# Thin ice

## Living with serious mental illness and poverty in Tasmania

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# EXECUTIVE SUMMARY

This report investigates the lives of Tasmanians with serious mental illness who are living on a low income from the perspective of both people who have a mental illness as well as their families. The principal concern of this report is to understand the interconnections between poverty and serious mental illness and the compounding effects of this experience. How does living with severely limited financial and social resources affect the course of their illness? What is required to increase the stability and security in their lives essential for them to best manage their illness?

This research addresses the experiences of people with 'serious mental illness', defined here as the spectrum of psychotic disorders such as schizophrenia, affective disorders such as bi-polar disorder and depression and severe and disabling anxiety disorders. This group of illnesses is characterised by fundamental distortions of thinking, perception and emotional response, hallucinations and disorganised communication, as well as mood swings and lack of motivation and planning ability. Although representing a relatively small proportion of the population, approximately three percent, the social, economic and personal disadvantages experienced by this group are multiple and extreme.

This report confirms that people with serious mental illness are among the most disadvantaged in the community. They face significant difficulties in finding and maintaining stable housing. They are often extremely socially isolated and face multiple barriers to participating in the community. A high proportion of people with serious mental illness are not able to study or find full-time employment and as a result the majority are dependent on government pensions or benefits as their sole source of income. Generally their physical health is much worse than the rest of the community.

A number of emergent factors over the past decade have created a socio-political context that makes life very difficult for many people with serious mental illness. The size of this group is growing at a time of significant cutbacks in real terms in government expenditure to health and community services; there is a national crisis in the availability of affordable housing and the agenda of both mental health reform and welfare reform is pushing towards greater social independence and individual financial autonomy. As a result people with serious mental illness are increasingly reliant on under-resourced carers in the community, either family or non-government support services.

The research uncovered a disturbing cycle of poverty and ill-health for many people with serious mental illness in Tasmania. Participants reported patterns of unstable housing, food insecurity, with a heavy reliance on emergency relief agencies, inadequate clothing, and regular disconnections from essentials such as telephones and electricity. Access to services such as general practitioners, the public dental service and public transport is made difficult by issues of cost. Without adequate support in the community to manage their accommodation, their finances and the tasks of everyday living, many found the stress of trying to survive alone exacerbated the symptoms of their illness, often resulting in relapse and re-hospitalisation.

This nexus between poverty and serious mental illness extended to the lives of the carers. The task of caring for people with serious mental illness tends to fall heavily on their families, usually parents. This research highlights the high toll taken in terms of their health in addition to their social, emotional and financial wellbeing. The dollar cost of care is no measure of the real price of anxiety and grief expressed by carers, yet it is a significant and largely unmeasured impost on families. This report documents the real cost for carers of providing accommodation, food, clothing and support to people with serious mental illness. This significant cost remains largely hidden, picked up by carers, who, if they are themselves on a low fixed income, may be forced on to income support, emergency relief services, charities, and crisis accommodation services. In addition to the financial impost of caring, carers report a critical lack of support in the form of community-based services, clinical, counselling, information and respite options. In particular they identified the lack of appropriate supported accommodation which denied their adult son or daughter the chance to live a meaningful independent life.

The overwhelming conclusion from this research is the urgent need for an increased range and supply of support services to assist people with serious mental illness and their families to live successfully in the community. Deinstitutionalisation has not failed. What has failed is the political will to fund essential support services in the community. The existing services are overwhelmed by the heavy demand they currently face and they are not able to provide the level of care and support required to assist recovery. This lack of support options dramatically increases the hardships faced by people who have a mental illness and their families, in terms of their health and their budgets. Ultimately, it is a failure of systems which is making people sick and forcing them into the costly acute care sector.

The mental health sector understands the pressing need for a comprehensive range of support services in the community. Policies specifically address the benefits of clinical and social support in the community to ensure the wellbeing of people with mental illness. Nonetheless there is no commensurate commitment in funding from governments at either the State or Commonwealth level, and the system of community support fails for the lack of resources. Specifically, the expenditure on mental health services represents only 5.6% of state health expenditure; the Tasmanian Government funded financial administration service for people under guardianship has the highest client costs in Australia; co-payments to the public dental services have recently been increased; funding to carer and community support services is woefully inadequate and proposed changes to the income support system appears set to drive people with serious mental illness further into stress and poverty.

Anglicare has made a range of recommendations for policy changes at the State and Commonwealth level. Each of these recommendations seeks to ensure that people with serious mental illness and their carers, as some of the most vulnerable members of our community, are given the support they need to create stable and fulfilling lives and realise their hopes for recovery.

**Recommendation 1**
That the State Government allocates $13.7 million in additional recurrent funding to Mental Health Services.

**Recommendation 2**
That the State Government makes a commitment to maintaining the Mental Health Services budget at no less than 7% of the total State health budget expenditure.

**Recommendation 3**
That the State Government directs $9.7 million in recurrent funding from the Mental Health Services budget to non-government organisations to deliver a range of community-based support, respite and recovery-based services for people with serious mental illness and their carers.

