Figure 9: Preferred hours of employment

3.5.3 Discrimination

A third of the survey respondents reported that had experienced discrimination in terms of employment due to mental illness in the past two years (Figure 10).

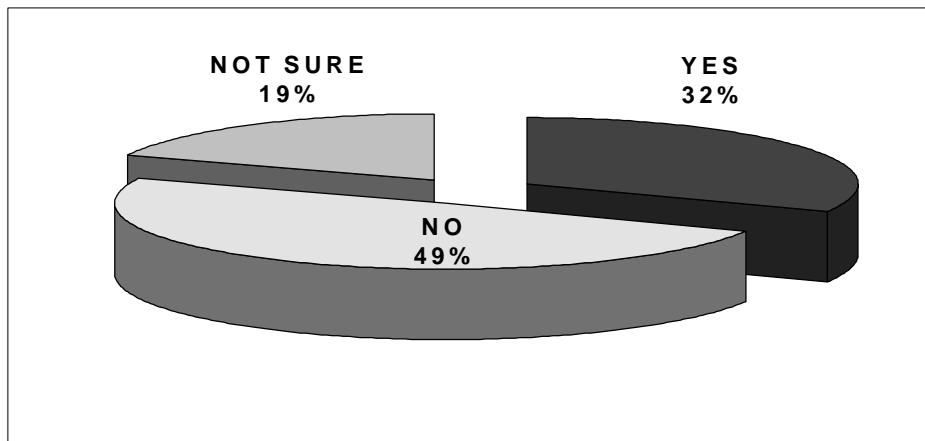


Figure 10: Employment discrimination

3.5.4 *Employment support*

Forty two percent indicated that there was someone available to help them get and keep paid employment (this figure included family/ friends, as well as workers from employment agencies). Thirty percent of respondents reported that they had been given choices about the kind of work that may be available for them. The most popular type of employment support was to have access to support both on and off the job (Figure 11).

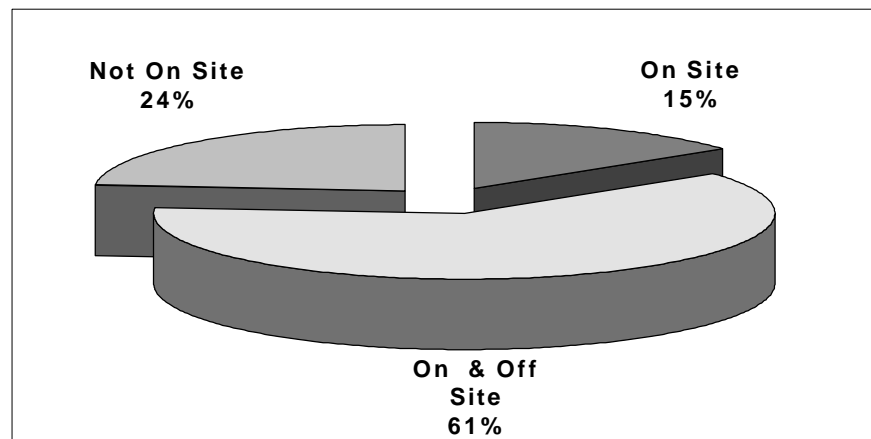


Figure 11: Employment support

The types of vocational supports (Table 3) that survey respondents identified as needing to use most were:

- pre-work training skills;
- vocational counselling;
- finding suitable employment.

Table 3: Types of vocational support

DESCRIPTION OF SERVICE	Currently Use	Needs To Use
Help to select a job or career (<i>eg.</i> vocational testing or job counselling).	4 (6%)	23 (36%)
Help to find a job (<i>eg.</i> Finding out where to look filling out applications, practice interviewing).	6 (9%)	18 (28%)
Training in the skills needed to get ready to work (<i>eg.</i> Training in following a schedule, getting to work on time.)	3 (5%)	31 (48%)
Help to improve skills like a training program that teaches the skill required for a particular job, following a supervisor's directions or working well with others.	2 (3%)	10 (16%)
Opportunities to work a few part-time jobs leading to a full-time job	12 (19%)	11 (17%)
Vocational support groups for clients returning to or entering the workplace.	1 (1.5%)	10 (16%)

3.5.5 *Employment issues*

Psychiatric disability impacts in fundamentally different ways to intellectual disability, physical disability or sensory disabilities in terms of employment. Research has shown that people experiencing psychiatric disability spend a much greater proportion of time in the pre-job phase (the 'choosing to work' phase), than in the actual 'getting a job' phase. They also experience more difficulty in keeping a job, unless appropriate supports are in place.

The Australian Social Security Review Papers (published by the DSS during the early 1990's) estimated the unemployment rate for people with serious mental illness to be 80%, while for other disability groups it was half (or less) this figure. American studies have estimated that the employment rate after being discharged from a psychiatric hospital is 10–30%, with only 10–15% of people sustaining their employment for 1–5 years after discharge (Anthony *et al*, 1984). The data from this Central Australian survey reflects these trends.

The factors most frequently mentioned as barriers to employment in the Burdekin Report (1993) were lack of access to vocational and educational training, the debilitating effects of psychiatric illness and treatments⁸, job design and negative employer and community attitudes. The implications of this high level of unemployment are high levels of poverty. Very poor people can make few choices about their lives, which restricts the recovery process.

⁸ The diagnostic groups generally represented are schizophrenia, major depression and organic brain syndromes. The difficulties this group experiences in employment can include a lack of work tolerance and endurance (people who become mentally ill in adolescence may have never worked), difficulty following instructions and cooperating with co-workers/ supervisors, and difficulties with problem solving on the job, sustained concentration, the ability to accept criticism and the inability to ask for assistance. This is on top of the stigma associated with major mental illness.

In Western societies, including Australia, employment plays a central role in an individual's development. Apart from providing economic independence, employment is a fundamental factor in the way individuals perceive themselves and relate to others. (HREOC, 1993: 404)

Part of the problem is a lack of access to support services for gaining and maintaining employment for people experiencing psychiatric disability. In an overview of employment programs for people with psychiatric disability in Australia, Hardy (1993) found that only 4.9% of the service users funded through the Commonwealth Government's Disability Service Program had a primary psychiatric disability. The majority of these people were working in sheltered workshops.

Over 80% of the unemployed residents in this survey wish to participate in some form of paid work. However, in Central Australia there are no specialist psychiatric vocational rehabilitation or employment services⁹. Therefore people who experience mental illness need to either use the mainstream employment services available for unemployed residents or the specialist employment services established for people with other disabilities. Accessing either system is challenging for people experiencing psychiatric disability.

3.5.6 Employment support services

In 1997 the Commonwealth Government formed a new government department, Centrelink, which amalgamated previous services provided by the Department of Social Security and Commonwealth Employment Service. Centrelink became the key assessment and referral agency for people wanting to receive income support and assistance with returning to work¹⁰. **Centrelink therefore is a resource for approximately three-quarters of the people in Alice Springs who experience psychiatric disability.** All job seekers are required to complete the Work Assessment Test (WAT) which attempts to establish the employability of the individual¹¹. If the individual reports that they have a disability they are then assessed with a further test, the Work Ability Index (WAI). This test aims to measure the impact of the person's disability on their capacity to work. Unemployed people are then referred to either a mainstream agency, called the 'Job Network' or a specialist disability employment agency.

9 The Heritage Clubhouse is trying to establish a transitional employment program, as well as a work contract program. At the moment the Clubhouse does not receive funding for the vocational and employment parts of the program. The Clubhouse model itself is based on a work ordered day which aims to assist people to become job ready. The transitional employment model essentially means that the Clubhouse secures a number of jobs in businesses / organisations and Clubhouse members rotate through these jobs over a period of months. The aim is to introduce a work hardening component in a less threatening environment. The Clubhouse guarantees the job will be undertaken even if the individual is unwell. This model is different to supported employment where on the job support may be required (this is more suitable for people with intellectual disabilities for example).

10 A significant feature of this change was that funding for employment assistance was shifted to case based payments, which are secured on outcomes. Agencies providing vocational assistance only attracted payments for individuals whom achieved certain levels of success in the job market. This is problematic for people who have a mental illness. The nature of mental illness is not stable. It therefore presents high risks for employment agencies in terms of payments for success.

11 Employability is then graded on three levels, which indicates the amount of funding available to assist that particular individual. This is undertaken through the Job Seekers Classification Index (JSCI) - and people are categorised as being either a Flex 1,2,3.

In Alice Springs the 'Job Network' consists of Employment National, Centapact and Asset Recruitment. When consumers from Heritage Clubhouse interviewed officers from these agencies it became clear that a number of barriers existed for people with mental illness. Generally these agencies reported that they could provide a service for people with a mental illness only when they were well. They indicated they would struggle to maintain service provision when people were unwell. There is no capacity within the structure of the current programs to deal with the cyclical nature of mental illness.

For people receiving the Disability Support Pension there are three agencies: Bindi Centresales (a supported employment workshop), Employment Access (supported employment in the open employment market) and the Commonwealth Rehabilitation Service (a brokerage case management service). Very few people with mental illness have accessed Bindi. The parents of intellectually disabled adolescents initially established this service as a sheltered workshop environment. This is not viewed as a suitable service by people with psychiatric disability. There is more interest in accessing the other two specialist disability services once people believe they are 'job ready' (access to these two services is targeted towards people who are 'job ready'). The transition between being 'a mental patient' to being an 'unemployed person', with varying levels of psychiatric disability, to being an unemployed person who is 'job ready', is currently not well supported in Alice Springs.

3.6 Education/ training

This part of the survey requested information regarding the final level of education achieved by respondents and whether they wished to undertake further training. We then asked a series of questions to try and understand more about future training requirements, such as which educational institutions people wish to use, what sort of supports they thought they required and if they had experienced any barriers in accessing further training.

An overview of this section of the survey indicates that the majority of people using mental health services have educational qualifications from secondary level. The majority are keen to improve their educational status/ qualifications. The most popular institution in which to undertake this improvement is Centralian College. However, there are a substantial number of respondents who do not know where they can go to achieve this goal. Accessing finances is the most outstanding barrier to pursuing further education and training.

3.6.1 Educational levels

Over 60% (39) survey respondents reported that they finished their education in secondary school (Figure 12). A small group had undertaken tertiary level training or trade training.

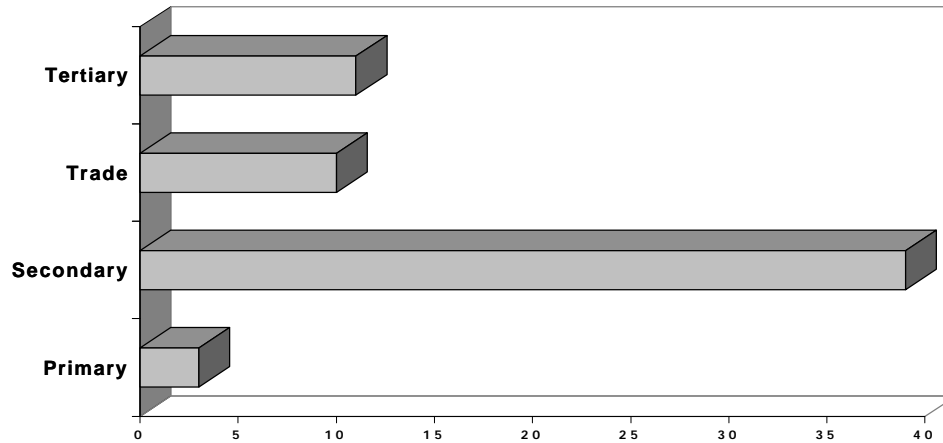


Figure 12: Educational level

3.6.2 Further training

Thirty-eight (59%) respondents would like to have more education/ training in the next few years. There was minimal difference between cultural groups (63% Indigenous and 60% non-Indigenous). The reason cited most often for wishing to participate in further education was associated with training for an occupational qualification (Figure 13).

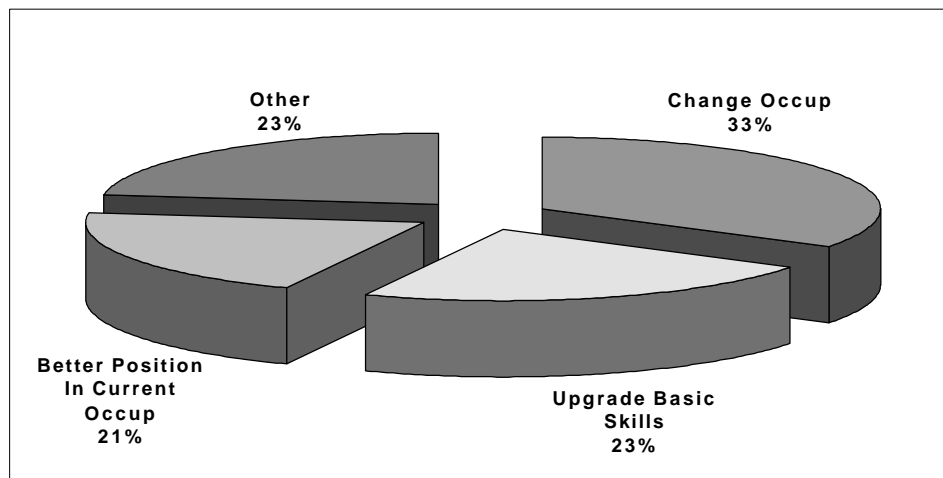


Figure 13: Reasons for seeking further training

3.6.3 Preferred training institutions

Centralian College was the most popular institution identified to access further education/ training (Figure 14). A surprisingly high number of respondents reported that they did know where they could go. There would appear to be a significant breakdown in the marketing and support available for residents with a mental illness in terms of accessing educational opportunities.

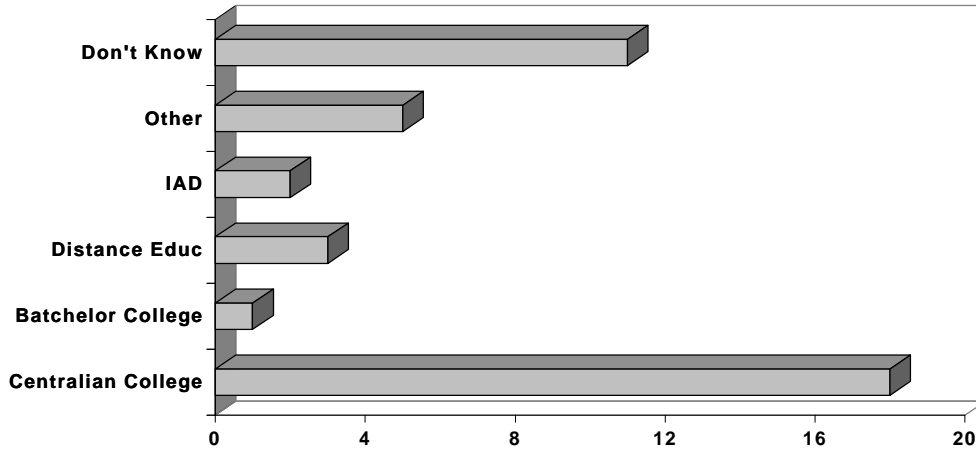


Figure 14: Preferred training institutions

3.6.4 Types of training support

Fourteen (21%) respondents had tried to get or use educational/ training resources in the past year or two. The two reasons cited most frequently for not receiving the service required were:

- there was not enough information available about the services that exist;
- the service was too expensive.

