ANGLICARE
TASMANIA

Response to

# *Inquiry into the provision of mental health services in Australia*

The Senate Select Committee on Mental Health

**May 2005**

**Submission from**

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## Introduction

Anglicare Tasmania would like to thank the Senate Select Committee on Mental Health for the opportunity to submit to the Inquiry into Mental Health Services.

Anglicare Tasmania is a non-government organisation that has been working for the Tasmanian community for the past 20 years. Since its establishment it has grown into a state-wide service responding to issues faced by Tasmanians such as financial crisis, homelessness, unemployment, the adverse health, social and economic consequences of alcohol and other drug use, and the challenges faced by people with physical and intellectual disabilities or mental health problems.

Part of Anglicare's mission is to speak out against poverty and injustice and to offer alternatives to decision-makers to help build a more just society. Anglicare practices this advocacy through its Social Action and Research Centre (SARC) established in 1995 to work with low income earners to identify the issues that affect them, and then carry these concerns to Government.

Anglicare has a long standing concern about the issues impacting on people with mental illness. Specifically, Anglicare's services for people experiencing mental illness include:

- **Club Haven**, a recovery-focussed service which provides a social network for support, enjoyment and benefit to adults with mental health problems.
- **Curraghmore Support Services**, supported medium to long term accommodation and short term residential respite for people with psychiatric disabilities.
- **Parent Assist**, which provides short-term, practical support to parents who have a mental illness, particularly those with young children.
- **TAMOSCH** (Towards A Model of Supported Community Housing), a community-based social support and housing initiative aimed at providing long-term supported accommodation.

This submission will discuss the experiences of people with what will be defined as 'serious mental illness', that is, the spectrum of psychotic disorders such as schizophrenia, affective disorders such as bi-polar disorder and depression and severe and disabling anxiety disorders. Although representing a relatively small proportion of the population, the social, economic and personal disadvantages experienced by this group are multiple and extreme. The submission will draw on the knowledge Anglicare has gathered from its experience as a service provider and its own research into the relationship between serious mental illness and poverty, (Cameron & Flanagan, 2004)**.** It will then address the specific terms of reference of the inquiry. Anglicare supports the recommendations made by the Mental health Council of Australia in its submission to this enquiry. Further specific recommendations which emerge from Anglicare's research are included.

## Poverty and mental illness

While the terms of reference of this inquiry are focused on service provision to people with mental illness it is critical to set the context in which these services operate and in which people with serious mental illness live out their lives. The poverty experienced by so many people with mental illness doesn't simply restrict their capacity to choose services or activities which are health promoting; it can actively aggravate illness and be a direct cause of hospitalization.

People with mental health problems are particularly vulnerable to being trapped in a cycle of social disadvantage. People with disabilities, including psychiatric conditions, are at high risk of poverty because of their lower participation in the workforce, the higher costs of living with their disabilities, the consequences of their illness and the absence of essential services including personal and respite care (ACOSS, 2003b:36-8).

Most of what is known about Australians living with serious mental illness comes from the Low Prevalence Disorder Study (LPDS), a component of the National Survey of Mental Health and Wellbeing. The study provides epidemiological, clinical and social data on the needs of people with psychotic disorders. A brief overview of some of the findings of the study conducted in 1997 - 98 provides a telling portrait of the social and economic status of people living with serious mental illness in our community:

- The great majority (72%) were unemployed; 85.2% were dependent on government pension or benefit;
- 47.8% had no school qualification;
- 63.6% of the participants were single and had never been married; with a further 20% separated, divorced or widowed; 31.3% lived alone in single person households
- 59.1% of the sample did not socialize outside the home; and in 57.6% of cases, this was rated as social withdrawal, self-isolation and avoidance of people;

- Only 9.3% lived with a carer who was most frequently their mother (41.8%) or their partner (24.2%);
- 44.7% lived in hospital or nursing home, hostel, group home, supported housing, rooming house, hotel, crisis shelter, or were homeless or with no fixed address;
- Almost 30% of participants showed impairment in self-care (personal hygiene, care for one's appearance and physical fitness) with 3.6% of participants showing marked self-neglect;
- Obvious or severe dysfunction in daily family or household activities (such as cooking, cleaning, sharing meals) was present in 25.8% of the sample;
- 51.6% of the participants had been admitted to hospital once or more in the preceding year, with 45.8% having at least one involuntary admission;
- A high proportion (43.9%) of the participants had at least one contact with an emergency service in the preceding year;
- 48.5% of participants reported having used street drugs or non-prescribed medications;
- While 91% received service in relation to medicine prescriptions, only 25.2% received help with self-management and care of the home; 30.7% received social support and only 33.5% received assistance with managing housing and financial matters;
- 10.2% had been arrested in the past year and 17.6% had been the victim of violence, with 15.3% feeling unsafe in their current locality in the past month;
- The participants who were marginalized or homeless and not in contact with mainstream mental health services reported a much higher arrest rate (20.8%) and was much more likely to be the victim of violence (30.8%);
- 16.5% had attempted suicide or self harm in the past year; this rate was also markedly higher for the marginalized or homeless group at 25.8%;
- 47% of all participants reported being unable to access a particular service they needed in the previous 12 months, including 25.6% who needed a mental health service;
- And only 19.1% of the sample reported participation in any rehabilitation activities in the previous year (Jablensky et al, 1999).

Anglicare's research has confirmed earlier research into the socio-economic condition of people with mental illness and has clearly identified the powerful link between mental illness and poverty. Anglicare's research found that the daily existence for many people with serious mental illness is a constant struggle to meet their basic needs. In some instances the people who participated in the research were destitute. Participants reported on a range of areas in which their poverty forced them into a position of profound social exclusion. Anglicare's research also investigated the issues facing people who were caring for people with serious mental illness and found that many of these people were also facing severe financial hardship. Our research highlighted how failures in the income support system, the mental health and housing systems and the lack of social support compounds the financial and emotional hardship they face in caring for a relative with a serious mental illness.

This desperate situation for people with serious mental illness occurs in a political and socio-economic context in Australia which has emerged over the past decade. A remarkable convergence of social forces has occurred. There has been, and continues to be, a significant growth in the number of people with serious mental illness. The mental health reform agenda and the process of deinstitutionalisation have increased the onus of care onto the community, in keeping with a model of care that is the 'least restrictive' possible. This has happened at a time when there is national crisis in affordable housing as well as escalating demands on public services including health and human services, resulting a significant decrease in availability of public housing and mental health services. Finally, the welfare reform agenda further exacerbates the vulnerability of people with mental illness, increasing pressure on them to meet requirements and to date, failing to provide safety nets when they cannot.

## The extent to which the National Mental Health Strategy, the resources committed to it and the division of responsibility for policy and funding between all levels of government have achieved its aims and objectives, and the barriers to progress;

There are few areas of Australian social life that have such a comprehensive policy context as mental health services, which makes the gap between the policy development and service development in this area particularly obvious. The National Mental Health Strategy sets out highly commendable goals and a framework for the optimal care of people with mental illness. However, in spite of the Third National Mental Health Plan outlining applaudable goals, priority themes and key directions, Anglicare's service experience has found, and our research has confirmed, that the experience of people with serious mental illness has lagged far behind the innovative policy directions. The Plan itself has been criticized for failing to set expenditure targets, define new mechanisms for accountability or prioritise areas requiring urgent attention (Groom, 2003) but perhaps even more critically, the failings of the National Mental Health

Strategy lie in the lack of commitment at Governmental level to implement the goals it articulates. In the Foreword to the Mental Health Council of Australia's report *Out of Hospital, Out of Mind*, Professor Patrick McGorry, Department of Psychiatry at the University of Melbourne, goes to the heart of the problem:

> *Despite its demonstrated capacity for innovation, Australia has not translated recent advances into better mental health care…this is primarily a matter of lack of political will and totally inadequate funding. The expertise and effective models of care are readily available but are not supported. Australia is still trying to deliver mental health services on the cheap. In the more visible post-institutional era this is now having serious consequences for our community as a whole. Only the bipartisan neglect of mental health by both sides of politics, and the lack of effective mobilization of the population, enable this to persist. Other societies would not tolerate this.* (Groom, Hickie & Davenport, 2003: iv*)*

The major conclusion Anglicare has drawn in its research is that there is a critical lack of services to support people with serious mental illness in the community with dire consequences for their health and socio-economic status. The mental health system is in desperate need of an injection of funds. In addition to adequately resourcing the growing non-government community-based service network, funding is required to consolidate government provided mental health services. Tasmania has the smallest mental health workforce per capita in the nation. Difficulties associated with the recruitment, retention and remuneration of staff need urgent attention. Anglicare's research has shown that the continuity of care to clients is compromised by both the high rates of staff turnover and the inability of Mental Health Services to provide backfill for staff on leave. Consumers of mental health services, carers and NGO service providers alike report that community mental health teams were not always able to provide a prompt and responsive service. The waiting period of several weeks for an initial appointment is indicative of this.