**Recommendation 4**
That the State Government adopts the proportion of 14% of total mental health services expenditure as the baseline for future increases for non-government organisations to deliver a range of support, respite and recovery-based services for people with serious mental illness and their carers.

**Recommendation 5**
That the Department of Health and Human Services conduct regular evaluation and review of the cost-benefits of increased mental health expenditure to non-government non-clinical community-based services.

**Recommendation 6**
That the State Government directs that Affordable Housing Strategy funding be allocated for the capital cost and operating budgets for cluster style two bedroom units in a supported community housing model in each region.

**Recommendation 7**
That the State Government allocate $344,000 per annum to fund programmes which provide personalised and intensive support for people with serious mental illness who are living independently either in Housing Tasmania properties or sustainable private accommodation.

**Recommendation 8**
Anglicare supports the recommendation of the Australian Council of Social Service that the Commonwealth Government progressively increases allowances up to the level of the pension and indexed to 25% of Male Total Average Weekly Earnings.

**Recommendation 9**
That the charities which run opportunity shops and recycling centres adopt the practice of offering 50% discount on prices to people holding Health Care Cards or Pensioner Concession Cards.

**Recommendation 10**
That the State Government provide additional funding to the Public Trustee to meet the costs of financial administration for Community Service Obligation clients. This would enable the abolition of establishment fees and ongoing charges for Administration clients relying on Centrelink pensions and with assets of less than $100,000.

**Recommendation 11**
That State Government extends eligibility for all motor vehicle and driver licence concessions to Health Care Card and Pension Concession Card holders.

**Recommendation 12**
That the Department of Infrastructure, Energy and Resources actively promote the Transport Access Scheme to the Tasmanian community.

**Recommendation 13**
That the Department of Infrastructure, Energy and Resources collect data on the type of disability of people eligible for the Transport Access Scheme to evaluate the access of people with psychiatric disabilities to this concession.

**Recommendation 14**
That the Australian Communications Authority ensures that people with a disability have satisfactory access to payphones.

**Recommendation 15**
That the Australian Communications Authority investigates breaches of the Telecommunications Act particularly in relation to mobile phone contracts.

**Recommendation 16**
That the State Government removes the upfront $30 fee for the Tasmanian Dental Service for adult concession card holders. This could be achieved with the addition of $1.17m recurrent funding based on 2000-2001 estimates and other improvements in the public dental health scheme.

**Recommendation 17**
That the State Government allocates $100,000 for a 12-month pilot project to increase access to dental health services for people with serious mental illness.

**Recommendation 18**
That the Commonwealth Government lowers the age of independence for income support purposes from the current 21 to 18 years for unemployed people in order to remove the financial burden on families of unemployed or ‘incapacitated’ young adults.

**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.

**Recommendation 23**
That Mental Health Services and Centrelink develop formal protocols to ensure that income and personal support is provided to people with mental illness who are eligible for it.

**Recommendation 24**
That the State Government and the Commonwealth Department of Family and Community Services (FaCS) provide funding to develop educational and vocational rehabilitation programmes for people with serious mental illness which would also provide expert assistance to employment services and educational institutions. This needs to occur in consultation with Mental Health Services and non-government service providers.

**Recommendation 25**
That Mental Health Services allocate additional funds to address mental health workforce issues throughout the system, including recruitment, high staff turnover, and to ensure positions are filled when staff leave is taken.

**Recommendation 26**
That Mental Health Services ensure that their effective discharge planning protocols include the following strategies specifically relevant to people experiencing socio-economic disadvantage:

- Ensure accommodation arrangements are in place at least one day before discharge;
- Ensure that in instances where a patient is being discharged to a carer's home, an assessment is made of the carer's capacity to provide care;

- Confirm transport arrangements from hospital to home at least one day before discharge;
- Contact the family/carers, GP, and, where relevant, Centrelink social workers and other community providers at least the day before discharge to confirm that the patient is being discharged and to ensure that services are activated or re-activated; and
- Ensure that an information kit outlining the mental health services system be distributed to patients and carers as part of a discharge kit.

**Recommendation 27**
That Mental Health Services implement a comprehensive professional development programme for all mental health workers to ensure that contemporary models of best practice are adopted in all settings. This professional development should cover:

- The social determinants of health, and in particular the causal factors for people with mental illness;
- Protocols for effective referral and discharge planning;
- Protocols for admission of people with serious mental illness;
- Management of people with co-morbidity;
- The principles and procedures of family sensitive practice; and
- Models for inclusion of carers in care plan development and management.

**Recommendation 28**
That Mental Health Services review the strategies used to provide information about the mental health service system, including community support services, to people with serious mental illness, their families and key support people on first presentation with a mental illness. Specifically Anglicare recommends that Mental Health Services develops a service directory to be distributed as part of a discharge kit.

**Recommendation 29**
That the Commonwealth Government improves 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.

**Recommendation 30**
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 31**
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, socio-economically disadvantaged, and from linguistically or culturally diverse backgrounds.