Of the 60% (38) respondents who reported that they wished to access educational/ training resources, the following supports were cited as being needed to reach educational goals. Access to financial assistance was the number one priority (Table 4).

Table 4: Assistance with training

Type Of Assistance	Respondent Numbers	%
Accessing financial assistance	27	71%
Strengthening basic study skills	23	61%
Support on/off campus - to stay in program	22	58%
Applying for and accessing the right educational program	22	58%
Choosing an educational goal	16	42%
Peer support group	11	29%

3.6.5 Educational/ training issues

Well over half of the people using the case management services for mental illness in Alice Springs wish to undertake some form of further training. However actually realising this goal appears to be highly problematic. People generally did not have a good grasp of what resources were available in this sector. Respondents generally do not know what programs/ courses are available, what would be suitable, what each institution has to offer.

Given that the majority of people experiencing mental illness have very low incomes, the financial barriers associated with training were significant. It would appear that training opportunities fall by the wayside as

part of the overall life style restrictions placed on this group of people because of poverty. Almost all the unemployed respondents wish to participate in paid employment. A significant reason cited for participating in training was to improve options for employment. These factors need to be urgently taken up by stakeholders in the mental health, employment and training sectors to develop an appropriate response for this target group.

3.7 Living situation support

This section of the survey sought information regarding a range of supports/ resources that people may use to assist with daily living situations. Overall there was not a high response rate to this set of questions. Generally less than 40% of respondents provided information. For example, responses to specific questions about 'home help' services were almost negligible. This may be because 'home help' is generally associated with physical or sensory disability, not psychiatric disability. One of the reasons for this may be the lack of awareness and acknowledgment in the community, and in community services particularly, regarding the intermittent nature of mental illness and also the consequences of disability associated with mental illness.

3.7.1 Access to living situation support

Only 6 (9%) of respondents had tried to get home help support services in the past year or two, with only 5% indicating that they satisfactorily did so. Generally there appeared to a lack of information regarding what home help services were available. Most respondents had used either the support available from their family/friends (50%) and/ or the mental health services (52%) to deal with daily living challenges. Very few respondents used any of the support services available from Tangentyere Council, Central Australian Aboriginal Congress or Anglicare (St Marys). Twenty five percent of respondents indicated that they made use of the support services available from the Heritage Clubhouse.

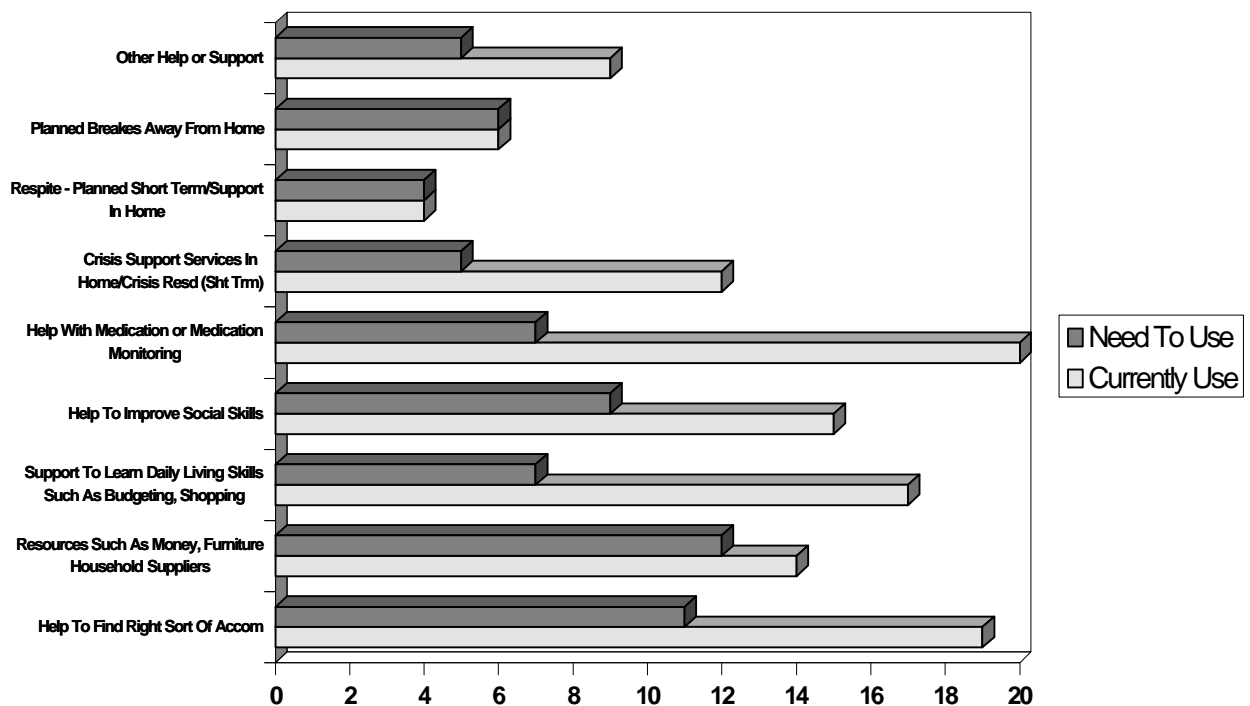


Figure 15: Living situation support

3.7.2 Types of living situation support (Figure 15)

The most popular types of supports that respondents currently used were:

- help with medication/medication monitoring (31%);
- help to find suitable accommodation (30%);
- assistance with daily living tasks, such as budgeting, shopping, cleaning etc (27%).

The top three resources that respondents wanted to use, but could not access, were:

- obtaining resources, such as furniture/ household supplies (19%);
- help to find the right accommodation (17%);
- help to improve social skills (14%).

Further into the survey a similar question was asked about social skills (in the somewhat different context of ‘social networks’) and 24 (38%) wanted help to improve their social skills, such as how to get along with other people in order to improve their social networks.

3.7.3 Transport

Nearly 80% of respondents indicated that they had transport to get to where they needed to go, either most of the time or all of the time (Figure 16). Few people reported that they experienced transport difficulties.

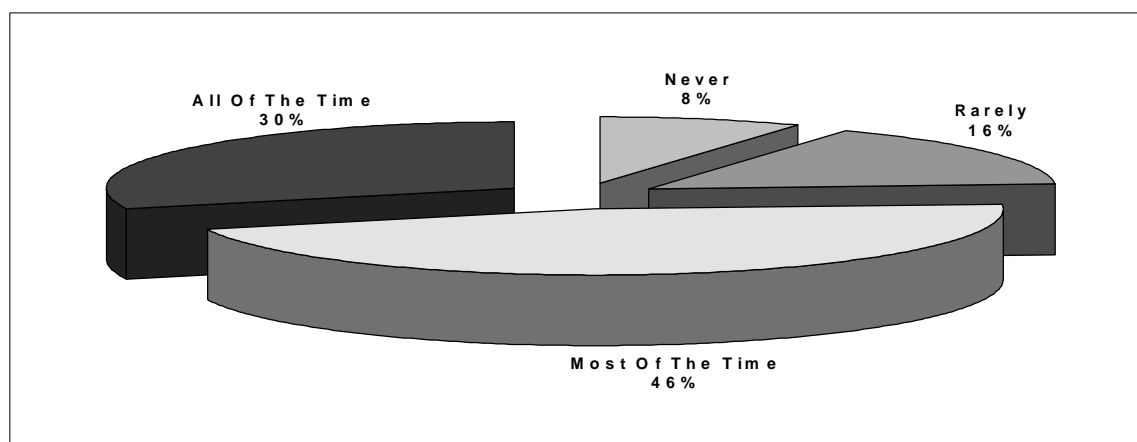


Figure 16: Transport availability

This was a surprising result as there is a restricted range of public transport options available in both Alice Springs and Tennant Creek. In fact 35% of respondents reported that their main form of transport was walking (Figure 17). Outside the urban areas it is very difficult to travel without access to either private vehicles or financial resources.

One explanation for the results expressed in this section of the survey may be that people using the mental health services have restricted their movements and lifestyle to accommodate their lack of options. In a latter part of the survey, when we specifically requested information regarding the barriers associated with pursuing hobbies, recreational activities and vacations, 33% of respondents reported that a lack of transport was a barrier. However, in the transport part of the survey these barriers were not in the forefront of people's minds.

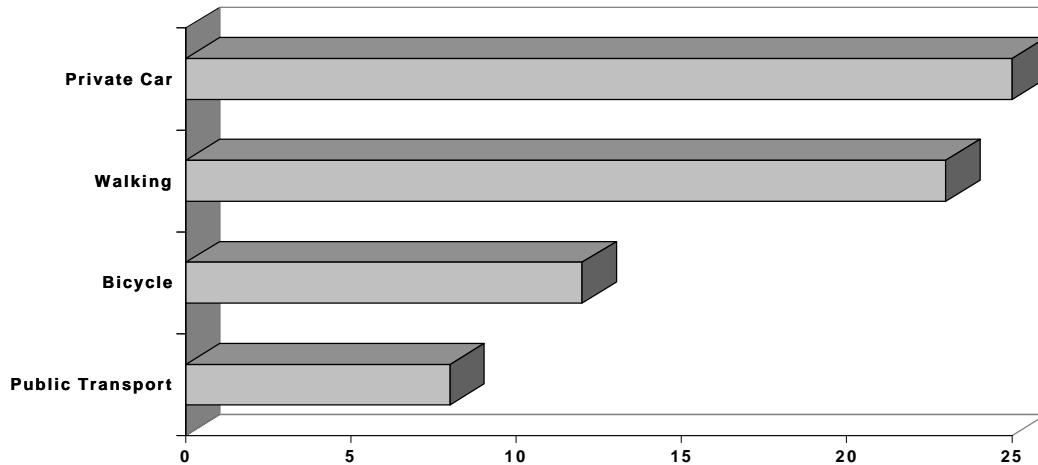


Figure 17: Forms of transport

3.7.4 Issues

People experiencing mental illness in Alice Springs are restricting the level of support they seek for daily living to either their family/friends or the staff from the Central Australian Mental Health Program. A smaller number are venturing out to seek support from the Heritage Clubhouse. It would be worth further investigation to explore whether this restriction in access is because:

- these options are the preferred ones;
- the stigma associated with psychiatric disability keeps people within a restricted circle;
- the disability services and other community services cannot/ do not provide what this target group requires.

3.8 Leisure and recreation

In this section of the survey we were interested in finding out more about how people spent their leisure time. We found that users of the specialist mental health programs are much more likely to pursue hobbies/ recreational activities by themselves than with others. In fact, nearly twice as many respondents are involved in individual recreational activities/ hobbies, compared to group or club recreational activities. In small country towns one of the major pastimes are sporting activities. However, there were very few survey respondents pursuing physical activity interests. The most commonly cited barrier to participating in activities, hobbies, holidays was a lack of finances.

3.8.1 Individual and group activities

Of the 42 (67%) respondents who indicated that they pursued individual activities or hobbies the two most popular pastimes were listening to music and reading. Both recorded 29 responses. Going to the movies was the third most popular individual activity (19 respondents).

Of the 24 (38%) people who indicated that they participated in some form of club/ group activity, the most popular activity is going to a social club (such as the RSL, Federals). It would appear that the users of the mental health services are not big fans of sporting or fitness clubs, apart from those involved in occasional

sports, such as bowling. The expense of group activities, such as aerobics, may be a prohibitive factor for people receiving a low fixed income.

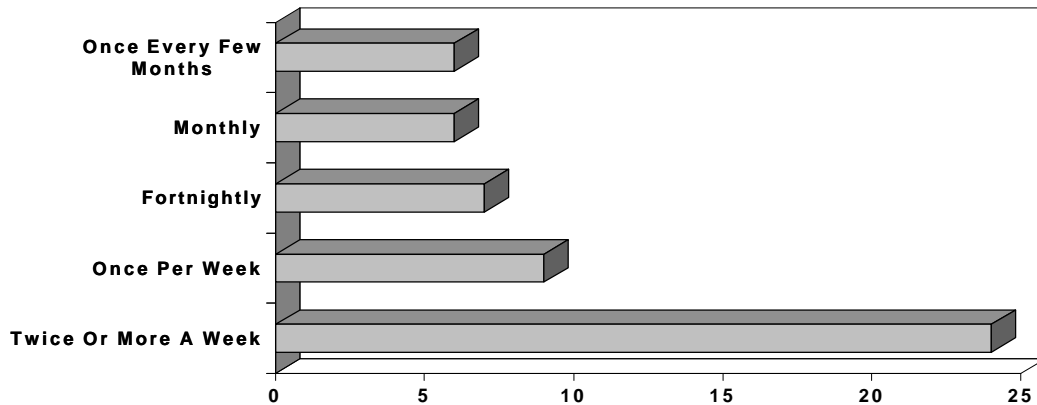


Figure 18: Frequency of participation in hobby/ recreational activity

When both the individual and group hobbies/ activities were combined, 25 respondents reported that they were involved in pursuing their activities twice or more a week (Figure 18). However, an equal number reported that they only pursued their activities on much more limited basis (fortnightly or less).

3.8.2 Vacations

Sixty one per cent of respondents indicated that they were able to have holidays or break from their general routine. The most popular holiday involved interstate travel (Figure 19). This is not surprising for a remote location like Alice Springs. If one wishes to experience city/ suburban lifestyles, there is only one other sizeable population centre in the Northern Territory (Darwin). It is just as challenging to go interstate to Adelaide, as it is to travel to Darwin. The non-Aboriginal population in remote locations has generally migrated from interstate before settling in these regions. Therefore visiting family and friends would involve interstate travel.

The other 60% of respondents either stayed at home or travelled around the region or camped for their vacation.

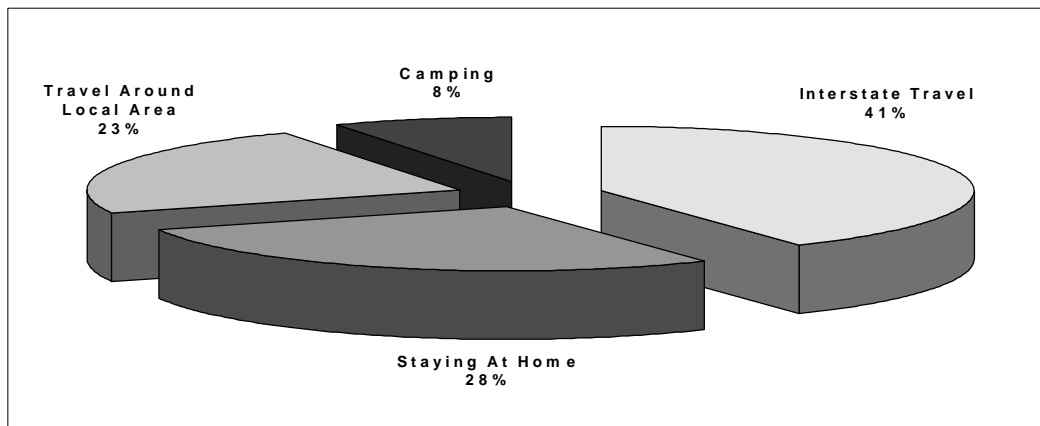


Figure 19: Vacation destinations

3.8.3 Barriers

Over 70% of respondents cited a lack of finance as the major barrier to pursuing hobbies, vacations and recreational activities (Table 5). This is expected given the low level of income received by the majority of respondents. Nearly half of the respondents cited a lack of confidence as a barrier. It would be worthwhile undertaking further investigation to explore this barrier and developing strategies to lessen its impact.