Acute care within hospitals plays an important role in the treatment of serious mental illness, even with full resourced comprehensive and effective community-based mental health support services. However, there are serious concerns in all three regions of Tasmania about hospital service provision. These include lengthy delays prior to admission, conditions in hospital, training of staff, lack of communication from staff during hospitalisation and premature discharge when consumers, carers and support service staff considered that patients were still unwell.

The problem of under-resourcing mental health services is a national one. A strong argument can be made for an increase of Commonwealth funding into this area in all states. However, the most recent Australian Health Care Agreements demonstrates that this cannot be assumed. Notwithstanding this important point, State Governments also have a responsibility to address this grave lack of funding to services for people with mental illness and their families and carers.

**Barriers to progress: inadequate funding of mental health services**

Although there has been an apparent rise in mental health service expenditure in Australia, the growth has simply mirrored overall health funding trends since the inception of the National Mental Health Strategy and has not increased in real terms (Commonwealth Department of Health & Ageing, 2002). According to the recent report by the Mental Health Council of Australia, the rise in mental health spending over the past decade is indicative of the increases in pharmaceutical costs rather than the expansion of mental health services (Groom, Hickie & Davenport, 2003: 10). More specifically, the analysis of the costs of psychosis undertaken by Carr et al (2002) for the Low Prevalence Disorders Study Group, found that Australia spends more than other countries on inpatient care and less on supported accommodation for people with serious mental illness. The study found that: "[W]e appear to be spending disproportionate amounts on 'housing' people in hospitals and not investing sufficiently in supported community accommodation" and "[I]f we invested more on certain evidence based psychosocial interventions we could achieve better outcomes and save money" (Carr et al, 2002:35).

The National Mental Health Policy contained a commitment by all governments to a degree of budget protection for mental health funding. This included a guarantee that the level of mental health service expenditure would be maintained and that any resources released through the closure or rationalization of services as part of mental health reforms would be reinvested back into mental health programmes (Commonwealth Department of Health & Ageing, 2002: 17-22). In the current Australian Health Care Agreement (2003 – 2008) mental health service funding is included through the broad agreement rather than in a dedicated section as was previously the case. This means that state expenditure in this area will be subject to greater accountability and benchmarking of core service objectives in the future.

The $47 million funding package dedicated to Tasmanian Mental Health Services in August 2004 will in the short term bring its level of funding to around that which the Mental Health Council of Australia estimates is the national average of state government expenditure on mental health services, that is 7% of their total health budget. The MHCA recommends that this amount should be increased to 12% over the next five years to adequately meet the needs of people with mental illness (Groom, Hickie & Davenport, 2003: 10). This would require further significant and long-term investment by the Tasmanian Government.

## Barriers to progress: staff shortages

While Tasmania has increased per capita funding for mental health services, significant staff shortages remain to be addressed in virtually every discipline and element of mental health services. Of particular concern is the reduction in the clinical workforce in per capita terms over the period from 1993 – 2000 to below the national average in 2000, making Tasmania the lowest ranking jurisdiction in relative size of ‘ambulatory care workforce’, ie that part of the workforce employed in non-acute care services (Commonwealth Department of Health & Ageing, 2002).

Tasmania has far fewer clinical staff per 100,000 population working in community mental health teams compared to similar services in mainland jurisdictions and New Zealand. Clinical staff levels are significant below benchmark levels in all services in the following areas: medical, nursing, occupational therapy, social work and psychology. More than half the current medical workforce in Mental Health Services are either trainees in the psychiatry registrar programme or medical officers without specialist qualifications. Submissions to the Statewide review of mental health services from all stakeholders consistently and repeatedly identified this as a very serious impediment to the delivery of quality mental health care in Tasmania and as an issue requiring urgent action (DHHS, 2004)

The barriers to the recruitment and retention of staff include conditions of work, remuneration that is lower than in other states, inequities and inefficiencies across the service system, and difficulty achieving satisfactory supervision and professional development.

This issue presents particular problems for both the non-government services and Mental Health Services in the development of the sector.

## Barriers to progress: inadequate funding of deinstitutionalization

One of the most significant effects of the National Mental Health Strategy has been to propel the process of deinstitutionalisation. In relation to mental health, this has meant a shift from institutional care to community based care with predominantly non-residential assistance; and mainstreaming of mental health services by establishing psychiatric wards in acute care hospitals to manage acute episodes. This shift was predicated on the need to provide a range of community-based services appropriate to individual need with a focus on maximizing individual independence. It was also about the need for cost containment and the need to reform institutional care generally (AIHW, 2001: 102-3).

While the move towards deinstitutionalisation has been driven by factors such as the social justice and moral discourse about the basic human rights and independence of people with disabilities it also offered a less costly alternative to institutional care (AIHW, 2001; Bostock et al, 2001). There was a presumption that the functions once fulfilled by institutions would be picked up by families, community and public services but the complex roles filled by the old institutions have been 'consistently underrated' (Green, 2003:6). The result has been cuts to government expenditure which ultimately saw a lack of support and care for many of the most vulnerable in the community.

Importantly, recent analyses have highlighted that the issue of housing and the support required for people with psychiatric and intellectual disabilities to secure and maintain appropriate housing has been submerged in debates about deinstitutionalisation. The focus of the debate has been primarily on the nature of social, financial and therapeutic supports for people leaving institutions rather than the type of housing in which they will live (Bostock and Gleeson, 2004). This is an oversight, as the availability and provision of appropriate housing is critical. According to Green (2003:5), there are three critical and interrelated issues which have impacted significantly on the outcomes of deinstitutionalisation, which have had significant consequences for people with mental illness across Australia. These are:

- an increase in the demand for low cost housing and services;
- a failure to recognize the necessary functions institutions formerly fulfilled (including the provision of housing) and to fully cost and transfer these functions to community programs; and
- an increased need for low cost accommodation for people with complex needs when there is a major decline in availability of low cost public and private rental housing throughout Australia.

Tasmania closed the Royal Derwent Hospital in February 2001 after 173 years of operation. The Royal Derwent housed approximately 1300 people with intellectual and cognitive impairment as well as mental illness at its peak during the 1960s. Psychiatric wards in the general hospitals in Burnie, Launceston and Hobart and a range of community-based clinical services were established in advance of the closure of the Royal Derwent Hospital. However, in Tasmania adequate funding has never been allocated to provide the range and sufficiency of housing, social, financial and therapeutic supports needed by people who would once have been housed in this institution.

## Barriers to progress: inadequate and insecure income support for people with mental illness

A review of mental health services in Australia must look at the critical role played by the income support system in ensuring the financial security and psychological health of the majority of people living with a serious mental illness.

Generally, people receiving income support have a much higher prevalence of mental disorders than non-recipients. More than 30% of income support recipients in Australia have a diagnosable mental disorder, compared to 18.6% of non-recipients (Butterworth, 2003). More specifically, 85.2% of people with psychotic disorders receive a government pension or allowance, with 68.3% receiving a disability pension (Jablensky et al, 1999).

Inclusion of the income support system in this inquiry is critical as detrimental health outcomes can occur for people with serious mental illness as a result of the lack of integration between mental health services and the income support system. The very low level of income for people on income support, particularly those people receiving allowances, also leads to poor health outcomes. After June 2005 people with mental illness who are assessed to have the capacity to do part-time work will move onto Enhanced Newstart Allowance rather than the Disability Support Pension and they will receive greater opportunities for support from employment services. They will also have reduced incomes, greater work obligations and be subjected to an administrative system which will stop their incomes for non-compliance. The problems caused by their vulnerability in the income support system will be discussed further in response to the Committee's enquiries about the coordination of services and special needs groups.

## Barriers to progress: the vulnerability of people with mental illness to changes in welfare policy

The welfare reform agenda in Australia is aimed towards increasing ‘economic and social participation of income support recipients’. The reforms are underpinned by the concept of ‘mutual obligation’, by which recipients of government pensions and benefits are required to fulfill a number of activities, principally directed towards ‘increasing opportunities for social and economic participation’, primarily finding paid employment as a condition to receiving their benefits.