## CASE STUDY: Don and Meredith's Story

**Don's story graphically illustrates the important interconnections between the mental health and income support systems for many people with serious mental illness. The ways in which this group engages with these systems, and the issues emerging about the role of support systems in the community for carers and people who have a serious mental illness, have a powerful effect on their mental health and wellbeing. These are the central themes addressed in this report.**

Don is 23. When he was 20, Don was diagnosed as having schizophrenia. He now lives on the Disability Support Pension and has enormous difficulty managing a small, fixed income. He experiences prolonged periods of food insecurity and as a consequence of his illness shows marked self-neglect, particularly around keeping himself or his flat clean. Don has difficulty maintaining tenancies and relationships, and paying essential bills. He now has a psychiatrist, but forgets to attend appointments and chooses not to have contact with the Community Mental Health Team.

Prior to his illness Meredith, his mother, says Don was a clever, gentle character who loved books and quirky jokes. But through his late teens, Don's behaviour became increasingly erratic. In Year 12, his school contacted his parents to discuss Don's disturbing and frightening obsessions. Alarmed, his parents saw the school counsellor and then took him to a private counsellor but no further referrals followed. In his second year, Donald dropped out of University complaining that he felt confused. After conflict with his parents about his obsessions and his inability to organise himself to look for work, Don left home and became homeless. Although entitled to a Health Care Card, Don was unable to organise himself to apply for one.

The first suggestion that Don was experiencing mental illness came when he presented at the hospital experiencing delusions. During the interview he threatened staff with a knife. He was hospitalised in the locked mental health unit. The first Meredith heard of it was when a friend's mother rang. Meredith found her first visit to the intensive care ward extremely traumatic. Meredith and her husband met once with a psychiatrist there but she could recall very little of that meeting.

Don was later moved to the open mental health ward where he continued to experience disordered thinking, paranoid hallucinations and extreme night disturbances. Meredith and her husband felt deeply frustrated at being unable to get information from doctors. Their repeated phone calls to the hospital were not returned. Meredith wanted information about Don's illness and prognosis as well as information about community services and accommodation options. This was not provided in any coordinated way. She gathered the information from nurses by asking a couple of questions each time she visited Don. Meredith reports that she and Don were both subjected to dismissive comments by the hospital psychiatrist based on the assumption that Don's psychosis was drug-induced.

After five days in hospital, Don was given weekend leave. He told Meredith he had been told to go to his parents' home. Meredith had not been consulted.

> *I found a nurse and I said 'But he doesn't live with us'. I said 'What should I do if he went off at night like he's been doing here?' The nurse said 'Put him in a car and bring him back'. I said 'He's 6'2" and very strong', and the nurse said 'Well if he gives you trouble call the police'. I said, 'But what about the other children? He scares them. He's been so upset at night you've been locking him in.'... [A]nd I just kept thinking, 'What if they see their brother being taken away by the police? I don't want them to see that'.*

When Meredith insisted that she was not able to take Don home, he was readmitted and stayed in hospital for another 3 weeks. The weekend leaves remained an issue through this hospitalisation. At his next hospitalisation, the problem of being discharged without any accommodation re-occurred.

> *I went in and he was sitting with all his goods in plastic bags, and he said 'I'm going home'. You know, they said 'Would you like to?' And he said 'Yes'. I think if they said 'Would you like to go to Moscow?', he would have said yes. And he was going back to sleeping on friends' floors, and he had enough pills for 5 days with him. And that was sort of it, and he had no money, no income, no Health Care Card, and he had a card saying he had an appointment with his GP. I found the doctor, and the social worker was there too. I asked if the hospital would give him ongoing medication but the doctor said no. I said that he had no money and no income, nowhere to live and no Health Care Card. I said that even if he could organise*

> *himself to make a doctor's appointment he didn't have any money to pay for it, or the drugs. And do you know what the social worker said? She said Don could get a loan. And I just found that absolutely amazing that the social worker would say that.*

Meredith didn't want to leave Don to fend for himself when she felt he was disorientated and confused and had no income, but she could only offer limited financial support and no accommodation. Don experienced repeated hospitalisations over the next 6 to 8 months. The hospital psychiatrist told his parents that his prognosis was poor and that it was unlikely that he would ever work or study again.

In view of this, Meredith got Don assessed for the Disability Support Pension (DSP). The assessment was unsuccessful.

> *Centrelink said it was his first presentation and he might get better. I had had to get special permission from the hospital to take him out to the appointment with Centrelink. The treating psychiatrist thought he was too unwell to be allowed out in the community. The doctor at the hospital, who had said that our biggest goal should be to try and get him to brush his teeth regularly, well she assessed him as capable of doing 30 hours of work a week. She said that it was Don's first episode and she didn't want to label him. She thought going onto the DSP was giving up hope of recovery. I said, 'It's not the label I'm worried about, he needs money to eat and pay rent', but she said she didn't know about Centrelink and just kept saying we shouldn't let Don give up hope.*

Three months of homelessness and some hospitalisations followed. Through friends, Meredith found out about community-based mental health services and contacted them.