Table 5: Barriers for social activities

Reason	Number	%
Finance	49	77%
Lack of confidence	31	48%
Lack of transport to activity	21	33%
No one to pursue activity with	16	25%

3.8.4 Issues

People with mental illness are not participating fully in recreational and leisure activities available in this community. Having a choice about how to spend time and engaging in meaningful social activities is a core component of the recovery process. It would also be a supportive way of re-entering the broader community. In turn this could be a powerful way of educating the community about mental illness in order to improve the overall understanding and lessen stigma and discrimination. There needs to be more work undertaken to work out ways to decrease the current identified barriers for people experiencing mental illness engaging in recreational activities.

3.9 Social life/ friendships

In this section of the survey we investigated the size and level of satisfaction associated with social networks. Overall, there was a significant group who had a very small social network (five or less people) and an equally significant group who had a large social network (twenty or more people). Research in the area of recovery from mental illness has shown that social support and friendship is a critical factor in assisting people to get on with their lives. The capacity of having other people available who maintain hope and belief is regularly cited as a turning point for people experiencing serious mental illness (Deegan, 1996; Anthony et al, 1993; Tooth et al, 1997). People in Alice Springs are indicating that developing social networks and the skills required for social interaction is an important resource to include in a package/ mix of services and supports. This is an area that will have to be pursued by non-clinical service providers/ organisations. The level of social interaction between mental health professionals and consumers is generally minimal.

3.9.1 Social networks

Forty eight percent (31) of respondents indicated that their social network included five or less people (Figure 20). However, over a third indicated that they had ten or more people who made up their social network. This included family, relatives, friends and acquaintances. Generally people were satisfied with their social network, although 17 (27%) reported that they were dissatisfied. Of those who were dissatisfied, all wanted to increase the size of their social network. Seventy percent of all respondents reported that they did have people in their life who they could go to for help or support, who were not mental health staff.

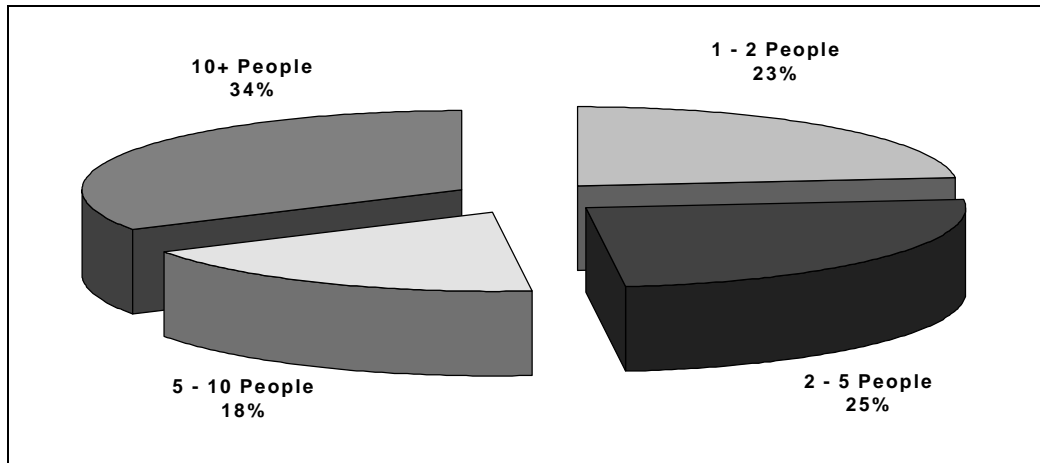


Figure 20: Size of social networks

3.9.2 Supports for social networks

The most popular forms of support for increasing the level of satisfaction with social networks was assistance to develop a social support network and make friends (41%). The next most popular form of support was assistance to improve social skills (38%) (Figure 21). There was also a significant interest in consumer social clubs/drop-in centres, as a way of increasing social networks. This is a service that is being provided by Heritage Clubhouse. However, currently this resource for social networking is popular with men and unpopular with women.

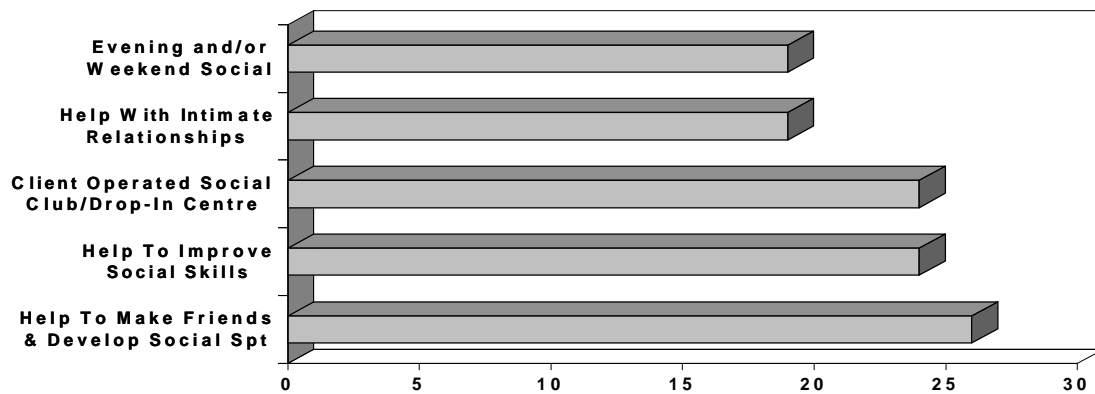


Figure 21: Support for social/ leisure activities

3.9.3 Family relationships

Twenty five (39%) respondents described their relationship with family members as 'OK', 23 (36%) described their family relationships as 'very good'. The majority of respondents reported daily contacts with family members (Figure 22).

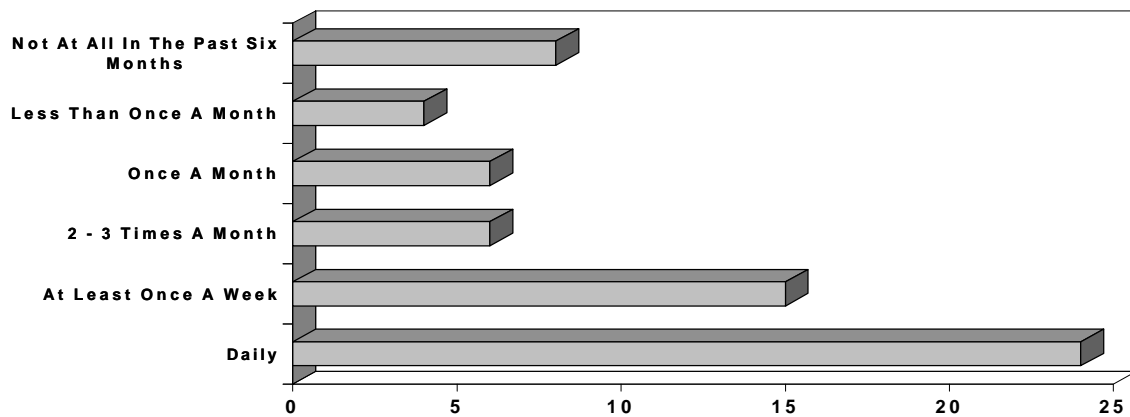


Figure 22: Frequency of contact with family members

A further breakdown of this data revealed that approximately 60% of Indigenous respondents described their family relationships positively (that is 'very good/ OK'), while over 80% of non-Indigenous respondents described their family relationships positively. A slightly higher proportion of women reported positive relationships with family members (83%), than men (75%).

Overall 11 (17%) people indicated that their relationship with their family was very poor. Of this group 8 wanted assistance to improve these relationships.

3.10 Mental health services

The majority of people who use the Central Australian Mental Health Program use medication for their mental health problems and have been hospitalised for acute episodes of illness. Nearly 60% wish to use alternatives to hospital treatment when they require acute care. The most popular form of alternative care was receiving clinical care in their own residence. Three quarters of respondents had someone to ring in a crisis and most relied on assistance from mental health professionals for planning admissions and discharges from hospital, rather than their family or friends. People were most comfortable talking to mental health workers about their medication and the least comfortable talking to psychiatrists.

3.10.1 Illness onset

Forty (63%) respondents had experienced a mental illness before the age of thirty-five years (Figure 23). This profile is similar to studies undertaken in Australia and other countries. It is now well established that the greatest burden for mental illness occurs with the young adult group of the general population (ABS, 1998).

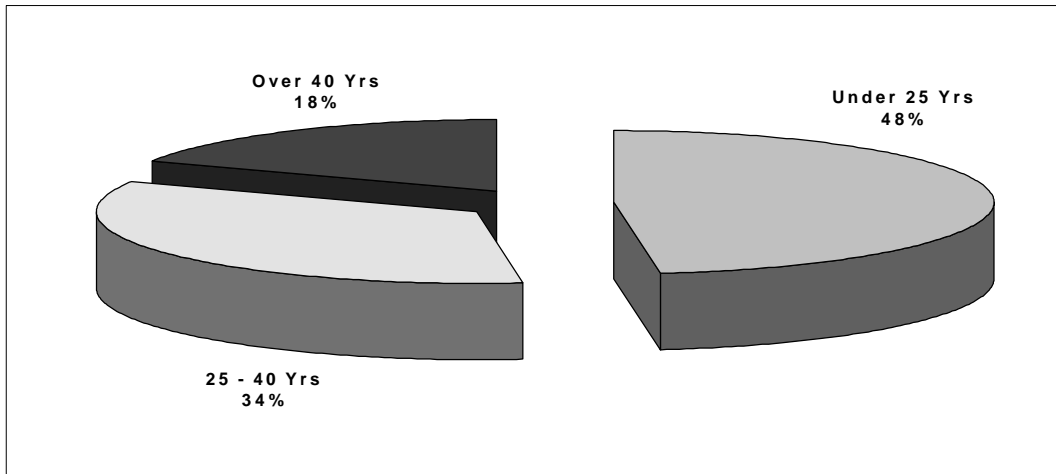


Figure 23: Age of onset of illness

3.10.2 Acute care

Just over three quarters of respondents (77%) had someone to ring in a time of crisis and a similar proportion, 72% indicated that they were able to get treatment and support when they needed it.

Nearly 70% of mental health service users reported that they had been hospitalised for a mental health problem. However, only 18 (28%) indicated that the people who are important in their lives, such as family and friends, had actually been involved in planning their admissions and discharges from hospital. Thirty-five (55%) respondents indicated that they received assistance from mental health professionals to be admitted and discharged from hospital.

3.10.3 Alternative acute care preferences

While 50% (30) respondents reported that their stays in hospital had been useful, 38 (59%) would you like to use alternatives to hospital treatment when they experience acute episodes. The most popular form of alternative acute care was clinical care provided in the person's own home (Figure 24).

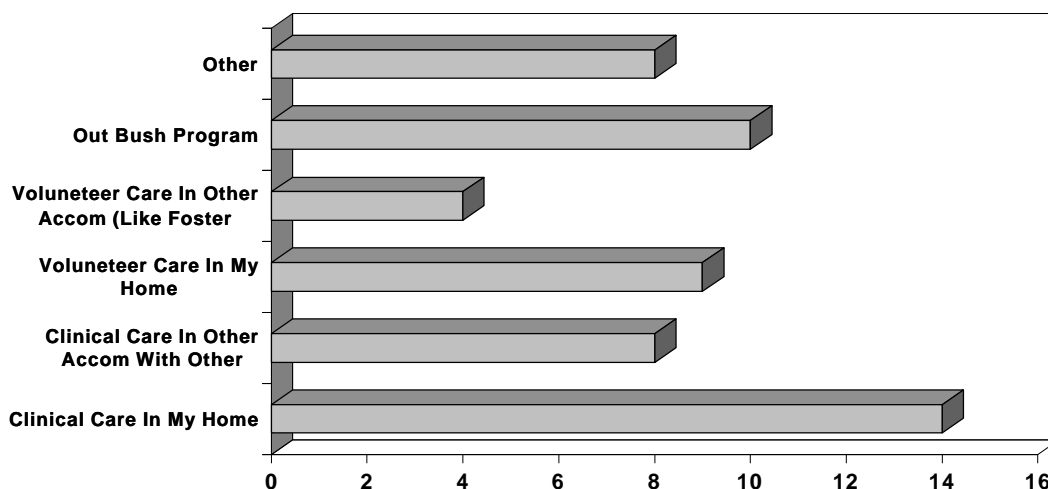


Figure 24: Preferences for alternative acute care

A further breakdown of the data investigated whether there was any trends between the persons desire to use alternatives to hospital and how satisfied they were with their current social network. We were interested in investigating links between whether support in the community influenced acute treatment choices. There was a minimal difference between respondents who wanted to use alternatives and those who did not, and their level of satisfaction with their social networks.

There was however a substantial difference between people from Indigenous and non-Indigenous backgrounds. Seventeen (90%) of Indigenous respondents wanted alternatives to hospital, while 21 (47%) of non Indigenous respondents wanted alternatives. Previous studies (Nagel et al, 1996; Hunter, 1992) have found that hospital treatment for Aboriginal residents experiencing mental illness to be a highly unsatisfactory experience.

3.10.4 Medication

Eight five percent of respondents had been prescribed medication for their mental illness (Figure 25). Forty (63%) respondents had been given information about side effects of medication and the same number had received information about the benefits of medication. These figures are almost equal to the number of service users who actually use medication regularly, as part of their treatment.

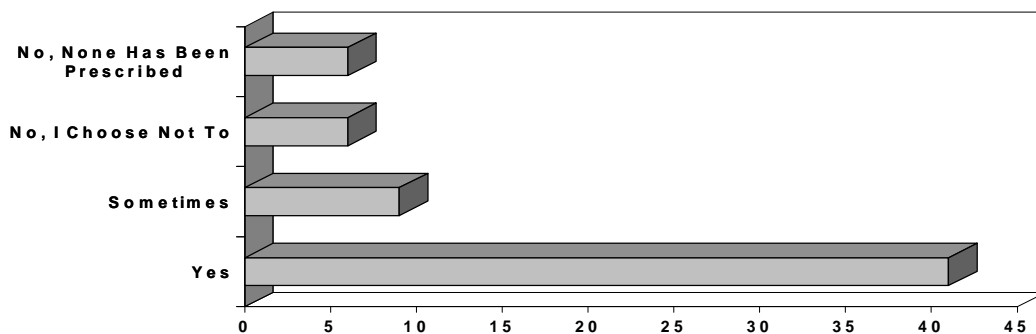


Figure 25: Use of medication

3.10.5 Satisfaction with medication information

Over 60% of respondents were satisfied with the amount and type of information provided about psychiatric medications. However, this left nearly 40% who were not (Figure 26).