While some of the welfare reform measures announced by the Government in May 2005 herald positive changes for income support recipients (the reduced taper rate on allowances, the increase to Mobility Allowance, increased investment in services for jobseekers) there are particular concerns for people with serious mental illness. An issue of concern is the suspension of income for non-compliance with the work obligations, the assessment requirements for the Disability Support Pension and the compliance regime for very long-term unemployed people, many of whom may be experiencing undiagnosed mental illness and/or co—morbid disorders.

There is already widespread evidence to suggest that the most vulnerable jobseekers are further disadvantaged by a harsh compliance regime. The Brotherhood of St Laurence recently conducted a study in Melbourne examining the experiences of disadvantaged job seekers with the mutual obligation regime. More than 50% of the participants in the study had a mental illness. It found that although a minority, a number of people in the study had problems, finding the system complex, confusing and highly stressful (Ziguras, 2003). In particular, the study that found that people ‘with mental health problems’ or a combination of conditions “often experienced difficulty with meeting deadlines for forms, remembering appointments, chasing up various forms from doctors and experienced problems with payments” (Ziguras, 2003:35). As well as increasing the pressure to comply with the mutual obligations requirements of the Newstart Allowance, the daily difficulties faced by many people in this situation are compounded by the lower income payment, compared to the Disability Support Pension and of particular concern in Tasmania, reduced eligibility for a range of critical State Government concessions.

In fact, while the underlying principles of the reform process have been broadly accepted, that is to provide opportunities to increase economic and social participation for vulnerable and disadvantaged people in the community, the reform process has a poor history in dealing with vulnerable jobseekers and the methods to achieve compliance have been widely criticized. The first phase of implementation resulted in an exponential increase in the number of financial penalties imposed for infringements of the social security 'mutual obligation' rules. Those most affected by the 'breaching' regime in which heavy fines were imposed as penalty for failing to meet activity testing requirements were the most vulnerable in the community and those least able to negotiate the complex system. People with psychiatric conditions[1] were among those most regularly having their payments cut for failing to comply to either administrative or activity test requirements, along with the homeless, the young, Indigenous Australians, people with low literacy skills, people with alcohol and drug problems and people with head injuries (ACOSS, 2001). Inability to understand a highly complex system, transitory and unstable accommodation or the effects of episodic illness, in addition to Centrelink's administrative errors and poor communications from Centrelink are factors which might explain this. The subsequent independent review into breaches and penalties in the Social Security System (Pearce, Disney and Ridout, 2002) recommended changes to the system which were reflected in the findings of an internal review of Centrelink and which have resulted in a substantial decrease in the number of breaches. In 2002, legislative amendments significantly reduced the first breach penalties for those in receipt of Newstart Allowance.

The new reforms are being heralded as introducing a better compliance framework, based on a new suspension model. However, this system also contains financial penalties for non-compliance (no back pay of suspended income if the allowee's excuse for non-compliance is not deemed reasonable, and 100% loss of income on fourth suspension). Very long-term unemployed people, some of whom are people with mental and/or substance use disorders, will be required to participate in full-time Work for the Dole for 10 months at a time if they breach the activity test more than three times in one year, and non-compliance with this direction will result in a 100% loss of income for an eight week period. Concerns about the fate of vulnerable jobseekers and children in households with suspended incomes have been responded to with the promise of more intensive case management of vulnerable jobseekers which will ensure that essential bills are paid

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[1] This group included people with a psychiatric illness who were no longer eligible for the Disability Support Pension (eg reforms in 1997 changed the eligibility assessment to a requirement that 'incapacity itself' and not related factors must be the reason for 'inability to work') and were on Newstart or Youth Allowance (ACOSS, 2001) as well as those with undiagnosed mental illness on Newstart or other benefits or allowances. For example Access Economics and Sane Australia estimate that in 2001 3,734 people with schizophrenia were on Newstart or other unemployment benefits (2002:27). They estimate that in 2003 5,467 people with bipolar disorder were on Newstart or other unemployment benefits (2003:31).

when suspension penalties are in place. However, with no funding apparently attached to this initiative it is not clear whether this means referral to the Emergency Relief network or a direct crisis voucher system administered by Centrelink. Nor is there any clarity about what constitutes an essential bill. Either way it appears to introduce more complexity into an already punitive and difficult system.

**Recommendation 1**
**That the Commonwealth Government develop and permanently fund better models of primary and secondary care service delivery which better meets the needs of, and is more inclusive of consumers and carers**

**Recommendation 2**
**That the Commonwealth Government address structural issues in the mental health care system such as lack of services, workforce issues, improving cross sectoral linkages, co-morbidity and protection of human rights.**

**Recommendation 3**
**That the Commonwealth Government establish and monitor National Standards of forensic and restrictive care, especially in its own detention centres.**

**Recommendation 4**
**That the Commonwealth Government increase expenditure on mental health by $1.1 billion per years over the next ten years, refocus funding on the full spectrum of service provision system and adjust existing funding mechanisms to bring them into line with the new funding .**

## The adequacy of various modes of care for people with a mental illness, in particular, prevention, early intervention, acute care, community care, after hours crisis services and respite care;

In the absence of a range of non-clinical community-based services to support people with serious mental illness the dominant experience of mental health services for Tasmanians with serious mental illness has traditionally been of acute clinical services in a hospital setting. People with serious mental illness who are living significantly disadvantaged lives face specific difficulties in their interactions with acute care services. Their poverty impacts on their admission to hospital, their experience of discharge and their capacity to engage with the mental health system.

Anglicare's research identified specific problems surrounding admission and discharge, particularly issues related to the provision of information and referral, carer support and support from mental health teams in the community. Consistent with the findings of the Mental Health Council of Australia report, there is considerable evidence throughout Tasmania that "insufficient rehabilitation and relapse prevention is contributing to the re-admission of people with severe and recurrent mental illness" (Groom, Hickie & Davenport, 2003: 19).

A common experience of people with serious mental illness is the oft-repeated cycle of episodes of illness triggered by the unrelenting difficulties of life on a low income. Participants in Anglicare's research described in detail how trying to survive the disarray of mental illness in the context of the stress of a very low income can lead to a worsening of their mental health, even to the point of developing suicidal thoughts. The severe shortage and limited range of community support services including supported accommodation, home help, recreation, family support, employment and education options – all services which assist people to recover from episodes of mental illness and to negotiate the complexities of life on a low income in the community - means that people's problems escalate until they become unwell and ricochet back into the acute care system. Insufficiencies in service provision have meant that acute care services and community mental health teams are over-stretched to the point where their work is largely reactive to crises and the demand for services continues to outstrip supply of beds, health workers and services. As one research participant said:

> *I think that the real tragedy of the system is that you have to get really sick before you are acknowledged and treated. So there is no backup to stop you getting sick. You have to be at death's door before the system will let you in and I think there should be more help available before it gets to that situation. (Dawn (45) depression and bipolar disorder)*

All the participants in Anglicare's research reported a pattern of repeated hospitalisations in acute care psychiatric services. In spite of this, people with mental illness may have enormous difficulty in gaining admission to hospital. There is considerable pressure on psychiatric beds across the State, with a consistently high occupancy rate. The rigorous triage assessment combined with the paucity of community follow-up or support options can result in people with mental illness being denied the only option available for support and help at a critical time. This is especially problematic when individuals have insecure housing and no support network. There was also a perception that communication between hospital staff and patients had deteriorated in recent years and they considered this to be due to cuts to funding and staffing levels. Participants also expressed concerns relating to the limited time spent on the wards by the nursing staff, cutbacks to in-patient recreational and rehabilitation services, and their perception that the length of stays in hospital were being determined by budgetary concerns.

The discharge of patients is key area of concern. Effective discharge planning is essential in a broader context of changes in treatment and hospital practice which have seen decreasing length of hospital stays and the shift of care once provided in hospitals to the broader health care system. In the case of people who have been hospitalized for serious mental illness continuity of care is critical in all aspects of their post-hospital recovery from clinical care, to social support, rehabilitation and accommodation needs. For people who are living on low incomes these fundamental elements of discharge planning are seriously compromised. There have been significant difficulties in achieving effective discharge planning in practice throughout the State. The lack of affordable or supported accommodation and insufficient community mental health services are fundamental problems. Anglicare’s research uncovered incidents of patients stranded by the discharge process; being left in the foyer of the hospital with no transport or money to get home, being discharged from hospital to situations of homelessness, to sleep in cars or make their own way to a crisis shelter.