Meredith managed to get Don assessed as eligible for Youth Allowance at the independent rate on the basis that it was impossible for him to live at home. But the income was uncertain. Each time Don failed to respond to Centrelink correspondence or submit a medical certificate his payment was suspended. Meredith began delivering the medical certificates herself. After 3 months on this payment, Meredith tried to break the cycle of suspensions by applying to be the Nominated Person to receive Don's mail, but correspondence continued to be directed to Don.

When Don turned 21, he transferred to Newstart Allowance (NSA). He had no stable accommodation and experienced regular food shortages due to loss of income. He was seeing the family GP regularly. The GP rang Meredith to say that Don's case should be reviewed by a psychiatrist. The social worker from the Community Mental Health Team told Meredith that no psychiatrist was available and recommended a medical officer. Meredith and Don both liked the medical officer but he was a locum who moved around the services. Meredith and Don followed him from service to service but unfortunately he resigned. Meredith, now aware of the role of the Community Mental Health Teams, rang the one for the area Don was then living in. He began to see a case manager who gave Don good support but Meredith worried that Don was still not seeing a psychiatrist and he was very troubled by his psychotic symptoms.

Meredith's troubles with Centrelink continued. She re-applied to be Don's Nominated Person for correspondence but his forms were still sent to an old address. Meredith told Centrelink repeatedly but the error persisted. Of the 16 payments for this period, 4 were suspended: 2 because Centrelink rejected medical certificates on the letterhead of a Government Mental Health Service, 2 because Centrelink said forms were not lodged. Don was without income for substantial periods. These suspensions were overturned after Meredith provided documentary evidence of the lodgment of forms and organised for new medical certificates. During this time Don had a series of failed tenancies due to self-neglect. He was hospitalised and lost his tenure and bond money. The only non-clinical support he received was from his parents, who provided him with financial support and bond money, food, clothing, and advocacy support.

After 12 months on NSA, Don was assessed as eligible for the DSP. To Meredith's relief, one and a half years after he was placed on the DSP, 3 years after his first hospitalisation, Don emerged from a stay in hospital with an appointment with a psychiatrist. But Meredith continues to be the main source of support and assistance for him.

> *Living is a huge worry… [A]nd it's all down to me, so I am on really thin ice with the whole thing. If they haven't got people like us constantly helping them, what, what would happen to them?*

# INTRODUCTION

## THROUGH THE LENS OF POVERTY

> *I find that poverty and mental illness are a wonderful marriage, you know, they still go together … [B]ecause you dress like a poor person they say 'Oh she's got schizophrenia'… (Alison, 38, with schizo-affective disorder, South)*

To live with a serious mental illness is to live a life dominated by that illness. Managing the all-consuming symptoms, treatments and effects of the illness or, for many just surviving it, preoccupies the daily lives and the emotional and physical energy of most people with serious mental illness and their carers. This focus on illness tends to be reflected in research and service responses to the growing prevalence of mental illness in the community. Access to treatment and medication, service needs and clinical support are the key themes which inform most of our understanding of the needs of people with serious mental illness. The social context of their lives is often ignored

This report takes a different approach. It investigates the daily lives of Tasmanians with serious mental illness through the prism of poverty rather than the prism of their illness. As Alison's quote states clearly, poverty and mental illness are inextricably bound for a significant group of people. Yet good mental health is best promoted through a healthy, stable life which is achieved through access to the essentials of life and a secure and adequate income.

This report details the findings from research undertaken by Anglicare in 2003 with Tasmanians living with serious mental illness. In a series of focus groups conducted around the State, people with serious and disabling mental illness and their family members and carers talked to us about their lives. We took as our starting point the relationship between low income and mental illness.

The high and increasing incidence of mental illness in Australia was first quantified in The National Survey of Mental Health and Wellbeing for Adult Australians 1997 (ABS, 1998; Andrews et al, 1999). This survey found that almost 1 in 5 people had experienced a mental disorder in the past year. However, this statistic encompasses the broad spectrum of mental health problems from anxiety and sleeplessness through to psychotic disorders. Within this group is a significantly smaller proportion of Australians who experience what are described as 'low prevalence disorders'. This category of mental illness includes a spectrum of psychotic disorders such as schizophrenia, affective disorders such as bi-polar disorder and depression and severe and disabling anxiety disorders. This group of illnesses is characterised by fundamental distortions of thinking, perception and emotional response, hallucinations and disorganised communication, as well as mood swings and lack of motivation and planning ability (Jablensky et al, 1999). In this report we refer to this spectrum of illnesses as 'serious mental illness'. Although representing a relatively small proportion of the population, approximately three per cent[1], the social, economic and personal disadvantages experienced by this group are multiple and extreme (Carr & Halpin, 2002; Frost et al, 2002; Harvey et al, 2002; Jablensky et al, 1999).