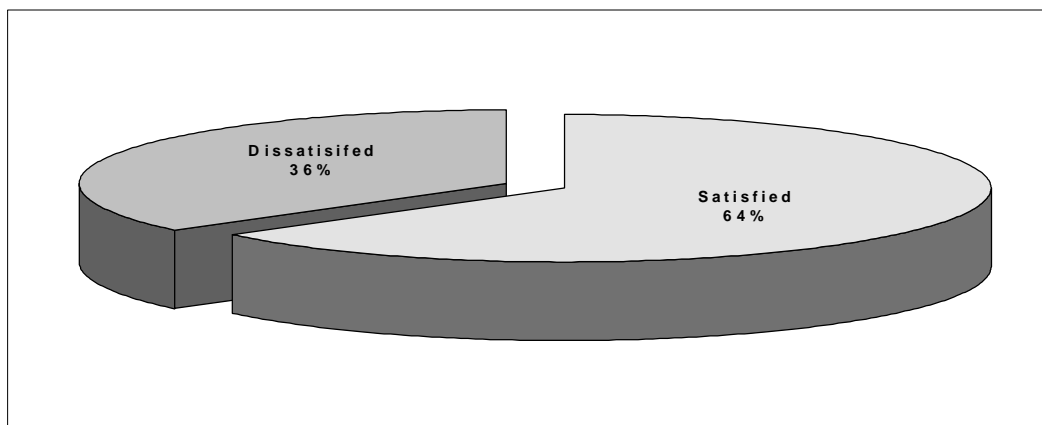


Figure 26: Satisfaction with medication information

A further question was asked regarding which health professionals were providing information about medication and whether respondents felt comfortable seeking information from particular professionals. A very high number of respondents answered this question (Figure 27). Respondents rated mental health workers as the professional group they felt most comfortable with in seeking information about medication. Psychiatrists and pharmacists were the least popular health professionals. A surprisingly high number of people reported that they were uncomfortable asking their GP about medication information. It would be useful to further investigate these issues. Medication is a central issue for people who experience mental illness. Being able to comfortably discuss medication issues with the treating clinician would be highly beneficial.

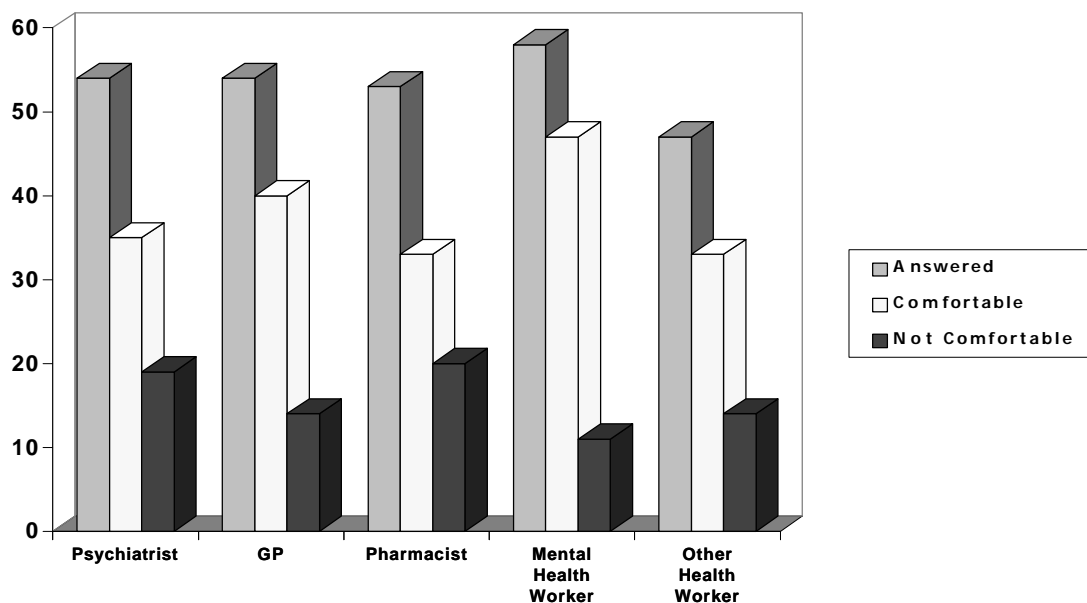


Figure 27: How comfortable are you asking about medication?

3.10.6 Other health problems

The ABS (1998) found that one half of the women, and one third of the men, with a mental illness reported a co-morbidity of another disorder (either physical or mental). The prevalence was age related (21% for people aged 25-34 years up to 77% for those aged over 65 years).

Table 6: Other conditions

Other Condition	Respondent Number	%
Drug and alcohol dependence	18	29%
Serious side effects from medication	15	23%
Effects of sexual or physical abuse	12	19%
Head injury/neurological impairment	10	16%
Physical disability	10	16%
Chronic physical health problem	10	16%
Sensory disability (blindness, hearing loss)	9	14%
Intellectual disability	9	14%
Other conditions	9	14%

Respondents to this survey were asked whether they experienced any other health problems apart from mental illness (Table 6). The following level of other health problems that were recorded amongst service users:

The highest self reported category of 'dual diagnosis' (that is a combination of two medical conditions) for mental health service users was drug and alcohol dependence (29%). This situation is expected, in fact the figure is low. In the ABS (1998) national survey of adult mental health co-morbidity of mental illness and substance misuse was found to be particularly significant. In studies targeting the service users of specialist mental health programs the figures cited rise to 50 - 60% of service users experiencing a drug and alcohol misuse problem (McKay, 1998).

In Central Australia screening for drug and alcohol misuse has been undertaken at Alice Springs hospital since 1992. For the past 18 months the mental health program has had a specific 'dual diagnosis' program to screen service users. Data collection from Ward One has revealed that in 1998 approximately 40% of people admitted to the ward had a substance misuse problem. It should be noted that the psychiatric in-patient units in the Northern Territory record much higher rates than expected of psychotic disorders from substance abuse. The community mental health team has recently commenced similar screening data collection, but do not have results available.

The ABS (1998) study found overall that nearly 40% of respondents who experienced a mental illness also reported the existence of one of the following physical conditions -asthma, anaemia, bronchitis, high blood pressure, heart problems, cancer, diabetes, kidney disease, arthritis, ulcer, hernia, liver problems. Over 30% of Australian adults who had a mental illness also recorded a disability. Disability increased with age and women were more likely to experience disability than men. Combinations of disorders have a cumulative effect on disability. People with a physical condition, plus more than one mental illness, were the worst affected.

It may be that the level of co-morbidity and disability recorded at a national level is an underestimate for Indigenous residents in Central Australia. The extraordinary high levels of ill health may mean that the level of combined physical and mental health problems is higher than in other populations. (O'Kane and Tsey, 1999). However, specific studies are required to investigate these issues.

3.10.7 Culture and language

Only 10 (16%) respondents answered the questions regarding culture and language. Of this group most were satisfied with the way the mental health services took account of their language needs and cultural/ethnic background. Over 90% of survey respondents had indicated that English was their preferred language. This situation would of course change dramatically if more remote area Aboriginal residents had been included in the survey. For example in Apatula region 97% of Aboriginal residents speak an Aboriginal language as first preference (ABS, 1998).

3.10.8 Case management services

Overall mental health workers played a significant role in assisting service users to access a range of resources. They provided information about the illness, made home visits, organised referrals and helped to solve difficulties with family/ friends.

Thirty-nine (61%) respondents indicated that they had been given information about their illness. When they were unwell 41 (64%) respondents reported that they had visits from mental health workers. Fifty three percent of respondents accessed mental health workers to help work through difficulties with their friends/ partner/ family members.

Just over 50% of respondents indicated that mental health workers had provided assistance in contacting other community agencies. A slightly higher proportion (58%) reported that mental health workers provided support for them to actually become involved in activities that interested them.

An even higher number 41 (64%) reported that there were other people also available to assist them in getting their needs met. In the next section of the survey a similar question was asked. Seventy percent reported that they did have people in their life who they could go to for help or support.

3.10.9 Issues

People using the Central Australian Mental Health Program case management services clearly rely on mental health professionals to provide information, crisis planning and on-going support. The major issues arising from this section of the survey are centred around acute care, medication and the level of co-morbidity of mental illness and other problems (notably substance misuse).

Psychiatrists, pharmacists and GPs are the 'clinical experts' available to provide information about medication. However, these three groups of professionals may not be providing a comfortable and informative environment for people with mental illness to discuss their medication concerns.

There is a very strong message, particularly from Aboriginal people using the Central Australian Mental Health Program, that alternative forms of acute care are desirable. There is a range of alternatives available. It would also be useful to undertake this type of investigation for Aboriginal residents in the more remote areas. In remote Western Australia there is currently an evaluation of alternative forms of acute care being conducted (personal correspondence, Associate Professor Janca, University of Western Australia). This work may assist planners in Central Australia in devising appropriate alternative acute care options.

The level of self reported co-morbidity of mental illness and substance misuse is significant. The complexity of treatment issues involved in this area is acknowledged, at both the national and international level. Further investigation into appropriate treatment options in central Australia is warranted.

3.11 Consumer involvement

In this section of the survey we were interested in seeking opinions about whether service users thought they could undertake a range of roles within the mental health service environment (apart from being a service user and using whatever service was being offered).

Mental health service users in Alice Springs and Tennant Creek believe that consumer self-help is possible and useful. The major function of this type of support would be sharing information, rather than advocating for change in service provision. To date very few people had actually been involved in helping to plan and make decisions about the way that mental health services are provided in this region.

There was a mixed bag of responses to questions about rights. While nearly everyone thought they had certain rights, this progressively dropped as questions related to actual practice were posed. An alarmingly small number of people had been involved in establishing plans for any mental health emergencies that they may experience.

3.11.1 *Self help group*

Thirty (47%) respondents indicated that they believed there was support from their peers (that is other people with mental health problems) available in the community. Just over 50% (34) mental health service users wish to participate in a consumer self help group. In answer to what they wanted the group to achieve the most popular function was to share information and experiences and then to give and receive support (Table 7).

Table 7: Reasons for consumer self help group

Reasons For Consumer Self Help Group	Number Of Survey Respondents	% Of All Survey Respondents
Share information and experiences	27	42%
Give and receive support	24	38%
Work towards educating the public	16	25%
Advocating to change mental health policies	13	20%

A similar question was asked in the social network section of the survey, where the emphasis was on increasing social networks and leisure activities. In this latter section 24 (38%) of all respondents wanted a client operated social club/ drop-in centre for this purpose.

Although 55% of service users believed that consumers could influence the way mental health services in Central Australia were provided, only 12 (19%) indicated that they had actually been involved in making decisions about the mental health services in Central Australia.

3.11.2 *Consumer rights*

Eighty- percent (51) respondents indicated that they believed they had the right to approve all the mental health services they received. However, this figure dropped as further questions about rights were posed (Figure 28):

- 40 respondents indicated that they felt comfortable enough to ask a mental health worker about the treatment they were receiving;
- 30 indicated they had enough information about their rights as a client;
- 22 reported that they knew whom to contact if they were concerned about a human rights grievance.

In terms of actual case plans for treatment and recovery, 29 (45%) of service users indicated that they had been involved in making decisions. Alarmingly only 3 (5%) reported that they had gone as far as making plans for any mental health emergencies they may experience.

3.11.3 Issues

Consumers presented a reasonably high level of confidence in their ability to take on roles which influence the way that the mental health program is provided. This may be an untapped resource for mental health service planners. At the moment it was reported that less than 20% of people using case management services had actually contributed to any decision making processes for mental health program planning.

Although nearly half of the respondents had participated in their treatment case plans, only 5% reported that they had made plans for emergencies. This situation requires urgent attention. Early intervention and prevention strategies would be a critical factor in promoting recovery. This section of the survey also indicates that consumers need to be more informed about their rights, both as a mental health client and about their human rights. As mentioned previously, although 50% of people wish to participate in a self-help group, the current organisation (Heritage Clubhouse) is unpopular with women. This may indicate that strategies are required to change the organisation or that an alternative consumer self help option needs to be facilitated.

3.12 Barriers and opportunities for recovery

In this section of the survey we specifically asked questions about recovering from the consequences of mental illness. A high number of respondents reported that they thought that mental health professionals believed they had the capacity to get on with life and recover. The major obstacles cited in efforts to cope with effects of mental illness were difficulties experienced with close relationships and the negative effects of medication. People generally felt welcomed in a range of organisations in the Alice Springs community.

3.12.1 Community support for the recovery process

Nearly three quarters of all respondents (73%) indicated that they thought that people within the mental health system believed in their ability/ capacity to grow, change and recover. Nine (14%) people did not believe this to be the case and 5 people had some other opinion.

Only 18 (26%) of respondents thought that people they came into contact with in the community had a good understanding of mental illness. Approximately 80% of respondents provided information regarding their level of comfort and feelings of being welcomed in various community venues/ agencies. As can be seen from (Table 8) there were more welcome responses, than unwelcome responses.

Table 8: Community agencies

Agency	Welcome	Unwelcome	N/A
Centrelink	66%	14%	8%
Local business	58%	17%	9%
Drug and Alcohol Services	31%	9%	33%
Recreation centres	47%	13%	17%
Churches	53%	8%	19%

3.12.2 Challenges to recovery

Just over 70% of respondents answered the questions relating to the types of challenges or obstacles that they had experienced which made it harder for them to cope and recover from mental illness. The most

frequently mentioned responses were associated with relationship issues between the person and their family/ friends (11 respondents). Equally commented upon were the negative experiences associated with medication. A range of psychological barriers were also mentioned, such as a lack of confidence, high levels of anxiety and confusion. Substance misuse and the effects of sexual abuse also featured. Five people cited barriers associated with the mental health service itself and 3 others indicated that financial difficulties played a key role in terms of challenging their capacity to recover.

3.12.3 Assistance to recovery

Over 50% of survey respondents provided suggestions for improving services and supports provided for residents with a mental illness in this region. There were positive comments about the current specialist mental health service provision. There were also suggestions provided to improve the overall quality and quantity of services available for people with mental illness. For example, respondents wanted:

- preventative counselling and not just crisis counselling to be available;
- more focus on recreational activities;
- the availability of traditional healers;
- improved understanding of drug and alcohol problems in association with mental illness.

Four people specifically wanted to see groups established for various mental health problems, for example a panic attack group. Seven respondents highlighted issues associated with their rights, for example client self respect, cultural understanding, making their own decisions about treatment, and limiting the level of discrimination.

3.12.4 Issues

The level of perceived misunderstanding about mental illness in the community has been well documented. In fact a major focus of the first National Mental Health Plan was an extensive media campaign to start trying to educate the general public about mental illness. This work has not been completed for the towns of Alice Springs and Tennant Creek according to the respondents to this survey.