After discharge from the hospital, people with mental illness should be offered a referral into the care of community mental health services for ongoing support and treatment. This is of critical importance for individuals and their families after their first admission. This has not happened effectively in Tasmania. In 2004, people emerging from hospital were facing a waiting time of several weeks to access a community mental health team. The length of this waiting list for essential treatment, rehabilitation and support services at a time when individuals and their family are in a state of crisis, confusion, fear and grief is inappropriate and potentially tragic. It highlights a system in crisis and the utter inadequacy of funding to these vital services.

In rural and remote areas around the State community mental health team workers have high case loads over wide geographic areas. In June 2003, when Anglicare’s research was conducted, a community mental health team worker had not visited the West Coast for many months as the service did not have funding to backfill maternity or long service leave. The consequences of the loss of this worker were felt acutely by people with mental illness in the remote towns of the West Coast where the social isolation experienced can be extreme.

In the absence of community support, the refusal of admission or early discharge means that the burden of care falls heavily on carers who may be in desperate need of respite. In Anglicare’s research, consumer and carer participants and mental health service providers identified support needs across a range of areas of daily living which are not being met. These included:

- Tenancy support, which includes assistance with costs in a crisis;
- Home based support, assistance with the management of daily living including medication regimes, shopping, nutrition and personal care;
- Social support in which a range of options are provided to increase opportunities for social participation;
- Recovery and rehabilitation services and programmes;
- Respite options;
- Vocational support; and
- Access to childcare places and family support programmes for people with serious mental illness who are parents of young or adolescent children.

In addition, the carers of people with serious mental illness also identified a range of their own support needs which include:

- Comprehensive and accessible information about acute care and community-based mental health services, as well as information about the relevant mental illness and treatments;
- Respite for carers;
- Access to emergency funding in a time of crisis;
- Mediation support;
- Individual counselling options;
- Family counselling and support for siblings; and
- Early intervention programmes for young people with emerging psychosis.

Anglicare's research documented the severe lack of services in the community to support and assist people with serious mental illness. The research found that existing services are struggling to meet the current demand, and many areas of need are simply not being addressed. The literature in this area makes a strong case that a community mental health sector that is well resourced would greatly enhance the positive outcomes for people with mental illness and their carers. The cost benefits derived from supporting people in the community and outside the cost-intensive acute care system would arguably be substantial. Furthermore, this approach is entirely consistent with the goals and objectives of the National Mental Health Strategy. All that remains to fulfill those goals is a commitment of funding.

**Opportunities for improving coordination and delivery of funding and services at all levels of government to ensure appropriate and comprehensive care is provided throughout the episode of care;**

The role of community sector agencies in Tasmania in the provision of support services for people with mental illness is important but its funding has until recently been insignificant. Throughout the State, non-government organisations such as The Association for the Relatives and Friends of the Mentally Ill (ARAFMI), the Richmond Fellowship, Anglicare, Tasmanian Association of Mental Health Inc. (TAMH), Eureka Clubhouse, Colony 47 and the Red Cross provide care in the form of accommodation, social support, advocacy and recovery-focused services. Policy makers and service providers agree the role of this sector will continue to grow in the future. However, the services provided by these organisations are severely limited by the lack of funding to address service gaps, the insecurity of funding for existing services and its inadequacy to meet current community need for established services. Mental Health Service funding for community support services is largely based on annual funding grants and traditionally made up a very small proportion of the total mental health service budget. In the past month a number of contracts have been dispersed to the non-government sector to develop a number of desperately needed support and recovery services and supported accommodation services as part of the package of investment announced by the Government in August 2004. While this investment is commendable, the Government has acknowledged that a great deal more is required to provide the range and sufficiency of services required. The adequacy and security of funding must also be addressed through ongoing funding arrangements.

Submissions to the 2004 Statewide Review of Mental Health Services identified widespread concerns about lack of communication between elements of the public sector and between the public and other sectors. This had a significant impact on the capacity of services to provide appropriate and effective care. Funding is required to implement the recommendations of the review to establish coordination between the public sector and other stakeholders.

## The appropriate role of the private and non-government sectors;

It is acknowledged by all stakeholders that non-government services for people with serious mental illness play a critical role in non-clinical community support in areas ranging from accommodation to advocacy. Anglicare's research has found that these services are struggling to meet the current demand. To ensure their sustainability, their funding must be stable and recurrent with core operational costs covered. Future budgets should be developed to accommodate the growing level of demand in this area.

In 2004-05 non-government organisations in Tasmania received 3.8% of the mental health services budget. The State Government has made a commitment to grow the non-government sector to deliver a range of non-clinical community-based mental health services. The range of community-based services required to create an effective support system for Tasmanians with mental illness is extensive.

Private providers of mental health services are a small but important part of the mental health service system in Tasmania. Some work in partnership is being contemplated by Mental Health Services to address specific service gaps and to open up opportunities to share workforce development resources. However, access to private services largely remains the domain of those able to afford private health insurance. The development of this sector should not occur at the expense of the public system.

## The extent to which unmet need in supported accommodation, employment, family and social support services, is a barrier to better mental health outcomes;

Anglicare's service experience and research all point towards the unavoidable conclusion that a dearth of supported accommodation options, and an insufficiency of respite and recovery services all contribute to making people with mental illness more sick and forcing them back into the acute care system. In this section the submission will focus on the critical areas of housing, health services, employment, transport, and access to essentials such as food, clothing and telephones.

**a. Supported accommodation**

Safe, secure, affordable and adequately supported accommodation is essential for people living with serious mental illness to manage their illness, maintain good health and maximise their capacity to participate in the community. Research shows strongly that this is the most critical and effective way to prevent frequent and prolonged hospitalisations that are both detrimental to the person with mental illness and extremely costly to the community. However, there is high level of homelessness among people with mental illness. All too often they have ongoing experiences of inadequate housing; often living in a cycle of inappropriate or unacceptable forms of accommodation including the range of hostels, boarding houses, caravan parks, staying with family or friends or living on the streets (Human Rights and Equal Opportunity Commission, 1993; Robinson, 2003). People with serious mental health problems experience significant difficulties in accessing and maintaining appropriate and secure housing for a range of reasons including poverty, discrimination, difficulties with managing finances, inappropriate type or location, and incapacity to maintain housing due to illness (Harvey et al, 2002; O’Brien et al, 2002; Robinson, 2003).

The maintenance of stable tenancies is most effectively achieved with appropriate housing, in terms of cost, location and housing type, in conjunction with comprehensive support in a co-ordinated case management model that incorporates elements of both clinical and non-clinical or disability support (Reynolds et al, 2003). Without adequate and appropriate support across the range of areas of daily living, people with serious mental illness can become stressed, triggering an acute episode of illness.

In spite of the clear importance of affordable and appropriate housing to the health of people with mental illness, there is a shortage of supported accommodation options for people with mental illness in Tasmania. A range of supported accommodation models is required with associated ‘packages of care’ to support people in their tenancies at a range of levels. The levels of supported accommodation required in the State include high-intensity support, for people unable to live independently and who require support 24 hours a day including clinical services, through to independent living with a low level of support from a visiting support worker. This range of needs has emerged in a very difficult housing market for low income Tasmanians, with very low vacancy rates and high rental costs in the private rental market, long waiting lists for public housing and the loss of accommodation available in boarding houses.

The launch of the State Government's $45 million *Affordable Housing Strategy 2004 – 2008* in 2003 included initiatives to develop a range of flexible, low cost supported housing options for people with mental illness. We are currently in Stage One of the Strategy, and four new accommodation facilities are being established around the State, providing housing for 80 people with low level support needs. However, further investment is required in public housing to meet the level of demand for this type of tenure. Tasmania has sustained a substantial debt to the Commonwealth Government accrued from loans through the Commonwealth State Housing Agreements between 1945 and 1986. In the current CSHA, the debt stands at approximately $260 million with the interest and repayment costs to Housing Tasmania are approximately $17 million. This is money which is returned to the Commonwealth Government through the Agreement with no benefit to the Tasmanian community. Freeing the Tasmanian Government from the onus of servicing this debt would directly enable Housing Tasmania to meet the needs for public housing outlined above. Anglicare therefore recommends that the Commonwealth Government forgive this debt.