The participants in this research are part of this group, which is arguably the most vulnerable and profoundly disadvantaged in our community. In addition to the mental illnesses outlined, comorbidity was common with many participants experiencing more than one mental illness, or a physical or substance use disorder in addition to their mental disorder. The majority of participants were so disabled by their illness that they were dependent on a Disability Support Pension as their sole source of income. To be eligible for a Disability Support Pension, the recipient must be 'assessed as not being able to work full time or be retrained for full time work for at least two years because of [your] illness, injury or disability' based on a medical examination and report. This payment is subject to an income and assets test.

Due to the chronic, long term and episodic nature of their illness, people with serious mental illness are highly vulnerable to the cluster of factors of social disadvantage, such as living in poverty, family breakdown, social isolation, poor general health and oral health status, a high risk of homelessness or inappropriate and insecure accommodation and unemployment. As a result of their illness, they often lack life skills, including social and occupational skills resulting in extreme financial hardship and social marginalisation. This in turn exacerbates the symptoms of their illness. Furthermore, as Jablensky et al (1999: 2) point out:

> *[O]ver and above the direct neuro-cognitive sequelae of the illness itself, such as impairments of concentration and memory, the sense of being in control of their own lives is profoundly compromised in many individuals with psychotic disorders. This contributes to a sense of despondency that may explain the high risk of self-harming and suicide associated with this group of mental disorders.*

As a group or individually, people living with serious mental illness face significant barriers to voicing their needs and concerns. A range of factors including social stigma and discrimination, means that this group tends to be largely invisible, essentially excluded from the public and political domain. However, because of their high dependency on a broad range of community support services, as well as mental health services, the needs of Tasmanians living with serious mental illness are becoming increasingly pressing for the State Government.

The majority of the participants living with a serious mental illness lived alone, tended to be socially isolated and most were estranged from their family. However, many families do maintain contact and a caring role for members of their family with mental illness. The process of deinstitutionalisation means that most people with a mental illness will be cared for in the community. In the absence of a range of community-based support

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[1] Jablensky et al (1999) found that between 4 and 7 adult Australians in urban areas are in contact with mental health services during any given month because of symptoms of psychotic disorder. This number increased by between 13 and 30% for the 12 month prevalence rate; Andrews (1994) found that 3% of the adult population in Australasia were seriously disabled by the symptoms of their mental illness.

services, the burden of care falls predominantly on informal carers, particularly family members. With this in mind, this research also focused on the experience and needs of carers and the impact of having a family member with serious mental illness on their lives and those of their family. In particular the concerns arising from financial support and hardship, general health and service support issues were addressed.

The impetus for this research came from the growing number of anecdotal reports from workers in a range of Anglicare services telling of a significant rise in the number of clients with mental illness across the State. Recent Anglicare research into the use of emergency relief and financial counselling services (Madden, 2004) confirms this with 25% of service users surveyed reporting having at least one household member with a mental illness.

**Project Objectives:**

The approach of this research intends to provide a clear and qualitative picture of the daily living experience and quality of life for people with serious mental illness. The aim is to deepen our understanding of this group in our community and provide a forum for them to tell their own stories.

Specifically the project objectives are:

1. To investigate the relationship between serious mental illness and poverty by examining:
    a) How poverty affects the physical and mental health of people with serious and disabling mental illness;
    b) In what ways mental illness deepens the experience of poverty;
    c) How the combined factors of mental illness and poverty work to increase risk of hopelessness, family breakdown and social isolation;

2. To investigate the experience of low income earners with serious mental illness in specific service areas, such as the health system, accommodation services, Centrelink, and emergency and community services; and

3. To identify how community support services and the mental health and income support systems could interact more effectively with this group to break the cycle of poverty, recurrent hospitalisation and social isolation.

Section One of this report outlines the research process and the demographic profile of the research participants. A brief overview of the critical concerns for people with serious mental illness in Australia is provided in Section Two. This section draws on the research literature to paint the national picture for this group. Section Three outlines the national policy context and the influence specific policies have on the lives of people with mental illness. The National Mental Health Strategy, deinstitutionalisation and mental health funding policy and the Commonwealth agenda for welfare reform are addressed in this section. The lives of people with serious mental illness tend to be constructed through a filter of statistics, medical terminology and abstract findings. In this report we draw heavily on the descriptions and narratives of the participants to allow the people to speak through the document. Section Four sets out accounts of their experience of illness provided by the participants in this research. The family members also describe the impact the illness has had on their own lives and the lives of their families. The findings from the focus group discussions are outlined thematically in Sections Five to Ten. Discussion of the findings, recommendations and conclusion comprise the final section of this report.

# SECTION ONE

## METHODOLOGY

### 1.1 Project Methodology

The first phase of the project involved a series of individual interviews with service providers, mental health workers and policy makers throughout the State. These interviews commenced in February 2003. Between June and September 2003, 27 focus group discussions were conducted statewide, 17 with people living with serious mental illness and 10 with the carers who had a family member or friend with a serious mental illness. The focus groups were held in the North, North West, West Coast and South of the State.