Consumers have shown a high level of positiveness towards the mental health programs. It would be equally positive for the mental health program managers to reciprocate this good will and consider ways of incorporating the types of improvements identified by consumers.

Summary

This was the first time a research project of this nature had been undertaken in this region. The snapshot of people experiencing serious mental illness revealed that the majority were non-Aboriginal males under the age of 40 years. It would be useful to repeat this type of survey periodically to check whether the profile of people with mental illness is changing and whether the services and supports they require are changing. Overall there was a high level of cooperation and a large amount of information provided by consumers to this survey. This demonstrates that people experiencing mental illness in the urban regions of Central Australia are keen to ensure that the services and supports required to get well are acknowledged and available.

The significant issues identified in this survey for people experiencing mental illness were associated with:

- limited access to appropriate and adequate accommodation;
- high levels of poverty;
- limited access to education/ training resources and employment support services;
- negligible use of disability support resources.

This research work was undertaken from a human rights perspective. It focused on what was required for recovery. It drew on the continuum of ability/ disability for people with mental illness. It did not take a clinical perspective focusing on disease and treatment of symptoms. Obviously this influenced the type of information that was gathered during this project.

The next section of this report is the Discussion. Issues associated with the results of the survey and the methodology used to obtain these results are explored.

Section Four

Discussion

The Discussion section of this report explores three key themes from the project. These are:

- the results of the mapping exercise and survey. These results will provide direction for future service planning and infra-structure for people experiencing mental illness in this region;
- the methodologies we have developed to investigate the services and supports required by people with mental illness;
- the implications of this innovative work. We have started to see shifts in ideas and ways of understanding within the mental health sector in Alice Springs. The data provides directions for the partnership platform of the second National Mental Health Program.

Using the *community resource base* and *knowledge resource base* frameworks, enabled the investigations to be undertaken at a number of different levels and perspective which enriched the outcomes of the project. These different levels included:

- looking at the question of services/ supports from the point of view consumers, who had expert knowledge of what helps to promote wellness for people experiencing mental illness;
- being able to step outside of a conventional and narrow approach to the question. We gave ourselves permission to investigate a broad range of services and supports, including the support provided by informal carers (family members and friends) and consumers themselves;
- the acknowledgment that in our society one of the major issues facing people with mental illness is discrimination and stigma. These frameworks encouraged the assessment of access to essential resources, such as, appropriate accommodation, education/ training, employment services and income support.

4.1 Results

We believe that the results of this survey provide a strong indication of what life is like for people experiencing the consequences of serious mental illness in the urban areas of Central Australia. We also believe that we can make reasonable assumptions regarding the mix of services and supports required by this group of people from the work we have undertaken. We succeeded in achieving approximately a 50% return rate for surveys from our overall target group. The respondents to the survey closely matched the overall target group in terms of key demographic characteristics (such as gender, ethnicity, and age)¹². Overall we found that survey respondents:

- had generally been hospitalised (70%) and were prescribed medication (85%) because of their mental illness;
- had experienced onset of symptoms of their illness in their early adult life (63%);
- were unemployed (only 20% in full time employment) and by community standards, very poor;
- were also experiencing difficulties in accessing resources in the community to assist in recovery.

¹² The survey respondents also had a number of characteristics similar to a national profile of users of specialist mental health programs (Case Classification Project, 1998), such as family status, dependants, age of onset of the illness.

In this section of the Discussion we will outline the key findings of the survey and mapping exercise and put forward options for future directions. The Discussion commences with the Results Section exploring levels of access to the resources needed for survival - accommodation, income support and employment and training resources. It then continues on to highlight consumer's experiences of clinical supports, daily living supports and the perceived level of understanding of mental illness in the Alice Springs community.

4.1.2 Accommodation

The majority of people with serious mental illness in Alice Springs are renting accommodation from the public housing department and sharing this accommodation with other people. This would appear to be the only affordable option. Respondents indicated that they were relatively satisfied with their accommodation options. However a third reported experiencing difficulty in obtaining accommodation. Getting advice and assistance in locating appropriate accommodation was one of the most used (and most sought after) supports recorded in this survey.

There is a significant under resourcing of accommodation and supported accommodation options currently available for this target group. Across the region the provision of supported accommodation for people under 65 years needs to be at least doubled (O'Kane and Tsey, 1999). The cost of spending a night in Ward One is between \$400 -\$500. One of the consequences of providing such a limited range of accommodation and supported accommodation options is that the expensive, least cost effective option of using Ward One may be occurring more often than necessary. This issue is worthy of further investigation.

The emergency accommodation services currently report that they are not resourced to provide services for people experiencing mental illness. The Central Australian Mental Health Program will need to:

- purchase a range of appropriate accommodation and supported accommodation options. Funding for these resources could come from sources such as SAAP, the mental health sector, disability accommodation funds, and public housing sector;
- establish much stronger partnerships with the resources available in the accommodation sector. Formal protocols will need to be developed with agencies such as the Department of Housing and the emergency accommodation services to ensure access and support for people with mental illness to use these resources.

The Department of Housing is the key player in providing accommodation for people on low incomes. The Department therefore is the major source of accommodation for people experiencing mental illness, as the majority of this target group receives income support from Centrelink (which puts them into the low-income bracket). The results of this project have identified that people with psychiatric disability are not receiving a proportionate level of access to either:

- priority housing options available from the Department of Housing; or
- disability supports. At the moment there are no specific resources provided to assist residents with psychiatric disability to successfully live in public housing. This is a different situation to the resources available for other disability groups. For example, the Department of Housing can and does provide resources to support people with physical disabilities to successfully live in public housing (such as ground floor accommodation, rails, wider accesses).

Resources from the public housing sector to support people with psychiatric disability will need to be allocated to provide accommodation support. These resources could be in the form of employing a liaison/support worker to improve, support and maintain access to public housing resources.

4.1.3 Income

Three quarters of the survey respondents receive a fixed income from Centrelink (primarily the Disability Support Pension). Living in a remote area of Australia is more expensive than living in other regions. Most of this income is spent on food and rent, with very little left over for anything else. However, 80% of respondents reported that they were satisfied with their level of income.

Overall, respondents indicated that they were relatively satisfied with many aspects of their daily living situation, such as their accommodation options, transport options, social networks and supports for employment and daily living challenges. However, this reported level of satisfaction was contradicted in other parts of the survey. For example respondents also reported that they could not access further training opportunities, get a job, or buy anything apart from the essentials, or undertake recreational activities that cost money, or travel interstate, go on vacations or acquire essential household items, because of financial constraints.

The majority of people who responded to this survey were poor and appeared to have adjusted their lifestyles and expectations according to their level of poverty. The overall impression gained from this survey is of a group of people who have restricted their options in order to cope with the consequences of mental illness (stigma and discrimination) and unemployment (poverty) in this community.

4.1.4 Employment and training

Only 20% people with serious mental illness are working full time. Over 80% of the unemployed respondents wished to undertake some form of paid employment and some had started undertaking voluntary work. However, less than half were accessing any of the employment support services that are available in the urban areas. People identified that they needed to access pre-vocational training, vocational counselling and assistance to find the right job. The current employment support system (which is available through Centrelink) appears complex. At the end of a series of steps (which are undertaken without specific assistance) people with mental illness were either referred to mainstream employment services or disability employment services.

There are no services tailored to meet the specific vocational needs of people with a psychiatric disability in Central Australia. Psychiatric disability is fundamentally different to other forms of disability. It does not result in a stable level of disability or symptoms. Mainstream employment support services reported that providing a service for this target group would be difficult because of the unpredictable nature of the illness, their lack of understanding of mental illness and the need to become 'job ready' fairly quickly (under the current system of purchasing services for outcomes). The Heritage Clubhouse has been trying to establish a transitional employment program for the last two years, alongside its work contracts program. People with mental illness have identified these sorts of vocational options as useful. They allow for a range of vocational options in the 'pre employment stage', which is critical for people with psychiatric disability.

Participating in further training was also popular, particularly to improve vocational options. Most people had left school at some stage during secondary education. Unfortunately few people knew much about the training institutions that are available, what they had to offer and what would be viable courses to enter. But they did know that educational courses may cost money and participating in further training then became prohibitive. It would appear that the education and training sector has not identified any strategies to assist people with psychiatric disability to access their resources.

This survey has identified a group of people with extraordinarily high rates of unemployment and relatively low rates of education, who are currently not accessing resources to improve their chances of entering paid employment or further training. Given the importance placed on work in Australia, the lack of dedicated employment and training services (and lack of a dedicated strategy), for a group of people with the highest rate of unemployment in the community, requires immediate attention. Access to employment and education is considered essential to ensuring the fulfilment of basic human rights. Key stakeholders in the mental health sector, the employment support sector and the training sector need to come together urgently to commence planning to overcome these identified deficits. Vocational services for people with a disability are a Commonwealth government responsibility. This responsibility is currently not being fulfilled for people with psychiatric disability.

4.1.5 Community understanding of mental illness

Overall only a quarter of survey respondents believed that there was a reasonable understanding of mental illness and the consequences of mental illness in this community. This lack of understanding may reflect situations that result in a lack of access to services for people in this target group. It may also reflect the levels of stigma and discrimination associated with psychiatric disability in the Alice Springs community. Torrey et al (1990) point out that it is impossible to quantify or evaluate in detail the human factor that can make such a tremendous difference to people with mental illness who use services.

This human factor is the single most important element in our daily lives whether we are psychologically impaired or not - at home, in our workplaces, in our interaction with shopkeepers and strangers and yet it is virtually immeasurable. (Torrey et al, 1990)

People in this target generally do not participate in the wide range of club/ group activities that are available. The majority have confined themselves to individual pursuits, such as listening to music and reading. The option of consumer self help programs was promoted as a way to increase social networks and participation in leisure activities. This option could be reflective of consumer's belief that there is little understanding of mental illness and could be considered the best alternative in light of the effects of stigma.

Mirowsky and Ross (1990) argue that strategies for preventing distress and psychological ill health can be centred on improving education levels, having a fulfilling job, having supportive relationships and a decent living. *These are to mental health what exercise, diet and not smoking are to physical health* (Mirowsky and Ross, 1990). Developing strategies to limit discrimination and stigma should also be viewed as a critical public health issue, comparable to developing strategies to improve physical health, such as immunisation campaigns and other illness prevention activities. The National Mental Health Strategy and the Second National Mental Health Plan identified discriminatory and stigmatising attitudes and behaviours as a key target for intervention. The need to enhance the level of mental health/ illness literacy was also identified. Mental health stakeholders, along with those involved in the public health and health promotion sectors, need to plan a strategy to develop on-going community education about mental illness and mental

health. Funding for these types of initiatives would be available under the reform incentive-funding package provided by the Commonwealth to Territory Health Services.

4.1.6 Daily living support

The results of this survey have indicated that people with mental illness are not accessing services that provide daily living support for people who experience a disability. Under the Commonwealth State Disability Agreement (1993) the Commonwealth provides and funds services relating to the employment of people with disabilities. The Northern Territory is responsible for accommodation and community support services including accommodation support, attendant care, home help, early intervention, respite care and community access. However, people with psychiatric disability are generally not able to access either levels of disability support. They are relying primarily on their family members and friends and also on the staff of the specialist mental health programs for on-going day to day support. Currently people with psychiatric disability are facing both:

- discrimination (by the disability support sector); and
- stigma (by limiting their requests for support to a very narrow circle that includes only informal carers and the staff in the mental health program).

There needs to be a concerted educative effort undertaken by the leaders within the disability sector to ensure that psychiatric disability is understood and resourced at a similar level to other disability groups. Disability sector policy makers and disability service managers will need to ensure that disability resources are available to people in this community who have a psychiatric disability and to their carers.

4.1.7 Clinical support

One of the significant issues that emerged regarding clinical support was that very few respondents had established any plans for mental health emergencies. This is despite an indication that over 60% would prefer alternatives to hospital in-patient care when they were acutely ill. Although people with mental illness rely primarily on their family and friends for day to day challenges, it appears that these carers are generally not involved in planning for mental health emergencies either. Given the episodic occurrence of a range of mental illnesses it would be beneficial for consumers and carers to establish pre-crisis planning processes. This would also improve the capacity for early intervention and possibly prevention. The facilitation of pre-crisis planning could be undertaken by either by the person themselves, or in conjunction with their friends/ carers or a respected health professional (mental health worker, GP).

There are significant communication barriers regarding medication and side effects with the medical practitioners providing mental health care. This information will be of critical importance to professional associations such as the Royal Australian and New Zealand College of Psychiatrists and the Central Australian Division of General Practice. These associations have a charter to ensure their members provide high quality care. Medication is often a central factor in the lives of people experiencing mental illness. Survey respondents identified that negative experiences associated with medication was one of the most significant barriers to coping and recovery.

The results of the evaluation being undertaken in Western Australia would be a useful starting point for gathering data about alternative acute care options (as identified by respondents in this survey). Indigenous residents in particular identified their desire for alternatives to hospital in-patient care. It would be useful

for an organisation such as the Mental Health Association of Central Australia to take the lead in developing a strategy to open up the community debates and discussions about investigating suitable options for acute care in this region.

The other significant issue emerging from the clinical care sector of the survey was the high level of co-morbidity of mental illness and substance misuse. This area was reinforced as an important issue in the final section of the survey as well. Respondents identified that a better understanding of dual disorders was needed to improve mental health service provision in the region. Given the extraordinary high levels of substance misuse in Central Australia, the links between the drug and alcohol sector and mental health sector require a great deal of attention and collaborative effort to:

- improve understanding of dual diagnosis issues;
- ensure that the levels and types of service provision available reach national standards;

This collaborative effort for assessment and treatment would also need to include the primary health care providers and other support options, such as self-help groups.

4.1.8 Intersectoral linkages

In 1995 the Mental Health Branch of the Commonwealth government released a report and series of recommendations on the intersectoral linkages required by people experiencing mental illness (DHCA, 1995). This report called for the Ministers for Health, Housing and Community Services to endorse the principle that agencies within their jurisdictions have a role and responsibility for people experiencing psychiatric disability.

The Report called for each state and territory to ensure:

- that their disability services sector developed state of the art programs for people with psychiatric disability;
- that formal arrangements and protocols between services were implemented for people with a dual diagnosis (mental illness and drug and alcohol misuse problems);
- a coordinated package of services and supports was developed for public housing tenants with psychiatric disability¹³;
- that SAAP and HAAC issues formal advice to funded service providers clarifying that people with psychiatric disability are eligible for these programs;
- That competency standards of workers in non-mental health agencies consider the need for basic knowledge about mental health issues.

Many of the recommendations and implications of this report are reflected in the current work undertaken through this project in Central Australia. Although there have been many words written, on the ground changes have been very slow to occur. In fact aspects of these issues were raised again at a Northern Territory Intersectoral Linkages forum held in Darwin in 1998 (NTMHA, 1998). Developing intersectoral linkages is not conceptually difficult. It requires co-operation, good will and commitment to limit discrimination and stigma.