In addition the State Government's $47 million Mental Health funding package has committed funds to establish 24 new beds in supported accommodation facilities, a 12-bed high support community facility, 62 additional packages of care, and a range of service development initiatives to strengthen clinical and non-government resources. However, substantial additional funding will be required from the State Government to address the recommendations of *Bridging the Gap: the Statewide Review of Mental Health Services in Tasmania*. This recommended significant developmental work of which the initiatives named above were very much a first step.

**Recommendation 5**

**That the Federal Government forgive the $260 million public housing debt owed by the Tasmanian State Government. That the Tasmanian State Government commit to ensuring that the funds which would have been spent servicing this debt are used to create additional public housing in Tasmania.**

### b. Food

The important preventative health care role played by non-government organisations for people with mental illness was highlighted by a number of participants in Anglicare's research who reported a regular pattern of accessing a number of social support services specifically for food. The participants reported that regular access to these services not only provided the opportunity to maintain regular and healthy diets in addition to social support, clinical support and access to Centrelink Community Officers. The availability of such services varies across the State, with most of the support services of this kind located in Hobart.

Anglicare's research found that the majority of the people interviewed reported regular food shortages and a heavy reliance on Emergency Relief services for food. Participants talked about relying on 'duck bread', the day-old bread donated by bakeries to community agencies, scavenging for food at the close of business, even relishing being in hospital because of the meals provided.

Emergency Relief (ER) is the last form of assistance for people who have fallen through the safety net of the Australian social security system. In Tasmania almost all the assistance given to people in financial crisis through the ER system is in the form of food vouchers and food parcels although many ER agencies supplement this with blankets, second hand clothing, new or used furniture and assistance paying utility bills. In Tasmania the funds are shared between 21 community agencies. These agencies report a high volume of demand for their services and in order to manage this demand have developed policies which generally restrict clients to 3 or 4 lots of relief per year and to assistance from a specified agency. Vouchers to the value of $25 or $30 are usually distributed with the intention that this food parcel will support the recipient until their next Centrelink pay, potentially up to 2 weeks away.

Anglicare's surveys of the causes of financial crisis for people using ER services have found that food costs are a major trigger of financial crisis (Wolstenholme, 1998; Madden, 2004) with the 2004 survey finding that 59% of respondents had gone without meals in the past year due to a shortage of money.  This survey uncovered a high level of usage of ER services by people with mental health problems and their carers. Twenty one per cent of the respondents in that survey were in receipt of the Disability Support Pension (DSP). Of those surveyed who were on the DSP, 17% were in receipt of the pension because of psychiatric disability. Furthermore, 24% of all respondents indicated that they or a member of their household had experienced mental illness in the past year (Madden, 2004).

Anglicare's research has also found a pattern of reliance on carers for the subsidisation of food costs either directly because the family member lived with them, or indirectly through providing groceries on an ad hoc or regular basis. The pattern of usage of ER by carers indicates that, like those directly experiencing the mental illness, their carers were likely to be in a state of ongoing financial crisis and in need of repeated support from ER agencies (Madden, 2004).

### c. Affordable clothing

Tasmanian researchers have repeatedly highlighted the difficulty faced by low income earners in affording clothing (Anglicare, 2001; Flanagan, 2002) and this has been supported by surveys of Emergency Relief outlets (Brimbank Emergency Relief Network, 2003; Madden, 2004). Similarly, the majority of the participants in Anglicare's research into mental illness and poverty reported having difficulty affording clothes. Many of the participants in Anglicare's research, all of whom were interviewed in the middle of winter, did not possess such items of clothing as would be deemed essential for a winter in Tasmania: a warm coat or polar fleece, a couple of woollen jumpers, shoes (rather than thongs), and/or a second set of basic clothing.

While charities would distribute goods free of charge to a client identified as being in a crisis, they are reactive to approaches by clients who must then go through an assessment process. The opportunity shops are an important source of revenue to fund the food distribution the charities coordinate as Emergency Relief providers and they concede that the level at which these prices are set can be a source of contention with low income clients.

Regular access to affordable clothing requires a response broader than the Emergency Relief system and more targeted than the current pricing system in charitable op-shops. The problem of access to affordable clothing for people with serious mental illness carries with it issues such as the lack of support for people who may give away possessions or make poor consumer choices while they are experiencing disordered thinking or confusion, and also the issue of the poor access they have to services such as the Public Trustee to help them in the management of their finances. However, the limited access to affordable clothing is not always associated simply with the symptoms of illness; there is also a clear issue with income levels for low income people which the cycle of food, energy and clothing shortages highlights. The situation of people on Youth Allowance and Newstart Allowance are particularly desperate, especially in the Tasmanian housing market which may see them paying between 50 and 60% of their income on rent (Wilson, 2005).

**Recommendation 6**
**That the Commonwealth Government progressively increases allowances up to the level of the pension and indexes them to 25% of Male Total Average Weekly Earnings.**

**Recommendation 7**
**That the Federal Government adjust family assistance payments based on the actual costs of raising a child in a low income family.**

**Recommendation 8**
**That the Federal Government adjust Youth Allowance, Rent Assistance and Family Tax Benefit Part B payments to ensure that family payments do not fall as children grow older.**

### d. Affordable, accessible transport

Without access to accessible and affordable transport people with mental illness run the risk of increased marginalization and isolation. This situation is further compounded by geographical isolation when, due to the lack of affordable housing options and the location of public housing, they are compelled to live on the fringe of cities or regional centres. Limited access to public transport in these areas results in further exclusion (Groom, Hickie & Davenport, 2003). Poor access to and inability to afford public transport have been identified as key factors in maintaining the social exclusion of disadvantaged groups (Saunders, 2003; Taylor & Jope, 2001). Anglicare therefore welcomes the increases to the Mobility Allowance announced in the May Budget.

People with serious mental illness have particular problems both accessing and using different forms of transport, with affordability of both private and public transport being a critical barrier to this group. The state concessions systems are an important mechanism for targeting assistance in key social policy areas to those members of the community who are most in need. However, the Tasmanian state concessions system is poorly targeted and inequitable, with transport concessions in particular privileging aged pensioners over other income support recipients. Those people with serious mental illness who are Health Care Cards holders are doubly disadvantaged by being on jobseeker allowances which are a lower level of income than pensions, and at the same time being ineligible to access State transport concessions such as the Motor Vehicle Registration Concession, the Motor Tax Rebate, the Drivers Licence Discount, and the Transport Access Scheme (Department of Premier and Cabinet, 2003). Without adequate transport the participants in this research were unable to access mental health or general health services or to maintain contact with family and friends.

The financial impact of transport costs in Tasmania is again evident in surveys of Emergency Relief agencies. Anglicare's 2004 survey identified transport costs as one of the primary causes of financial crisis. The problem was particularly significant for people living in non-metropolitan areas and for those people who had experienced a mental health problem in the past year or had someone in their household who had experienced a mental health problem (Anglicare, 2004, unpublished data).

Because of problems with the availability of public transport and/or their anxiety about using public transport (anxieties included the fear of being in enclosed spaces, fear of strangers and fear of being bullied or ridiculed as well as general feelings of anxiety, threat and confusion in dealing with bus routes and timetables), Anglicare's research has found that many people with serious mental illness are dependent on either walking or using taxis. Disability Pensioners with 'permanent and severe psychiatric impairment' are eligible for the Transport Access Scheme which provides a 50% concession on the cost of travel by non-wheelchair accessible taxi. The purpose of the scheme is to enable aged and disability pensioners 'independent access into the community'. However, the assessment for the scheme appears to privilege people with physical and intellectual disability over people with mental illness.

### e. Telephones

People with mental illness are necessarily very reliant on the telephone for emergency contacts, for support and counselling and for companionship. However, telephone debt was identified as another cause of financial concern for the participants in Anglicare's research into poverty and mental illness. Access to a telephone was vitally important to them, for social support and in emergencies. This confirms that for low income households, access to a telephone is 'a constant trade off between the cost of the service and the importance of maintaining communication' (MacNeill, 2002).

However, in many cases extensive use of expensive mobile phones and high cost contract commitments resulted in huge debts which they found difficult to manage. Carers reported this to be one of the largest and most regular debt problems which they are required to pay on behalf of their family member. A number of research participants, however, could not afford either a mobile phone or a landline and the consequences of this absence are exacerbated by the diminishing number of public pay phones. This reflected previous Tasmanian research which found a very high rate of phone disconnection due to a shortage of money for people who are in financial crisis (Madden, 2004). For people whose mental health crises are often extremely frightening and debilitating, the lack of a telephone can be devastating. The Australian Communications Authority has acknowledged that people with a disability and indigenous Australians have fallen behind the rest of the community in their access to payphones (ACA, 2004).