Participants were:

- aged 18 years or over;
- eligible for a Health Care Concession Card or Pension Concession Card; and
- living with a medically diagnosed mental illness which regularly prevents them from participation in the labour market, education or training for periods of three months or more.

Participants in the carers' groups had a family member or friend who met the participants' eligibility criteria.

Recruitment of participants was conducted through mental health and general health services and community service organisations, as well as placing advertisements in the regional newspapers. A number of participants heard about the research through word of mouth. Detailed information about the focus group process was provided to service providers and other contact people. People seeking specific or detailed information were asked to leave their contact details at the local Anglicare office and one of the researchers phoned them back. Many participants had lengthy telephone conversations with the researchers prior to attending the focus groups.

The focus group method was selected as the most effective means of gathering the research data for this specific group. The interactive narrative approach of facilitated focus group discussions ensures that a detailed and contextualised understanding of individual experiences is produced (de Laine, 1997; Rice & Ezzy, 1999). As Rice and Ezzy (1999:91) point out the method is particularly useful when researching issues which are sensitive, as the shared discussion can encourage people to speak about experiences which they may have felt embarrassed to discuss in individual interviews. Due to the particular characteristics of this group which often include social phobias, depression, shame and disordered thinking, the researchers ensured that the discussion groups were kept to a minimum number of participants, with one facilitator working with no more than four individuals in each group. The restricted size of the group created a more intimate and less threatening atmosphere and enabled a more indepth discussion. A semi-structured interview schedule was used to guide but not restrict the discussions. This schedule had previously been piloted and modified in response to feedback from a person meeting the eligibility criteria. The discussions were audio-taped and transcribed and the transcripts subjected to thematic analysis to draw out key themes.

### 1.1.1 Limitations of this study

In choosing to focus on this statistically small group in the community, Anglicare is deliberately highlighting a group with complex needs. We were particularly keen to recruit participants, family carers as well as people with serious mental illness, who were not in regular contact with mental health services or community based support groups. The selection criteria targeted people on Health Care Concession Cards in an attempt to capture those with a serious and disabling mental illness who may not have been in receipt of, or eligible for, a Disability Support Pension. For a range of reasons, including the fact that this group may be more likely to be accessing support from mental health services, the majority of our participants were Disability Support Pensioners (79%) with only 7 (13.5%) participants with a mental illness receiving Newstart Allowance. Therefore the issues raised in this report are more reflective of the experiences of those living on the Disability Support Pension.

The debilitating nature of serious mental illness on the lives of people added to the problems of attracting participants in the research. Paranoia, agoraphobia, and extreme social anxiety are among the many symptoms experienced by people with mental illness, making the prospect of talking with a group of strangers quite unattractive, if not very frightening. Many of the family members who participated in the carers' focus groups reported that the sense of shame and stigma is still a heavy burden for many people and that alone would prevent them talking publicly about their experiences. The study is further limited by the fact that none of the participants were from the indigenous community or specifically represented culturally or linguistically diverse groups. We did not actively seek to recruit participants from these groups and the factors outlined above could have potentially created even greater barriers to participants from people in these social groups. Therefore, although a small minority of the research participants were not connected to services and had responded to the newspaper advertisements, the majority of participants were recruited through existing services and support groups. We acknowledge that there are many other individuals living with serious mental illness in the Tasmanian community whose experiences of social isolation and poverty may be even more profound than those documented in this research.

### 1.2 Demographic profile of research participants

In all, 78 participants took part in the focus groups, comprising 52 people with serious mental illness and 26 family members or carers. Amongst the group with a mental illness, 30 were men and 22 women. Not surprisingly, in the carer group, the majority (21) of participants were women, with only 5 men attending.

***1) Type of mental disorder (principal diagnosis):***

The most common diagnosis reported by the participants for themselves or their family members was schizophrenia, with a total of 36 (46%). Seventeen people with schizophrenia participated with a further 19 (24%) having a family member with the illness. Bi-polar disorder was the second most common illness for the research participants with a total of 17 (22%). Of this group, 13 participants had bi-polar disorder and 4 had a family member with the illness. Nine participants experienced schizo-affective disorder, which included seven of the participants and a further 2 family members. Nine participants had serious depression, with the remainder suffering from anxiety (2), anxiety and depression (4) and one participant cared for a parent with dementia.[2]

### *2) Income source*

The majority of research participants were dependent on the Disability Support Pension. A total of 46 participants (59%) identified the DSP as their main source of income.[3]

| | ***People with mental illness*** | ***Carer*** |
|---|---|---|
| Disability Support Pension | 42 | 4 |
| Newstart Allowance | 7 | 1 |
| Aged Pension | 1 | 10 |
| Carers' Payment | 1 | 1 |
| Parenting Payment | | 2 |
| Widow's Pension | | 1 |
| Wife's Pension | | 1 |
| Self-funded retiree | 1 | 1 |
| Wages (full-time/part-time) | | 4 |
| Casual work | | 1 |