13 This is in line with Australian Housing Research Council Report, *The Needs of People with Psychiatric Disability Living in Public Housing – Issues and Operations*.

4.2 Methodology

The initial question for this research project emerged from local stakeholders who wanted to know whether the mix of services available in the specialist mental health programs were appropriate and adequate.

We expanded the question to incorporate not just specialist services, but also both general and informal supports. Therefore the question we ended up answering was fundamentally different to our initial brief which was focussed on investigating what mix of services are required to stabilise the effects of mental illness and keep people with mental illness out of hospital and living independently.

We added another factor which shifted our focus even further. We claimed that the reason for providing services and supports should be to facilitate wellness and recovery.

The literature that is developing about the recovery process emphasises a number of important issues:

- firstly, the capacity to have belief, hope and choice are seen as key ingredients. (It is difficult to categorise this component solely within a specialist mental health/ clinical framework);
- the second major ingredient is to negate attitudes and behaviour, which stigmatise and discriminate. (Again this requirement does not fit neatly into a specialist mental health/ clinical framework, but more into a human rights framework);
- the third major ingredient is to open up opportunities to access and support from many resources within the community. There is a strong belief that recovery can and does occur with a whole range of supports apart from (in addition to) the specialist mental health programs.

Just as the focus of our question changed, so did the methodology. The methods we used centred on establishing collaborative partnerships between researchers and consumers. We decided that the group who would have expertise about services and supports, was the group that actually needed to use these services and supports. The strategy of employing consumers as research assistants in this research task was a challenging decision and a challenging process. It was challenging for the consumer research assistants, the Menzies research officer, the work crew supervisor from Heritage Clubhouse, as well as the mental health professionals in the Central Australian Mental Health Program and other service providers in community organisations. In hindsight this was a major project that required specific training, one to one supervision, debriefing and intensive discussion and reflection. The processes for the methodology were developmental and were put in place as we resolved emerging issues. The process ended up being a participatory action research project. We did not allocate enough time or resources to this section of the research, given the complexity of the processes we used.

Assumptions regarding both the consumers and service providers were made which were inappropriate. For example, we assumed that the:

- consumer research assistants would share similar values about issues such as social justice, rights, etc, however this was not the case;
- consumer research assistants would be able to communicate via the phone and in person (with the support of either the Menzies research officer or the Work Crew Supervisor). This was also not always a correct assumption;

- service providers in the community would have some reservations about being questioned by consumers about the services they were providing for people with mental illness. However, we did not expect such a clear response from these service providers that the specialist mental health services should be providing whatever is needed by people with mental illness to get on with their lives;
- mental health professionals who participated in the project would be busy and find it difficult to allocate the extra time needed for the project. However, we did not assume that they would see this sort of investigation as not being particularly relevant to the 'real' work of the mental health sector. This 'real' work was encased within the clinical realm and concentrated on crisis response and ensuring that the symptoms of mental illness were treated. Recovery and 'getting a life' were not the priority issues of mental health professionals.

To resolve the issues experienced by consumer research assistants we would recommend preparing a training package that incorporated a brief overview of the following types of subjects:

- stress management, coping strategies and maintaining wellness, time management;
- using telephones, computer skills;
- action research/ participatory research methods;
- data management and input;
- committee work and making decisions;
- interviewing and interpreting information and recording information;
- values and being judgemental.

This list of skill training areas was provided as feedback through reflective discussions with consumers who participated as research assistants in this part of the project. Consumers commented that:

The tasks were too big a step.

It was very frustrating as they often got the run around from service providers.

It was very difficult as they lost confidence in face interviews.

They needed stress management for their 'nerves'.

For the mental health professionals who participate in these sorts of projects we found that there needs to be consistent on going discussions and workshops for clarification and feedback. As mentioned this group of service providers often questioned the value of this project. They questioned their role in encouraging *'their clients'* to participate. A significant amount of service provider's time is devoted to crisis intervention and clinical work. To request a busy, crisis orientated mental health professional to become involved in the issues raised in the *community resource base* mapping and survey work required quite a paradigm shift.

Various service providers in Alice Springs were surprised when they were interviewed by consumers who were investigating what their services offered residents who experienced psychiatric disability. It would be fair to say that consumers are generally the ones being interviewed and the group being researched. They are not usually the interviewers or the researchers.

Overall we would recommend that future projects using this methodology should take a significant amount of time to adequately prepare the 'environment' for this type of innovative approach. Another major shortfall was the inability of the project team to undertake a similar process of mapping and assessing access of the *community resource base* in the more remote regions. This would be another substantial stand-alone project.

4.4 Implications

We believe there are a number of implications arising from this research project. Firstly, the consumer research assistants who worked on the mapping and survey have been strengthened in speaking out about what is really required to get on with their lives. This was evidenced during a consultation in 1999 regarding the next five year strategic plan being developed by the Territory Health Services Mental Health Branch. Consumers from Heritage Clubhouse provided a powerful response about future directions for mental health service provisions in the Northern Territory based on the work that they had undertaken within this project. Documenting the outcomes of this project in the form of this report has the potential to assist in reinforcing any shifts that have occurred for mental health professionals and workers in community agencies during the project.

Another major outcome of the mapping exercise and the survey has been to commence the process of providing direction for the implementation of the 'partnerships' platform in the Second National Mental Health Plan (1998) in this region. There are clear directions that need to be developed for the accommodation, employment, training and disability support sectors. There are also layers and layers of information associated with many of the services and supports required for wellness and recovery. For example, there are directions for the professional associations for psychiatrists, doctors and pharmacists regarding their capacity to assist with medication issues. There are directions for recreational clubs regarding their capacity to be inclusive of people experiencing mental illness. There are directions for the drug and alcohol sector to improve its capacity of providing interventions for people with mental illness.

Another implication of this project is that it has provided a methodology that can now be adapted and adopted by mental health stakeholders in other parts of Australia. It provides a practical and relatively user-friendly approach for both services users and services providers. The survey and Microsoft Access database are available from the Mental Health Association of Central Australia in Alice Springs (Ph, 08 8952 3311). The area that requires more work is the preparation required to adequately deal with the challenges outlined above - that is, more time and effort has to be put into preparing the environment when this type process is undertaken.

We have recommended in the larger report '*Shifting the balance for people with mental illness in Central Australia*' (O'Kane and Tsey, 1999) that the Mental Health Association of Central Australia be funded from National Mental Health Strategy reform incentive allocation to progress this methodology. It would also be useful for the Association to complete the project by finishing a user-friendly guide/ directory of services and supports available for people with psychiatric disability. This type of directory would provide a powerful force in shifting ideas and paradigms about the sorts of resources required by people with mental illness to recover.

Summary

The outcomes of mapping the *community resource base* have been to:

- provide employment for consumers and to provide data for the Menzies research project. It has also meant that there is direct consumer input and direction into this project;
- provide the potential to develop a 'user friendly' resource for consumers, carers and service providers of a directory of services/ resources available for people with mental illness;

- provide the key stakeholders in the mental health sector with solid starting points for prioritising which sectors of the support and service network require urgent attention in order to enhance access and opportunities;
- alert key stakeholders in other critical sectors such as disability support, accommodation, education, employment, medical support that they have a significant role to play in facilitating recovery for people experiencing mental illness;
- commence a paradigm shift in terms of what services/ resources are required by people in this community who experience mental illness.

Although there were shortcomings and parts of the project have not been completed this contribution is a significant step towards working out how to operationalise the policy directions from the Second National Mental Health Plan. The methodology used in this section of the research project is particularly suitable for regional Australia - for locations where both the population and *community resource base* can be identified. It is also suitable for planners who wish to attempt to shift the focus of understanding the service and support needs of people with mental illness from a medical model, towards a model that takes on board a human rights framework.

Conclusion

This innovative survey and the mapping exercise presented challenges and surprises in terms of methodology, philosophy and relevance. Consumers, researchers, direct service providers in mental health, as well as direct service providers in the full range of agencies that make up a *community resource base*, are generally not accustomed to working together. All have different agendas, priorities, experience and views. However, the end result was worth while in attempting to overcome these challenges.

A major shift started to occur during this project because consumers collected their own information, both for the mapping exercise and for the survey. They decided what questions they wanted to include and why the answers to those questions were important. They decided which agencies to interview. Consumers took on the role of investigators, rather than the more usual role of being the group under investigation. This was challenging for workers in various agencies. There were also a range of challenges for consumers in terms of training and the level of support required to undertake these tasks.

One of the most significant outcomes has been a shifting of attitude about the rights of people experiencing mental illness to access a full range of resources. This is a paradigm shift that will have on-going implications for the planning of services and supports for people with mental illness. It shifts the debate about services and resources more towards a human rights framework, and less towards the medical model.

This project also provides practical suggestions for future planning of services and supports for this target group. It provides the detail for interpreting the broad concepts outlined in the Second National Mental Health Plan. Mental health stakeholders now have knowledge about the employment and training issues for people experiencing mental illness. There is data recorded about the need to expand daily living support options. Consumers want better information about medication. There is an identified need to improve public housing options. There is an increased impetus to keep mental health on the health promotion and public health agendas of this community. People with mental illness have stood up and clearly explained what life is like for them at the moment in Alice Springs and Tennant Creek. These concerns and issues are no longer esoteric concepts. They are real statements that require acknowledgment and action.

In conclusion, the methodology for the project posed risks which have paid dividends in terms of the information collection. The real test of work such as this will be seen in the implementation undertaken by those in the mental health sector and the other key sectors identified as integral to the support and service network for people experiencing mental illness to recover.

References

- Australian Bureau of Statistics, 1998, *Indigenous Profile – ATSI Regions – Alice Springs, Tennant Creek*, Apatula, Publication No. 2020.0
- Australian Bureau of Statistics, 1998, *Mental health and well being profile of adults*, Catalogue No. 4326.0
- Anthony, W.A., Howell, J. & Danley, K., 1984, 'The vocational rehabilitation of the psychiatrically disabled', in Miriabi, M., (Ed), *The Chronically Mentally Ill, Research and Services*, Medical and Scientific Books, New York
- Anthony, W., 1993, 'Recovery from mental illness: the guiding visions of the mental health service system in the 1990s', *Psychosocial Rehabilitation Journal*, Volume 16, No. 4, 11–23
- Chamberlain, J., 1998, 'The role of consumers in the transformation of mental health services: Mental health in Australia', *Australian National Association of Mental Health*, Vol. 8, Nos 1 and 2, 4–6
- Deagon, P., 1988, 'Recovery: the lived experience of rehabilitation', *Psychosocial Rehabilitation Journal*, Vol. 11 No. 4, 11–19
- Deegan, P., 1996, 'Recovery as a journey of the heart', *Psychiatric Rehabilitation Journal*, Winter, Vol. 19, No. 3, 91–7
- Department of Health and Community Services, 1995, *Report on the Mental Health Forum on Intersectoral linkages*, Mental Health Branch, AGPS
- Department of Health and Family Services, 1998, *Mental Health Classification Service and Costs Project*, AGPS
- Department of Health and Family Services, 1998, *National Mental Health Report – 1996, Annual Report Changes in Australia's Mental Health Services under the National Mental Health Strategy*, AGPS
- Department of Health and Family Services, 1998, *National Mental Health Report – 1997, Annual Report Changes in Australia's Mental Health Services under the National Mental Health Strategy*, AGPS
- Goldberg, D. & Huxley, P., 1980, *Mental illness in the community*, London, Tavistock
- Goldberg, D. & Huxley, P., 1992, *Common mental disorders: A bio-social model*, London, Routledge
- Hardy, J., 1993, *Employment and psychiatric disability*, DHHCSLG, AGPS, Canberra
- Hermann, H., 1991, Homelessness and severe mental disorders, Monograph Series 2, *National Health and Medical Research Council*, AGPS
- Human Rights and Equal Opportunity Commission, 1993, *Human Rights and Mental illness*, Vols 1 and 2, AGPS
- Hunter, E., 1992, 'Aboriginal adolescents in remote Australia', in Kosky, R. & Eshkavari, H., (Eds), *Breaking away – new challenges in adolescent mental health*, AGPS, Canberra
- McKey, J., 1998, What's in a name?, *Connexions*, August/September
- Mirowsky, J. & Ross, C., 1990, *Social Causes of Psychological Distress*, Aldine de Gruyter
- Nagel, T., Mills, R. & Adams, M., 1996, *Summary of findings – evaluation of urban mental health service delivery to Aboriginal people*, Territory Health Services, Darwin

- New Zealand Mental Health Commission (1998), *Blueprint for mental health services in New Zealand, How things should be*, Mental Health Commission, Wellington
- Northern Territory Association for Mental Health, 1998, *Report on the Intersectoral Linkages Forum*, Darwin 21-22 May
- O’Kane, A., & Tsey, K., 1999, *Shifting the balance - services for people with mental illness in central Australia. A framework for resource allocation and planning*, Menzies School of Health Research, Central Australia Unit
- Tooth, B., Kalyanansundaram, V., Glover, H., 1997, *Recovery from Schizophrenia: a consumer perspective*, Centre for Mental Health Nursing Research, Queensland University of Technology
- Torrey, E.F., Erdman, K., Wolfe, S., Flynn, L., 1990, *Care of the seriously mentally ill – a rating of state programs*, 3rd Edition, A joint publication of public Health research Group and the National Alliance for the Mentally Ill.
- Trainor, J., Church, K., Pape, B., Pomeroy, E., Reville, D., Tefft, B., Lakaski, C. & Renaud, L., 1992, ‘Building a framework for support: developing a sector based policy model for people with serious mental illness’, *Canada’s Mental Health*, March, 25–9
- Trainor, J., Pape, B. & Pomeroy, E., 1993, *A New Framework for Support*, *Canadian Mental Health Association*, Toronto
- Trainor, J., Shepherd, M., Boydell, Leff, A. & Crawford, E., 1996, *Consumer/survivor Development Initiative – Evaluation report*, Ontario Ministry of Health
- Trainor, J., Pape, B. & Pomeroy, E., 1997a, ‘The Knowledge Resource Base: Expanding our understanding of serious mental illness’, *Canadian Journal of Community Mental Health*, Vol. 16, No. 1, Spring, 109–16
- Tsey, K., Scrimgeour, D. & McNaught, C., 1998, *An Evaluability Assessment of Central Australian Mental Health Services*, Menzies School of Health Research
- Warner, R., 1994, *Recovery from schizophrenia: Psychiatry and political economy*, 2nd. Edition, Routledge & Keegan Paul, London
- World Health Organisation, 1980, *Schizophrenia: an international follow up study*, Wiley, London

Appendix A

Community Resource Base Mapping Project

Information provided to community agencies

Community Resources

The Menzies School of Health Research and the Mental Health Association of Central Australia are currently undertaking a joint project to map out which services are available for residents with a psychiatric disability in Alice Springs.

The end result of this project will be the production of a directory of services, clubs and organisations in Alice Springs that are accessible and identified as useful for people with a mental disorder. We will also be able to work out what services or supports are considered to be necessary by people with a psychiatric disability, but are not available in this area.

This project is viewing services and supports for residents with a psychiatric disability in a broad way. Instead of only concentrating on the specialist mental health services that are available, we are also investigating many other potentially useful services.