The Telecommunications Act 1997 aims "to enforce that standard telephone services, payphones and other services of social importance are supplied at performance standards that reasonably meet the social, industrial and commercial needs of the Australian community". It also aims to "provide appropriate community safeguards in relation to telecommunications activities and to regulate adequately participants in sections of the Australian telecommunications industry." Anglicare's research raises concerns about the nature of mobile phone contracts, particularly whether accurate information is provided to disadvantaged consumers in a clear and intelligible way. Anglicare therefore recommends:

**Recommendation 9**
**That the Australian Communications Authority ensures that people with a disability have satisfactory access to payphones.**

**Recommendation 10**
**That the Australian Communications Authority investigates breaches of the Telecommunications Act particularly in relation to mobile phone contracts.**

**Recommendation 11**

**That Telstra distribute posters and small cards about key products including InContact, MessageBox, and the Pensioner Concession to all Emergency Relief, Financial Counselling Services and Neighbourhood Houses for provision to clients. Ongoing monitoring of awareness of these products by members of the target group should also be undertaken.**

**The special needs of groups such as children, adolescents, the aged, Indigenous Australians, the socially and geographically isolated and of people with complex and co-morbid conditions and drug and alcohol dependence;**

### Children

Research has established that children raised by parents experiencing mental health issues are at greater risk of themselves developing psychological and behavioural problems and of experiencing an adulthood of social exclusion and disadvantage (see for example Beardslee et al, Biederman et al). Support for people experiencing mental illness is essential to maximize the opportunities for healthy development of children. However, recent Australian research has found that while parents who have mental health problems might receive psychiatric support, support was seldom given in their role as parents, and the effects of their health issues on their children went unrecognised (Cowling, 1999)

Compounding this, significant gaps in service provision exist for families in Tasmania in which the parents are experiencing mental health issues. With some small but significant exceptions, that is, projects which aim to provide social support and respite for children, such as Champs Camps and Taz Kidz Club, children of parents experiencing mental health issues are not provided for unless they have begun to demonstrate problematic behaviours and are themselves clients of child and adolescent mental health services. Drop-in centres for people experiencing mental health issues, key points for information, support and referral, do not currently allow parents to bring children on site because they cannot guarantee the safety of the children. There is also no public mental health inpatient facility for mothers with acute mental health problems who have infants. These considerations effectively marginalize and isolate parents further.

Grandparents who provide care to the children of people with mental illness are also largely unsupported yet increasingly, children under care and protection orders are placed with family members rather than in foster care with non-relatives. Grandparents also provide a significant number of informal care arrangements. It is estimated from Centrelink data on recipients of Family Tax Benefits that, in Tasmania in 2004, approximately 7% of primary carers of children were grandparents. The significant financial concerns that this responsibility poses for older people has been well documented (COTA, 2003).

One of the primary concerns identified by grandparents providing kinship care is the lack of financial support to help them meet the needs of grandchildren who are not under care and protection orders. Grandparent advocacy groups are currently asking for parity with foster carers.

For children and adolescents who are themselves in need of mental health services, it appears that the Child and Adolescent Mental Health Services have also been inadequately resourced. Substantial investment needs to be made to bring current CAMHS services in Tasmania up to the benchmarks set in other Australian jurisdictions. Currently there are long waiting lists for initial assessment at the Southern CAMHS service and there are no inpatient facilities for this age group. When young people are hospitalized it is either in the paediatric wards or the adult psychiatric wards, both of which are unsuitable.

### People with complex and co-morbid conditions and drug and alcohol dependence

The co-existence of problems such as alcohol or drug use disorders with mental illness undoubtedly compounds the difficulties faced by people with serious mental illness in terms of physical, emotional and financial health as well as their social interactions. It increases the likelihood of a range of negative outcomes including increased levels of medication non-compliance, depression, suicidal  behaviour, rehospitalisations, homelessness, poorer mental health and higher family burden (Hall et al, 2001).

In response to the complex treatment and management issues and the significant disease burden raised by high rates of co-morbidity, Governments are moving towards a more collaborative response to the issues of mental health and drug and alcohol service delivery but the implications of this are still being explored and issues clearly still exist in the delivery of separate services with different service cultures. The judgmental treatment of young people by hospital staff during early episodes of psychosis where there is a suspicion that they are experiencing a drug-induced psychosis is a recurrent issue for consumers and carers interviewed by Anglicare researchers. Their stories suggest that attempts to remove the ‘silos’ between mental health and drug and alcohol services will require changes in service culture, practice and assessment. Further, the structural problems of poverty and homelessness affecting people with mental illness act to undermine the efforts of service providers to work with complex issues of drug and alcohol use.

However it has been identified that Tasmanian Mental Health Services budgetary projections in the past did fully anticipate the rate of  increase in coexisting alcohol and drug use disorders, or the increase in aggression and violence associated with acute presentation of clients within the public health system (DHHS, 2004:26).

### Older people

The Statewide Review of Mental Health Services identified that there are no dedicated acute inpatient beds for elderly people with mental illness in Tasmania, with many placed in acute beds in general hospitals because of a lack of alternatives. The review noted that this is both inappropriate and expensive (DHHS, 2004).

## The role and adequacy of training and support for primary carers in the treatment, recovery and support of people with a mental illness;

Anglicare's research has found that the adequacy of training and support for primary carers in the recovery and support of people with mental illness currently provided in Tasmania is woefully inadequate. This is consistent with the findings of the national Mental Health Council of Australia report (2003). The findings of Anglicare's research indicate that there is currently no routine assessment of the physical, emotional or financial capacity of carers to provide care for a relative with serious mental illness.

While many people with a serious mental illness do not have any continuing contact with their family there are many cases in which families do take up the responsibility for caring. This is particularly true since policy change has shifted care of people with mental illness into the community with a corresponding increase in reliance on the support of families and social networks. The impact on a family when a family member develops a serious mental illness is almost without exception profound, and the responsibility for caring for family members with a disability is often not a choice. When questioned about their reasons for being carers, people in Anglicare's research gave a complex mix of motives including feelings of family responsibility, a desire to provide the best possible care, and a sense of emotional obligation. Other important drivers of the decision were the absence of choice, no other family or friends willing or able to care, and no other care being available or affordable.

However, the benefits of family support for a person with a serious mental illness are substantial. If they are living with their family, they are less likely to experience patterns of homelessness, they have more disposable income because they pay less rent, they are better nourished and have less need to access mental health services (Frost et al, 2002:22).

The Mental Health Council of Australia report on the needs of carers of people with mental illness found that individual carers on average contribute 104 hours per week, suggesting that “it is primarily carers who are sustaining the fabric and operational effectiveness of mental health service systems across Australia” (MHCA, 2000:4). Care described as ‘informal’ can encompass an exhausting array of tasks ranging from ‘emotional support through financial and practical assistance to supervision and assistance with personal care, mobility and communication for extended periods’ (AIHW, 2003: 66). Anglicare’s research found that in spite of operating with little professional assistance, carers are called upon to provide substantial housing, financial and advocacy support.

However, despite their fundamental role, the research indicates that informal carers do not feel adequately supported to carry out their role. In nationwide research, the Mental Health Council of Australia found that “carers expressed low levels of satisfaction with service provision in key support areas such as accessing personal information; information, education and training, emotional and social support; being consulted by professionals; policy decision making; having a break; back up help; and rights and responsibilities” (MHCA, 2000: 4-5). The report found that carers felt locked out of, and discounted by the mental health system.

Further, there is strong evidence that informal carers experience a decline in their physical, mental and emotional health, increased social isolation and a reduction in education and employment potential as a result of their caring responsibilities (AIHW, 2003, MHCA, 2000). Stressors which negatively affect the carers of people with schizophrenia and bipolar disorder include: mourning the loss of hopes and plans for the person with schizophrenia; feeling ashamed of the illness and guilty that they may have contributed to it; fear for their personal safety and difficulties dealing with demanding behaviours; fear of leaving the person alone, of taking holidays or having visitors to stay; and strain on marriages (Access Economics, SANE Australia 2002; 2003). That research also identified substantial negative effects on siblings and families as a whole.