### *3) Age range of participants*

Not unexpectedly the majority of participants fell into a broad age group of 30 - 59 years. Forty-two participants with a mental illness (81%) were included in this group. Most of this group had been experiencing the symptoms of serious mental illness for many years. As the majority of psychotic illnesses begin in early adulthood, for most, the illness will last a lifetime (Jablensky et al, 1999). The ages of the family member or carer group were strongly skewed to an older age range, with 20 (77%) aged between 50 - 60+ years. This powerfully illustrates the life long responsibility for family members of people with serious mental illness. Their comments in this research reflect the burden of anxiety and care they continue to carry for their middle-aged sons and daughters, long after they had anticipated a retirement and older age free of those pressing daily responsibilities.

| | ***People with mental illness*** | ***Carer*** |
|---|---|---|
| 18 - 29 years | 9 | |
| 30 - 39 years | 18 | 3 |
| 40 - 49 years | 11 | 3 |
| 50 - 59 years | 13 | 9 |
| 60 + years | 1 | 11 |

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[2] This data is not included in the analysis.

[3] Maximum rate of Disability Support Pension (over 21 or under 21 with children) for a single is $452.80 per fortnight and a couple is $378.00 each per fortnight. Maximum rates for people under 21 range from $264.40 per fortnight if living at home to $408.60 if living independently. A member of a couple under 21 is entitled to $378.00 a fortnight. (Centrelink, January 2004)

***4) Type of accommodation of participants with a mental illness***

The majority of participants with a mental illness (32 or 61.5%) were currently living in rental accommodation. Of those 19 (36.5%) were in private rental and 13 (25%) were living in public housing. Of the remainder, five participants were living with family, eight owned their own home, six were currently in crisis accommodation and one participant was living in a shed, without electricity or running water. Consistent with research showing that people with mental illness have difficulties maintaining stable and secure housing, 20 (39%) participants with mental illness reported moving five times or more within the past five years with one participant moving 14 times. Almost half of the participants with a mental illness (25 or 48%) lived alone.

## 1.3 Estimating the number of Tasmanians living with serious mental illness

The problem of accurately measuring the number of people with serious mental illness is widely acknowledged. This is due to a range of factors including the fact that many people do not access mental health services and because, until recently, mental health services have not routinely collected data on service users. This is a national problem and by no means unique to Tasmania. The recent introduction of a national database for mental health service users will dramatically assist in the development of services in response to need.

However, drawing on data from different sources it is possible to give a broad picture of the numbers of Tasmanians with a serious mental illness. The picture we have drawn is at best a sketchy one and certainly a conservative estimate. Drawing on the population prevalence estimates adopted in the Low Prevalence Disorders Study (LPDS) (Jablensky et al, 1999) and The Tolkien Report (Andrews, 1994), it can be concluded that up to three per cent of the adult population has a serious mental illness. On these figures, there are approximately 9,500 adult Tasmanians who are seriously disabled by the symptoms of a mental illness.

An alternative estimate is based on the numbers of recipients of the Disability Support Pension. Of the 24,159 Tasmanians receiving this pension in January 2004, 6,493 (27%) had a psychological or psychiatric condition. The proportion of disability pensioners with psychological or psychiatric conditions in Tasmania is higher than the national average of 24.7% (FaCS, 2003). Additionally, in March 2004, a further 862 Tasmanians were receiving the Department of Veterans' Affairs Disability Pension[4] because they are deemed to be 'Totally and Permanently Incapacitated' with a 'mental condition' (DVA, 2004).

Data provided by Mental Health Services shows that in June 2003, the number of 'mental health patients in active community care' (ie. receiving service from Community Mental Health Teams) was 4,902. Of the total group, 2,919 (59.5%) have been diagnosed (1) psychotic disorders, including schizophrenia, (2) mood disorders, including depression and (3) anxiety and stress-related disorders. The participants in this study largely fall into these three diagnostic groupings. Notably, there was an increase in the total number of 'mental

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[4] This is compensation payment to veterans for injuries or diseases caused or aggravated by war service or certain defence service on behalf of Australia. Dependents of deceased or incapacitated veterans may also receive this payment.

health patients in active community care' in 2002-03, with the largest increase in the categories previously described, an additional 325 people representing 6.6% of the total.

Another measure comes from the Australian Bureau of Statistics. In response to the National Survey of Mental Health and Well Being conducted in 1997, 51,102 adult Tasmanians reported having a mental disorder in the 12-month period prior to the interview. These mental disorders included anxiety disorders as well as affective mood disorders such as bipolar affective disorder, schizophrenia and depression. This accounts for 15% of the Tasmanian population at the time (ABS, 1998). The great disparities in the statistical data in this instance may be explained by the different interpretations of the assessment tool used and the small sample size used for the Tasmanian data.

Whether 6,500, 9,500 or 51,000 is a correct estimate, with only 4,900 receiving active case management it is clear that only a small proportion of Tasmanians with serious mental illness are accessing mental health services and that this is a population group which is largely invisible and extremely difficult to measure, and definitely being under-serviced.