We are using the concept of a Community Resource Base. This includes services to assist with:

- Accommodation
- Employment
- Training
- Income support
- Being involved in recreational, social and fitness activities
- Assisting families and carers of people with a mental disorder
- Health and welfare services
- and many other resources in our community.

We are interested in finding out more information about your organisation. Members of the Heritage Clubhouse will be working as research assistants to collect the information. If you would like further clarification about this project please contact either:

Ann O'Kane	89517757	(Menzies School of Health Research)
Paul Hills	0419031120	(Mental Health Association of Central Australia)

Interview questions for service providers

1. Name, address and all relevant contact information for the organisation, club, agency, business
2. Type of services and supports and activities that are provided
3. Target group (age, type of person who uses the service etc)
4. Costs associated with this service/ support/activity
5. Specific features of the services/support/activity for people with a disability
6. Specific features for people with a psychiatric disability
7. Any barriers for this service
8. Follow up action required

Appendix B

Example of request to Barkly Mental Health staff to collect information for the remote sector project (detailed in O’Kane and Tsey, 1999)

Dear

I am writing to request your assistance with the evaluation project currently being undertaken by the Menzies School of Health Research. As you are aware there has been a survey developed to investigate how people who use the mental health services are using resources in the community. This survey is not suitable for the more remote communities or indigenous people who have a more traditional lifestyle.

Eva Briscoe and I have travelled to a few remote communities with nurses from the Remote Mental Health Team. So far we have gathered information from three Nganampa Health Service clinics and Hermannsburg and Maryvale.

I would like to request your assistance over the next few months. It would be useful for the purposes of this project to gather opinions from as many communities as possible. I would like to request that you investigate this information as part of your regular service delivery and contribute your findings to the research project. The type of information that has been gathered falls into the following categories:

- the general experience of mental health issues in specific communities
- the responses that are provided, including successful, not so successful ones as well as challenges and barriers experienced
- ideas to overcome the challenges
- what are people currently using to get well or to recover from acute episodes of mental illness
- what do people really need to get on with the job of getting well again

We have not interviewed enough people as yet to gather a clear picture to these sorts of questions. We may not even be able to gather one clear picture - a number of trends or patterns may emerge, depending on the characteristics of different regions and communities. There also may be distinct differences depending on who contributes information - clinic staff, other service providers, family members, consumers.

Could you let me know whether this is a possibility and which communities you may be visiting over the next few months? I know that it is a difficult time over summer. Thanks for your interest and assistance

Yours sincerely

Ann O’Kane
Senior Research Officer
14 December 1998

Appendix C

Copy of the *Community Resource Base Survey* developed jointly by Menzies School of Health Research and the Mental Health Association of Central Australia/ Heritage Clubhouse. This survey is based on previous survey work developed by the Centre for Psychiatric Rehabilitation, Boston University and the Canadian Mental Health Association (British Columbia Division)

COMMUNITY RESOURCE BASE SURVEY

PREFERENCES FOR SUPPORT SERVICES

THIS IS A SURVEY FOR PEOPLE LIVING IN CENTRAL AUSTRALIA WHO HAVE EXPERIENCED MENTAL HEALTH PROBLEMS.

*Menzies School of Health Research
PO Box 8569
Alice Springs
Northern Territory 0871
Ph: 08 89517757*

14 December 1998

Dear Mental Health Service User

Community Resource Base Survey

The Menzies School of Health Research is conducting a survey regarding the types of community supports and services required for residents with mental health problems.

This survey is part of a larger evaluation of mental health services in Central Australia. A small committee made up of people from Menzies, plus members of the Mental Health Association of Central Australia have put this survey together. The information you provide will assist in making recommendations about how to improve service delivery and support for people with mental health problems in this region.

People with a mental health problem use many services and supports in order to recover and get on with their life. This survey is asking questions about these services, such as housing and accommodation support, income, employment and training opportunities, social activities, the type of service you get from mental health services and other community services, self help activities. We are also interested in knowing how much involvement you have in planning what sort of treatment you need and how you stay well.

We have used the idea of a 'Community Resource Base'. This concept looks at the needs of people with mental health problems from the viewpoint of the person concerned, rather than from the viewpoint of the service provider. It aims to put you in the centre. Before you commence filling in this survey have a look at the diagram outlining the 'Community Resource Base' and think about the services and supports that you have used (or would like to use) to assist you get on with your life. Feel free to jot down the services you use next to the categories.

The survey has ten categories. There are questions about:

- | | |
|-----------------------------|----------------------------|
| 1. Accommodation | 6. Consumer involvement |
| 2. Support you need at home | 7. Recreation and leisure |
| 3. income | 8. friendships and family |
| 4. employment | 9. recovery |
| 5. education | 10. mental health services |

You have been given this survey by someone you see from the Mental Health Services Program (Territory Health Services). It will take about 20 -30 minutes to complete. As you answer the questions could you please base your responses on your recent (past 2 or 3 years) experiences. If you do not want to answer any question just leave it blank.

There are options for completing the survey:

- You can fill the survey in yourself while you are at mental health services and hand it straight back to the person who gave it you
- You can ask for assistance. Eva Briscoe and Matthew Fowler are employed as research assistants (consumer consultants) and they are available to assist you. They can be contacted on 89517757 (Menzie's) or alternatively at the Heritage Clubhouse on 89523311. They will arrange a convenient time and place to assist you to complete the survey.
- You can take the survey home and fill it in and then return it to the mental health services. We want to get as many surveys back as possible. If you take it home and forget to bring it back, Eva or Mathew will call you, or drop around to your place, to pick it up.

Your survey is confidential. When you have finished it, place it in the envelope provided and seal it. We will be conducting a small number of personal interviews and a group discussion to go with the survey results. If you are prepared to be involved in a follow up interview or group discussion, fill in your contact details on the enclosed page and leave it outside of the sealed envelope.

Thanks for agreeing to fill out this survey. We appreciate your willingness to be involved in this process. The deadline for the completed surveys to be returned is 12 February 1999. A report on this work will be available to you in June 1999.

Yours sincerely

Ann O'Kane
Senior Research Officer

BACKGROUND INFORMATION

This section of the survey asks questions about you such as where you live, your age etc. Please put an "X" in the box that applies to you for each of the following:

1. **Where do you live most of the time?**

- | | |
|--|---|
| <input type="checkbox"/> Alice Springs town | <input type="checkbox"/> Tennant Creek |
| <input type="checkbox"/> Alice Springs town camp | <input type="checkbox"/> Other remote situation |
| <input type="checkbox"/> Remote Aboriginal community | <input type="checkbox"/> Other |

2. **How long have you been living in Central Australia?**

3. **How long have you been using the mental health services?**

4. **Gender:** Female Male

5. **Age:** 15 - 24 years 25 -34 years 35 - 44 years 45 -54 years
45 - 54 years 55-64 years over 65 years

6. **What is your ethnic background?**

- | | |
|---|--|
| <input type="checkbox"/> Australian (non -indigenous) | <input type="checkbox"/> Australian (indigenous) |
| <input type="checkbox"/> Other nationality | _____ |

7. **What is your preferred language ?** _____

8. **Please describe your family status:**

- | | | |
|---------------------------------|---|--|
| <input type="checkbox"/> Single | <input type="checkbox"/> married /defacto | <input type="checkbox"/> Separated /divorced |
|---------------------------------|---|--|

How many dependants (children, family members) do you have? _____

9. **What is your main form of transport?**

- | | | | |
|---|----------------------------------|--------------------------------|-------|
| <input type="checkbox"/> Private car | <input type="checkbox"/> bicycle | <input type="checkbox"/> other | _____ |
| <input type="checkbox"/> Public transport | <input type="checkbox"/> walking | | |

10. **Do you have transport to get to where you need to go?**

- | | | | |
|--|---|---------------------------------|--------------------------------|
| <input type="checkbox"/> All of the time | <input type="checkbox"/> Most of the time | <input type="checkbox"/> Rarely | <input type="checkbox"/> Never |
|--|---|---------------------------------|--------------------------------|

If you answered rarely or never, what ideas have you got for overcoming your transport difficulties? Please comment

ACCOMMODATION

This section of the survey will ask you questions about your accommodation and the types of assistance you may need in your everyday day living situation.

1. What sort of accommodation do you currently have?

- | | |
|---|--|
| <input type="checkbox"/> House | <input type="checkbox"/> Town camp house |
| <input type="checkbox"/> Flat / unit | <input type="checkbox"/> Nursing home |
| <input type="checkbox"/> Priest Street flats | <input type="checkbox"/> Caravan park |
| <input type="checkbox"/> Backpackers /tourist accommodation | <input type="checkbox"/> Streets / river |
| <input type="checkbox"/> Camping out | <input type="checkbox"/> Other |
| <input type="checkbox"/> Shelter (eg crisis or emergency accommodation) | |
-

- 2. Are you:**
- buying your accommodation
- Renting your accommodation
- Other _____

If you are renting, are you in the:

private rental market

public rental market

Please answer yes or no and provide additional comments

Yes No

- 3. Have you experienced difficulty in finding a place to live in the last year or two?**

- 4. Did you have to go on a waiting list to find a place to live?**

- 5. Do you know people with a mental health problem who have had a hard time finding a place to live in the Alice Springs / Central Australian region?**

- 6. Do you think you will be able to stay where you are now for as long as you want?**

- 7. Were you given choices about where you live?**

- 8. Do you live with anyone?**

Yes No, I live alone

If yes with who do you live with?

- | | | | |
|--------------------------|--------------------------------------|--------------------------|-----------------------|
| <input type="checkbox"/> | Family / relatives | <input type="checkbox"/> | friends / roommate(s) |
| <input type="checkbox"/> | Husband/wife or boyfriend/girlfriend | <input type="checkbox"/> | children |
| <input type="checkbox"/> | Other _____ | | |

9. ***How satisfied are you with where you are living?***

Satisfied

Dissatisfied

Please comment on your answer? _____

10. ***If you had your choice, where would you prefer to live?***

- | | | | |
|--------------------------|--|--------------------------|-----------------|
| <input type="checkbox"/> | House | <input type="checkbox"/> | Town camp house |
| <input type="checkbox"/> | Flat / unit | <input type="checkbox"/> | Nursing home |
| <input type="checkbox"/> | Priest Street flats | <input type="checkbox"/> | Caravan park |
| <input type="checkbox"/> | Backpackers /tourist accommodation | <input type="checkbox"/> | Streets / river |
| <input type="checkbox"/> | Camping out | <input type="checkbox"/> | Other _____ |
| <input type="checkbox"/> | Shelter (eg crisis or emergency accommodation) | | |

11. ***In the past 2 years, do you feel you have been discriminated against in getting accommodation due to mental health problems?***

Yes

No

If you answered yes, please explain _____

12. ***Have you been homeless (ie not having anywhere to live)in the past 2 years?***

Yes

No

If you answered yes what has this has been due to?

- | | |
|--------------------------|--|
| <input type="checkbox"/> | Being hospitalised and losing your accommodation |
| <input type="checkbox"/> | Being unable to afford a rent bond and/or rent /mortgage |
| <input type="checkbox"/> | You were asked to leave (or evicted) |
| <input type="checkbox"/> | Other _____ |

INCOME

This section of the survey asks you questions about the income you get and any difficulties you experience with your level of income

1. ***What sources of income do you receive?***

- | | |
|--------------------------|---|
| <input type="checkbox"/> | Earnings (from employment) |
| <input type="checkbox"/> | Centrelink |
| <input type="checkbox"/> | disability support pension |
| <input type="checkbox"/> | jobsearch |
| <input type="checkbox"/> | other benefit / pension |
| <input type="checkbox"/> | Regular contributions of money or goods from family / partner / friends |
| <input type="checkbox"/> | No income |
| <input type="checkbox"/> | Other (please specify) _____ |

2. ***What is your monthly income from all your sources of income? Please estimate if you are not sure of the exact amount? \$ _____***

3. ***How well do you live on this level of income?***

- Very well OK Very Poorly

If you answered 'very poorly' do you

- | | |
|---|--|
| <input type="checkbox"/> Run out of food and other essentials | <input type="checkbox"/> Seek emergency relief |
| <input type="checkbox"/> Have essential services stopped eg telephone | <input type="checkbox"/> Need to borrow money from friends and relatives |
| <input type="checkbox"/> Other ways your level of income affects you | |
-

4. ***Please estimate which of your expenses takes the most of your income- 1 (takes the most) to 9 (takes the least)***

- | | |
|---|---|
| <input type="checkbox"/> Rent | <input type="checkbox"/> Clothes |
| <input type="checkbox"/> Food | <input type="checkbox"/> Savings |
| <input type="checkbox"/> Family members /dependants | <input type="checkbox"/> Recreation |
| <input type="checkbox"/> Medical expenses | <input type="checkbox"/> Alcohol, cigarettes, other drugs |

5. ***Have you been given information to resolve problems with your finances, such as:***

- | | |
|--------------------------|---|
| <input type="checkbox"/> | Receiving the correct level of income support |
| <input type="checkbox"/> | Receiving rental assistance |
| <input type="checkbox"/> | Budgeting services to pay bills, rent |
| <input type="checkbox"/> | Information about subsidies available |
| <input type="checkbox"/> | Other _____ |

EMPLOYMENT

This section of the survey asks questions about whether you are in paid employment or whether you want to be in paid employment, whether you do any voluntary work, what sort of support you need to be employed, who provides that support.

1. ***Are you working at paid employment at the present time?***
 Yes (continue to question 2,3,4) No (continue to question 5)

2. ***If yes, how many hours a week do you work?***
 Less than 5 11 - 20 36 or more
 5 - 10 21 - 35

3. ***Which of the following categories best describes the type of job you have***

- Supported employment at Bindi Centre sales
 Work crew at Heritage Clubhouse
 CDEP
 Open employment (with support from an employment agency)
 Open employment (without support)

4. ***How satisfied are you with your current employment situation and job support services you receive?***
 Very Satisfied Somewhat Satisfied Very Dissatisfied

5. ***Do you want to get paid work?*** Yes No

6. ***About how many hours do you want to work each week?***

- 1-2 hours (minimal) 11-20 hours (quite a bit)
 3-5 hours (a little) more than 20 hours
 6-10 hours (some)

7. ***Have you been given choices about the kind of work (paid /or volunteer) that you could have?***

- Yes No

8. ***Is there someone available to help you get and keep paid employment.***

- Yes No

If you answered yes, please indicate which support you have used and how you would rate that support.