Anglicare's research found that caring for someone who has a serious mental illness can have profound financial consequences, both directly and indirectly. Carers too can find themselves caught in a spiral of socio-economic disadvantage if they lose the financial support of family, their family homes or their savings as a repercussion of the care they provide. The carers interviewed reported that the financial cost of caring for their family member was significant, with several of the participants reporting that they had been driven into a situation of financial hardship as a consequence. While the poor financial situation of carers generally is reflected in national data (AIHW, 2003) little research has been done on the particular patterns of expense for the carers of people with mental health problems.

In the course of Anglicare's research carers were asked to consider the financial support they provided in terms of food, housing costs and other debts and to estimate the amount they spent on their family member each week, adjusting for income they receive as board payments. Eleven carers responded to this question and their estimates ranged from $10 - $125 a week. On average carers estimated that they spent $50 per week[2]. The majority of carers who responded to this question were dependent on Commonwealth income support (Aged Pension, Disability Support Pension and Newstart Allowance). Their level of income may have determined the level of financial support they provided.

The carers interviewed outlined a range of direct costs they incurred as a result of their family member's mental illness. As discussed earlier in this submission, people with serious mental illness are highly susceptible to unstable tenancies and patterns of homelessness. With the person with a mental illness receiving minimal support to maintain tenancies or manage their finances it is often their families who are compelled to supply money for bonds when previous bond monies have been kept by landlords. They also report having to cover the cost of lost clothing, repairs and replacement furniture when tenancies are lost or family homes damaged as a consequence of mental illness. Other typical costs dealt with by carers were court fines, parking fines, credit card

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[2] For those carers who were dependent on Disability Support and Aged Pension or Carers Payment, this represented 22% of their income where individuals were already close to the poverty line. This is a figure consistent with a survey carried out by the Carers Association in 1998, which found that the costs reported by carers represented 26% of all weekly household expenditures (CAA, 1998).

debts, hire purchase debts and phone debts. Carers reported that they were anxious to pay these to ensure that their son or daughter was not prosecuted or forced to live without essentials such as food or power.

The impact of these costs on parents who were themselves on low incomes was significant. Carers may have entered into an agreement with a relative who has a mental illness to receive board money, but for some the agreement was hard to enforce. This may be because of the financial management difficulties experienced by the person with mental illness or because of a sense of threat. The carers in Anglicare’s research who reported feeling physically intimidated were more likely to be women who were living with their young adult or middle-aged sons.

Government pensions and allowances are the principal source of income for 40% of carers generally in Australia (AIHW, 2003: 79). Given the many benefits which flow from family support, it is a major concern that so few carers of people with a mental illness receive financial support for their role. Only 14% of designated carers of people with a mental illness receive the Carer’s Payment (Carr et al, 2002). Given the positive contribution that carers make to the clinical outcomes of people with psychotic disorders, improved access to the Carers Payment would have the dual benefit of compensating carers and families for the burden they carry as well as reducing the costs of the illness on the health and community services systems (Carr et al, 2002:35).

**Recommendation 12**

**That the Commonwealth Government improve access to the Carer’s Payment and Carer’s Allowance for people providing a substantial level of care for people disabled by serious mental illness.**

The carers of people with serious mental illness provide the community with substantial and largely unremunerated community care services. Carers across the age spectrum interviewed by Anglicare’s researchers articulated similar concerns about the advocacy, housing, support and financial needs of their relatives. The research found that providing care to an adult son or daughter with serious mental illness has a considerable and deleterious effect on the health, well being and financial status of the carers interviewed. In order to best support carers and ensure that relationships between people with serious mental illness and their families are sustainable, the development of a comprehensive and co-ordinated system of community-based services to assist people with serious mental illness is required. These services must include a range of programmes to meet the needs of carers and the families, both siblings and children of people with serious mental illness.

**Recommendation 13**

**That funding for support programmes for the carers of people with a mental illness is increased to ensure that these services are delivered in all regions of the state to contemporary standards of best practice. These need to include in-home support, befriending services, and information.**

**Recommendation 14**

**That carer support organisations be funded to investigate and implement support initiatives for carers of people with serious mental health issues who are geographically-isolated or from socio-economically, linguistically or culturally disadvantaged backgrounds.**

## The role of primary health care in promotion, prevention, early detection and chronic care management;

### a. Access to primary health care providers

The National Mental Health Strategy and subsequently the Third National Mental Health Plan recognizes the critical role of general practitioners for this group. General practitioners are in a position to make early diagnosis and referral, provide continuity of care and identify emerging family issues for people with mental illness as well as address general health needs in a holistic way. This is very time and cost intensive for general practitioners. While a substantial number of the participants in Anglicare's research spoke very positively of their relationship with their GP, others identified barriers to adequate health care. These included the cost of gap charges to see general practitioners, and the cost of pharmaceuticals and the fact that the burden of mental illness was so significant that it made all other health issues of little concern.

However, their access to primary health care is of critical importance given that the general health of people with mental illness is significantly worse than the general Australian population. Research has found that people with mental illness have considerably higher mortality rates than the general population from all the main causes of death (2.5 times higher) and alarmingly elevated rates of physical illness and suicide. Researchers have concluded that people with mental illness face major health problems strongly associated with their life circumstances, including poverty, poor diet and limited physical activity and access to health services (Lawrence et al, 2001)..

Anglicare commends the Commonwealth Government investment in the Better Outcomes in Mental Health initiative, a project designed to improve the quality of care provided through general practice to people with a mental illness. However, the achievements of this and the National Mental Health Plan are likely to be undermined if Medicare does not provide sufficient safety nets for disadvantaged and low income patients.

**Recommendation 15**
**That the Government ensure that the goals of the national Mental Health Plan are supported by ensuring access to GPs who bulk bill for people on Enhanced Youth Allowance, Enhanced Newstart Allowance and the Disability Support Pension.**

### b. The cost of pharmaceuticals

People with serious mental illness are often on multiple courses of medication, with a number prescribed medications for both their mental illness and other physical ailments. While there are many reasons for non-compliance with medication, the cost of medication is an issue for people with mental illness who are living on low incomes. In Anglicare’s research, those experiencing physical disorders which required medication in addition to their mental health problems, reported particularly severe problems with affording medication. Some participants had organised ongoing credit arrangements with their pharmacists, but this had a significant and negative impact on their overall budgets.

Since the January 1 increases in charges in the Commonwealth Pharmaceutical Benefits Scheme (PBS), concession card holders have been charged a co-payment of $4.60 on each prescription and the Safety Net Threshold has been increased from $198 to $239 (DoHA, 2005).While the Government subsidy covers the real and substantial cost of the medication, the cost of a regular psychiatric medication can make a significant impost on the budget of a pensioner or allowee, making these price increases a further burden on disadvantaged people. Anglicare’s research found that people were typically taking at least 3 or 4 types of medication, pushing their costs upward. The interviewees also described times when they rationed their medication because of its cost. Continued increases in costs of pharmaceuticals are extremely detrimental to people who have serious mental illness and are dependent on income support. More research is needed into the impact of pharmaceutical co-payments on people with chronic illnesses, within a context of understanding the impact of other costs in accessing health care.

**Recommendation 16**

**That the Pharmaceutical Benefit Scheme Safety Net Threshold for concession card holders be adjusted fro family size, to approximately $55 for a single person, $110 for a couple of a single parent with one child and $165 for a three person family. The $239.20 threshold should be retained for all other concession card holding families.**

### c. Oral health care

The particular need for general oral health care for people with serious mental illness is worthy of separate comment given the particular political and funding contexts in which public dental services exist and the extremely poor oral health status of so many people with serious mental illness.

People with mental health problems are extremely vulnerable to oral disease and have a high need for gum treatment, restorations and extractions. However, research shows that their extensive oral health needs are largely unmet, as they  are less likely to access available dental care, unless for an emergency leading to more complex and invasive treatment and they are more difficult to provide appropriate and acceptable care to (Chalmers et al, 1998). Yet good oral health is critical for people with mental illness. Pain and discomfort associated with oral disease can result in a cycle of poor diet, poor sleep and aggravation of their mental health problems.

Both mental illness itself and the medication prescribed to address it contribute to the significant oral disease experienced by people with mental health problems. For example, both depressive illness and schizophrenia are associated with disinterest in oral hygiene, some psychotic conditions are linked with high levels of smoking, which both causes dry mouth and affects the process of periodontal healing. Other psychiatric conditions can lead to a disinterest in a balanced diet, disordered thinking and difficulty performing tasks, remembering appointments or homecare instructions. Psychiatric medications also have side-effects that compromise oral health. Some anti-psychotics have the side effect of creating sugar cravings or dry mouth (a reduction in the saliva flow, reducing the mouth’s natural cleansing process and increasing plaque build up and the incidence of oral disease). Similarly, the lithium treatment commonly prescribed for bipolar disorder increases dental decay and disease (Chalmers et al, 1998; Yarra Oral Health Project, 2003).