- | | Good | OK | Poor |
|--|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> Commonwealth Rehabilitation Service | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> Employment Assistance | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> Access Employment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> Centacare | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

<input type="checkbox"/>	Heritage Clubhouse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	Employment National	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	Friend /family member	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	Other _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

9. *Where do you want the help and support?*

On the job site both on and off the job site
 Not on the job site

10. *Do you do any voluntary work?* Yes No
If yes, where do you work? _____
How many hours per month do you contribute? _____

11. *In the past two years, do you feel you have experienced employment discrimination due to your mental health problem?*
Yes No Not sure

Comments _____

12. *From the following services or supports please mark which ones you currently use and which ones you need to use but do not have access to*

	Currently use/	Need to use
A. Help to select a job or career (e.g. vocational testing or job counselling)	<input type="checkbox"/>	<input type="checkbox"/>
B. Help to find a job (e.g., Finding out where to look filling out applications, practice interviewing etc.)	<input type="checkbox"/>	<input type="checkbox"/>
C. Training in the skills needed to get ready to work (eg. Training in following a schedule, getting to work on time etc.)	<input type="checkbox"/>	<input type="checkbox"/>
E. Help to improve skills like following a		
D. Training program that teaches the skills required for a particular job a supervisors directions or working well with others	<input type="checkbox"/>	<input type="checkbox"/>
F. Opportunities to work a few part-time jobs leading to a full-time job if desired	<input type="checkbox"/>	<input type="checkbox"/>
G. Vocational support groups for clients returning to or entering the workplace	<input type="checkbox"/>	<input type="checkbox"/>
H. Other vocational help or support		

EDUCATION / TRAINING

In this section of the survey you will be asked questions about your educational background and whether you want to undertake any further training and what sort of support you may need

1. ***How much education or training do you have?***

- | | | | |
|--------------------------|-----------------------|--------------------------|-------------|
| <input type="checkbox"/> | Never attended school | <input type="checkbox"/> | Trade |
| <input type="checkbox"/> | Primary | <input type="checkbox"/> | Tertiary |
| <input type="checkbox"/> | Secondary | <input type="checkbox"/> | Other _____ |

2. ***Would you like to have more education /training in the next few years?***

- | | | | |
|--------------------------|-----|--------------------------|----|
| <input type="checkbox"/> | Yes | <input type="checkbox"/> | No |
|--------------------------|-----|--------------------------|----|

3. ***If you answered yes, what sort of training do you want?***

- | | |
|--------------------------|--|
| <input type="checkbox"/> | Training to change occupations |
| <input type="checkbox"/> | Training to upgrade basic skills (maths, reading etc) |
| <input type="checkbox"/> | Training to get a better position in my current occupation |
| <input type="checkbox"/> | Other _____ |

4. ***If you answered yes, please indicate which support(s) you would need to reach your educational goals?***

- | | |
|--------------------------|--|
| <input type="checkbox"/> | Help in choosing an educational goal |
| <input type="checkbox"/> | Staff support on or off campus to help you stay in the program (e.g., Ongoing counselling, tutoring) |
| <input type="checkbox"/> | Help accessing financial assistance to be able to afford to study |
| <input type="checkbox"/> | Help in strengthening basic study skills |
| <input type="checkbox"/> | Peer support groups of students who experience mental health problems |
| <input type="checkbox"/> | Applying and getting into the educational program of your choice |
| <input type="checkbox"/> | Other educational support _____ |

4. ***Where would you prefer to go for training and support?***

- | | | | |
|--------------------------|--------------------|--------------------------|-------------------|
| <input type="checkbox"/> | Centralian College | <input type="checkbox"/> | Batchelor College |
| <input type="checkbox"/> | Distance education | <input type="checkbox"/> | Don't know |
| <input type="checkbox"/> | IAD | <input type="checkbox"/> | Other _____ |

5. ***Have you tried to get or use educational /training support services in the past year or two?*** Yes No

If you answered yes, have any of the following reason kept you from getting education/training services in the past year or two?

- | | |
|--------------------------|---|
| <input type="checkbox"/> | A. There was not enough information available about the services that exist |
| <input type="checkbox"/> | B. The service or program you needed was full or there was a waiting list |
| <input type="checkbox"/> | C. The service or program you needed didn't exist in your area |
| <input type="checkbox"/> | D. You were asked to leave a program or involuntarily terminated |
| <input type="checkbox"/> | E. The service you wanted was too expensive |
| <input type="checkbox"/> | F. The way the service or program was provided was unacceptable to you so dropped out |

CONSUMER INVOLVEMENT

This section of the survey asks questions about how involved you think you can be (or want to be) in the planning of mental health services

1. ***Do you want a self-help support group where you meet with others who have experienced mental health problems ?*** Yes No

If yes, what do you want the group to do?

- | | |
|--------------------------|---|
| <input type="checkbox"/> | To give and receive support |
| <input type="checkbox"/> | To share information and experiences |
| <input type="checkbox"/> | To work towards educating the public |
| <input type="checkbox"/> | Advocating to change mental health policies |

Please answer yes or no to the following questions and provide additional comments

- | | Yes | No |
|---|--------------------------|--------------------------|
| 2. <i>Do you believe that, together with other consumers, you can influence the way mental health services are provided in Central Australia</i> | <input type="checkbox"/> | <input type="checkbox"/> |
| <hr/> | | |
| 3. <i>Have you been invited to be involved in making decisions about the mental health services in Central Australia</i> | <input type="checkbox"/> | <input type="checkbox"/> |
| <hr/> | | |
| 4. <i>Do you feel you have the right to approve all the services you receive</i> | <input type="checkbox"/> | <input type="checkbox"/> |
| <hr/> | | |
| 5. <i>Have you been involved in planning for any mental health emergencies</i> | <input type="checkbox"/> | <input type="checkbox"/> |
| <hr/> | | |
| 6. <i>Have you been involved in deciding any case plans that are made for you</i> | <input type="checkbox"/> | <input type="checkbox"/> |
| <hr/> | | |
| 7. <i>Do you feel comfortable asking mental health workers about your treatment</i> | <input type="checkbox"/> | <input type="checkbox"/> |
| <hr/> | | |
| 8. <i>Do you feel you have enough information about your rights as a client</i> | <input type="checkbox"/> | <input type="checkbox"/> |
| <hr/> | | |
| 9. <i>Do you know who to contact if you had a concern or human rights grievance</i> | <input type="checkbox"/> | <input type="checkbox"/> |
| <hr/> | | |
| 10. <i>Do you think that there is support from peers (other people with mental health problems) available to you in this community</i> | <input type="checkbox"/> | <input type="checkbox"/> |
| <hr/> | | |

MENTAL HEALTH SERVICES

This section of the survey asks questions about the clinical service you receive. Specific information is sought about acute care treatment when you are unwell, any medication you may take and any other health problems you have.

Acute care

1. *How old were you when you were first became unwell?* _____ years

Please answer yes or no to the following questions and provide additional comments

- | | <i>Yes</i> | <i>No</i> |
|---|--------------------------|--------------------------|
| 2. <i>Do you have someone to ring at time of crisis?</i> | <input type="checkbox"/> | <input type="checkbox"/> |
| _____ | | |
| 3. <i>Are you able to get treatment and support when you need it?</i> | <input type="checkbox"/> | <input type="checkbox"/> |
| _____ | | |
| 4. <i>Have you ever been hospitalised for a mental health problem?</i> | <input type="checkbox"/> | <input type="checkbox"/> |
| _____ | | |
| 5. <i>Have the people who are important to you (family / friends) been involved in planning your admissions and discharges from hospital?</i> | <input type="checkbox"/> | <input type="checkbox"/> |
| _____ | | |
| 6. <i>Have community mental health workers and hospital staff assisted you to plan your admissions and discharges from hospital?</i> | <input type="checkbox"/> | <input type="checkbox"/> |
| _____ | | |
| 8. <i>Overall, have your hospital stays been helpful?</i> | <input type="checkbox"/> | <input type="checkbox"/> |
| _____ | | |
9. *Would you like to use alternatives to the hospital treatment when you are acutely ill?*
- Yes No

If you answered yes, which of the following services would you prefer?

- | | |
|--------------------------|--|
| <input type="checkbox"/> | Clinical care in my own home |
| <input type="checkbox"/> | Clinical care in other accommodation with other acutely ill people |
| <input type="checkbox"/> | Volunteer care in my own home |
| <input type="checkbox"/> | Volunteer care in other accommodation (like foster family program) |
| <input type="checkbox"/> | Out bush program |
| <input type="checkbox"/> | Other _____ |

Medication

10. *Do you currently take psychiatric medication?*

- Yes Sometimes No, I choose not to No, none has been prescribed

11. *Have you been given information about:*

What side effects to watch for Yes No
 The benefits of your medication Yes No

12. **How satisfied are you with the amount of information given to you about the psychiatric medications you take ?**

Satisfied Dissatisfied

13. **Please indicate whether you feel comfortable asking the following people about your medications.**

	Comfortable	Not comfortable
Psychiatrist	<input type="checkbox"/>	<input type="checkbox"/>
GP	<input type="checkbox"/>	<input type="checkbox"/>
Pharmacist	<input type="checkbox"/>	<input type="checkbox"/>
Mental health worker	<input type="checkbox"/>	<input type="checkbox"/>
Other health worker	<input type="checkbox"/>	<input type="checkbox"/>

Other medical conditions

14. **Do you have any of the following conditions? If you answer yes, do you receive any help?**

Have the problem

Receive help

<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>

- A. Sensory disability (blindness, hearing loss)
- B. Physical disability
- C. Head injury/neurological impairment
- D. Intellectual disability
- E. Chronic physical health problem
- F. Serious side effects from medication
- G. Drug or alcohol dependence
- H. The experience of being physically or sexually abused
- I. Other condition

If you answered yes to receiving help with any of these conditions, who provides this help?

Please comment _____

15. **How satisfied are you with the service you receive for this problem?**

Satisfied Dissatisfied

Culture and language

16. **If English is not your preferred or first language, how satisfied are you with the way the mental health services have taken into account your language needs?**

Satisfied Dissatisfied

17. **Do you feel that the people within mental health services are sensitive to your cultural /ethnic background?**

Yes No

General casemanagement services

Please answer yes or no to the following questions and provide additional comments

- | | Yes | No |
|--|--------------------------|--------------------------|
| 18. <i>Have mental health workers assisted you in contacting other appropriate community agencies (through referrals, other)?</i> | <input type="checkbox"/> | <input type="checkbox"/> |
| <hr/> | | |
| 19. <i>Do mental health workers support you to get involved in things that interest you?</i> | <input type="checkbox"/> | <input type="checkbox"/> |
| <hr/> | | |
| 20. <i>Do mental health workers come to visit you when you are not doing well?</i> | <input type="checkbox"/> | <input type="checkbox"/> |
| <hr/> | | |
| 21. <i>Do you feel that there are people available to assist you in getting your needs met (advocates, other)?</i> | <input type="checkbox"/> | <input type="checkbox"/> |
| <hr/> | | |
| 22. <i>Have you have been given information about your illness?</i> | <input type="checkbox"/> | <input type="checkbox"/> |
| <hr/> | | |
| 23. <i>Are mental health workers available to help you work through difficulties you may be having with your friends / partner / family members?</i> | <input type="checkbox"/> | <input type="checkbox"/> |
| <hr/> | | |

SOCIAL LIFE / FRIENDSHIPS

This section of the survey asks questions about your social network and your relationships and contact with friends and family members.

1. *Have you got people in your life, who are not mental health staff, who you can go to for help or support?* Yes No

2. *How large is your social network (friends, family, acquaintances etc)?*
 1-2 people 5-10 people
 2-5 people more

3. *In general how satisfied are you with your social support /network?*
 Satisfied Dissatisfied

4. *If you are dissatisfied, would you like to increase your social network?*
 Yes No

5. *Which support(s) you would need to increase your satisfaction with your social or leisure life?*

- A. Help to make friends and develop a social support network in the community.
- B. Help to improve social skills such as how to get along with other people.
- C. Help with intimate relationships.
- D. Client operated social club/drop-in center.
- E. Evening and/or weekend social program.
- F. Other leisure /social help or support.

6. *How often do you see or speak with any family members?*

- Daily
- At least once a week
- 2-3 times each month
- Once a month
- Less than once a month
- Not at all in the past six months

7. *How would you describe your relationship with key family members?*
 Very good OK Very poor

If it is poor would you like to improve these relationships?

Yes No

8. *What supports would assist you to improve relationships?*

LEISURE AND RECREATION

This set of survey questions asks you about any hobbies you have or clubs you are a member of and what types of recreational activities you would like to pursue.

1. **Are you involved with any social or recreational group or club activity?**

Yes No

If Yes, which group or club are you involved with from the following:

Social Club (eg RSL, Federals)	Gym (eg Body Dynamics)
Sport Club (eg Football, Running, Rugby)	Tennis Club
YMCA (eg aerobics, martial arts, gym)	Interest Group or Society
Occasional sport (eg bowling)	Indoor Games
<input type="checkbox"/> Other (please state) _____	

2. **Are you involved with any individual activities or hobbies?**

Yes No

If Yes, what kind of activities?:

Hotel/Club	<input type="checkbox"/>	no	<input type="checkbox"/>	Music	_____
Night Club	<input type="checkbox"/>		<input type="checkbox"/>	Hobbies	_____
TAB	<input type="checkbox"/>		<input type="checkbox"/>	Reading	_____
	<input type="checkbox"/>	Movies	<input type="checkbox"/>	Computer	_____
	<input type="checkbox"/>	Going out for meals	<input type="checkbox"/>	Handicrafts	_____

3. **How often would you participate in recreational activities or hobbies?**

<input type="checkbox"/> More than twice per week	<input type="checkbox"/> Once per month
<input type="checkbox"/> Once per week	<input type="checkbox"/> Once every few months
<input type="checkbox"/> Once per fortnight	

4. **Do you ever have holidays or breaks from your general routine?**

Yes No

If you answered Yes, what kind of holiday you have most?

<input type="checkbox"/> Staying at home	<input type="checkbox"/> Travel overseas
<input type="checkbox"/> Travel around local Alice Springs area	<input type="checkbox"/> Camping
<input type="checkbox"/> Travel interstate	<input type="checkbox"/> Other _____

5. **If you would like to pursue any of the above leisure activities, hobbies or holidays, are there any factors which prevent you?**

<input type="checkbox"/> Finance	<input type="checkbox"/> Lack of confidence
<input type="checkbox"/> No one to pursue activity with	<input type="checkbox"/> Lack of transport to activity
<input type="checkbox"/> Other reason _____	

6. **Are there activities or groups you would like to participate in the future? Please describe :**

BARRIERS AND OPPORTUNITIES FOR RECOVERY

This is the last section of the survey. It asks questions about what you do to feel better and get well. It also asks what you think about the level of support and understanding about mental health problems in the Central Australian community

Please answer the following questions and provide additional comments

1. *Do you feel that people within the health system believe you can grow, change and recover?* Yes No
-

2. *What if anything has made it harder for you to cope with or recover from your mental health problems?*
-
-

3. *What have you found to be most useful in your attempts to cope with and recover from your mental health problems?*
-
-

4. *Do you feel that people you come into contact with in this community have a good understanding of mental illness?* Yes No

5. *Please put an x to indicate whether or not you feel welcomed in each of the following places in your community.*

	welcomed	not welcomed	not applicable
Centrelink	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Local businesses	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Drug and alcohol services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Recreation centres	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Churches	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Additional Comments

6. *Do you have any suggestions to make for the mental health services in this region?*
-

7. *What other kinds of support would be helpful to you?*
-