However, in spite of these particular and pressing oral health needs, people with serious mental illness face multiple disadvantages in trying to access the Tasmanian Public Dental Service. Currently patients are required to make appointments by telephone at set times, to wait for lengthy periods on waiting lists and to pay $25 up front for an assessment. The symptoms of mental illness often makes the organization of personal resources required to access preventative or emergency dental care almost impossible

Programmes to maximize access for this group within existing resources have been piloted successfully in Victoria and NSW (Yarra Oral Health Project; Chalmers et al, 1998). Using models of group appointments, peer support, cross-disciplinary training, and case management the pilot programmes have successfully addressed client anxiety, problems with access, ensured consistency of treatment, maximized usage of dental appointments and reduced problematic behaviour. Addressing the oral health needs of low income Tasmanians who are experiencing mental health problems requires an inter-disciplinary and strategic response from Mental Health Services and Oral Health Services. Such projects require funding.

Exemption from fees for service is also critical to access for people with serious mental illness. Currently patients are required to pay $25 for a general appointment and failure to pay means the loss of the appointment and a return to the waiting list. While the co-payment raises little for the Government in revenue it is seen as an important mechanism for managing unmet need on this service.

The Tasmanian Government has resisted all calls from the community to increase funding to the Public Dental Service. Substantial funding and workforce issues dog this sector and require decisive action from the Commonwealth.

**Recommendation 17**

**That the Commonwealth Government include oral health care in the Medicare funding framework.**

**The overrepresentation of people with a mental illness in the criminal justice system and in custody, the extent to which these environments give rise to mental illness, the adequacy of legislation and processes in protecting their human rights and the use of diversion programs for such people;**

Without adequate support people with serious mental illness can become unwell due to the stresses of everyday living in what can be a self-perpetuating cycle. While for many this can result in periods of hospitalisation during which or prior to, they lose their current accommodation, for others, the lack of support can lead to criminality and imprisonment. The Low Prevalence Disorder Study found that 10.2% of people with psychosis had been arrested for a criminal offence (Jablensky et al., 1999). There is no national data on the rates of imprisonment of those with psychiatric disability, but reports from New South Wales show that in 1995 an increasing number of prisoners were transferred from prison to hospitals because of chronic mental illness which existed prior to their imprisonment (AIHW, 2001). In 1999, the New South Wales Corrections Health Service reported that 18% of male and 30% of female inmates had schizophrenia and 11% male and 20% female inmates had bipolar illness (AIHW, 2001: 133-4).

The high prevalence of mental health problems in prison is found in Tasmania. While there is currently no data collection to enable accurate measurement, the number of people with serious mental health problems is estimated at approximately 10% of the total prison population with approximately 28% receiving treatment for mental health problems during their incarceration (Henderson, pers.comm, 2004). This is consistent with the findings of the National Study of Psychiatric Morbidity in New Zealand Prisons, which is the most comparable epidemiological study with the Australian prison system and population (Simpson et al, 1999). This study found that 9.9% of male and female inmates had prior treatment for a mental illness before entering prison and just over 20% of male and female inmates had received treatment for mental health problems in prison. In Tasmania, a new prison development seeks to address this problem with a new Correctional Health Centre to replace the old Prison Hospital. This will include a Secure Mental Health Unit for those with severe mental health issues which will be run by the Department of Health and Human Services, but co-located on the prison site at Risdon Vale.

There is a critical need for supported housing for prisoners leaving the prison system.

**Recommendation 18**

**That the Commonwealth Government provide additional funding through SAAP to support the specific needs of prisoners with clinically diagnosed mental illness in the transition from prison to the community.**

**The proficiency and accountability of agencies, such as housing, employment, law enforcement and general health services, in dealing appropriately with people affected by mental illness;**

### a. Centrelink

While Centrelink is not named in the list of agencies in the Committee's terms of reference, the delivery of its service in an efficient and appropriate manner is critical to the health and well being of many people with serious mental illness

The majority of people with serious mental illness are dependent on Centrelink payments as their sole source of income. The participants in Anglicare's research reported mixed experiences of this agency. Those people in receipt of the Disability Support Pension generally reported higher levels of satisfaction than people on Newstart Allowance, with people particularly satisfied with the with the Centrelink Community Officers which visit community-based mental health services. Where concerns were raised they related mostly to eligibility criteria and assessments, systemic and bureaucratic complexity, a high level of administrative errors and a lack of sensitivity about mental health issues by front desk staff.

Another important issue which emerged from Anglicare's research was the detrimental outcomes which can occur as a result of the lack of integration between mental health services and the income support system. People with serious mental illness are heavily reliant on the judgement and efficiency of professionals in these two areas and where system linkages fail, they are at risk of falling through the net. Access to Centrelink payments is dependent on assessments by health professionals and failure to get reliable and adequate income support precipitates deteriorating health. Yet too often it appears that the interaction between these agencies breaks down. From the perspective of the health system, this might be due to a reticence to make a diagnosis, failure to follow up paper work or inadequate understanding of the Centrelink system, and in particular the requirements for assessment for the DSP. Participants in Anglicare's research gave examples of mental health professionals unable to assist them with Centrelink requirements, General Practitioners who were unwilling to write medical certificates in the prescribed Centrelink framework, and psychiatrists making decisions about assessments for the Disability Support Pension based on their personal judgements about its purpose, particularly if there are issues with substance use. Participants described multiple examples of being failed by Centrelink, through their experiences of a system of fines and penalties widely criticised as harsh and punitive, by administrative errors, bureaucratic inflexibility and a trend towards increasingly harsh assessment measures for people with disabilities. The following roundabout is a typical scenario described by participants in Anglicare's research: Centrelink demanding multiple health certificates when it refused to accept letters from clinical Mental Health Service providers and Mental Health Service employees taking weeks to fill in Centrelink forms required immediately to secure income for clients.

In a number of instances, the narratives of Anglicare's research participants demonstrated that inadequate interaction resulted in them being left without any income, reliant on relatives and charity. The stress this caused was also recounted by the carers.

Anglicare's research also revealed a number of anomalies in the income support payment system which particularly disadvantages young adults with serious mental illness. The parents of young adults with emerging psychosis were frustrated and exhausted by the tenacious effort required to ensure that their son or daughter received an appropriate form of independent payment. The cases documented in Anglicare's research, like those in other national studies (eg Welfare Rights Centre, 2002) highlight the structural flaws in this system. Young adults with emerging psychosis need access to a regular income but the lengthy process of diagnosis may mean that they cannot immediately access the Disability Support Pension or other allowances with exemptions. A diagnosis of schizophrenia cannot be made until a second psychotic episode occurs. The current income test places unreasonable burdens on families of adult children. None of the families interviewed in Anglicare's research had sufficient income to support a second household. Young adults with serious mental illness for whom it is inappropriate or impossible to live at home must have access to the Youth Allowance at the independent rate with specialist vocational and educational support. Further, young adults under 21 who receive the Disability

Support Pension and do live at home are not eligible for Rent Assistance, which they would be if they lived in any other care arrangement.

In order to address these concerns Anglicare recommends that the Commonwealth Government ensures that the implementation of welfare reform is consistent with the National Mental Health Plan Principles of early intervention and prevention and the recovery needs of people with serious mental illness. Specifically Anglicare recommends the following:

**Recommendation 19**
**That the Commonwealth Government adjusts the criteria for Rent Assistance to ensure that young people under 21 years receiving the Disability Support Pension and living at home are eligible for this payment.**

**Recommendation 20**
**That the Commonwealth Government ensures that the system of breaches and penalties imposed on recipients of income support be reviewed in accordance with the recommendations of the Independent Review of Breaches and Penalties in the Social Security System.**

**Recommendation 21**
**That the Commonwealth Government provide discretion to Centrelink staff to apply retrospective exemptions to activity tests when dealing with people with a diagnosed mental illness who are in crisis and who have not been able to study or meet activity test obligations because of that crisis**.

**Recommendation 22**
**That the Commonwealth Government increases the availability of Disability Support Officers in each Centrelink Customer Service Office to deliver front desk services if requested.**

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