# SECTION TWO

## BACKGROUND: WHAT WE KNOW ABOUT THE LIVES OF PEOPLE LIVING WITH SERIOUS MENTAL ILLNESS IN AUSTRALIA

### 2.1 Poverty, relative poverty and social exclusion

Many Australians struggle with the idea that their fellow citizens are living in poverty. Buffered by steady employment and good wages, it is difficult to imagine the anxiety of being unable to afford food or a trip to the doctor, of having an unpaid utility bill or of having to ask a charity for food. However, there is considerable evidence that in the past few decades poverty has become widespread and entrenched, with high rates of hidden unemployment, large numbers of children living in jobless households, nearly one-quarter of people of working age dependent on social security payments, affordable housing hard to find, and a widening disparity between the lowest and highest family incomes (ACOSS, 2003a:6).

Poverty in the developed world is a complex experience of relative deprivation and the concepts of participation poverty and social exclusion have emerged to explore the experience of deprivation against a relative living standard. This definition of relative poverty relates to an individual's capacity to participate in social and economic life. In these terms poverty is classically defined as:

> *Individuals, families and groups in the population can be said to be in poverty when they lack the resources to obtain the type of diet, participate in the activities and have the living conditions and amenities which are customary, or at least widely encouraged, or approved, in the societies to which they belong. Their resources are so seriously below those commanded by the average individual or family that they are in effect excluded from ordinary living patterns, customs and activities. (Townsend (1979) cited in Saunders, 2003:3)*

With this definition, income remains an important constituent factor in determining poverty, but access to social support, health and education services, affordable housing and transport also become critical. It is this broader definition of poverty that this research seeks to explore. By facilitating discussions with participants about the linked problems of poor health, unemployment, low incomes, family breakdown and their lack of access to education, transport and health services, the research investigates the key areas in which people with serious mental illness experience social exclusion and what the outcomes of this exclusion are.

## 2.2 Poverty and mental illness: What the national statistics tell us

The link between low-income and poor health is well established. There is an extensive literature showing that people who suffer the greatest social disadvantage have the worst health status across a range of indicators (AIHW, 2000; NHS, 1992). There are conclusive indications that mental illness, whether as a causal factor or a result of social disadvantage, significantly exacerbates these negative outcomes. The literature in this area strongly identifies the many barriers faced by this group, highlighting the fact that people with mental health issues are particularly vulnerable to being trapped in a cycle of social disadvantage. The nature of mental illness means that this group find it more difficult to get a job and much more difficult to maintain employment (Frost et al, 2002). Correspondingly, research also shows that unemployment and poverty are major causes of mental health problems. Research in Tasmania has demonstrated the strong link between low income, unemployment and self-assessed levels of poor mental health (for example DHHS, 1999; Cameron et al, 2000).

In June 2003, 673,334 Australians were receiving a Disability Support Pension.[5] Of those 24.7% were disabled by a psychological or psychiatric condition, making this the second most common form of disability after musculo-skeletal or connective tissue conditions (FaCS, 2003). There is a strong connection between disability, illness and poverty which affects both the people with disabilities and their carers (Harvey et al, 2002; ACOSS, 2003b). 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). People with disabilities are disproportionately represented in the two lowest income quintiles. (Raper, 2001).

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 pensions or benefits;
- 47.8% had no school qualification;
- 63.6% of the participants were single and had never been married; 20% were separated, divorced or widowed; 31.3% lived alone in single person households;
- 59.1% of the sample did not socialise 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%);

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[5] To be eligible for the Disability Support Pension, the recipient must be aged 16 and over, and under the Age Pension age, assessed to be unable to work full time or be trained for full time work for at least two years due to illness, injury or disability, or be permanently blind or participating in the Support Wage System. A report from a doctor confirming impairment and work capacity as well as an independent medical examination are required in addition to an impairment rating of at least 20 points on the Social Security Law impairment tables. This rating is assessed by Centrelink staff based on medical reports (Centrelink, 2004).

- 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 marginalised or homeless and not in contact with mainstream mental health services reported a much higher arrest rate (20.8%) and were 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 marginalised 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).

## 2.3 General health and mental illness

In addition to the list of social, personal and economic disadvantage outlined above, the general health of people with mental illness is significantly worse than the general Australian population. A major study in Western Australia 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. Lawrence et al (2001) studied the health records of people using Western Australian mental health services in the period from 1980 - 1998 to develop a comprehensive picture of the over all health of people with mental illness in that state. People with mental illness made up almost 50% of suicides. However, the greatest number of excess deaths in people with mental illness was due to heart disease, even though the mortality rate for this disease has decreased in the general population. This trend was explained by the fact that people with mental illness, particularly those with psychotic illnesses, were less likely than the general population to have medical procedures to improve their condition. The study also found that people with mental illness were less likely to receive hospital treatment for physical illness and more likely to die from cancer than the general population. People with mental illness had higher rates of infectious diseases, deficiency anaemias, digestive system disorders and were more likely to have complications from surgery leading to hospital readmission than the general population.

The authors of the Western Australian study state that their findings indicate major health problems for people with mental illness that are strongly associated with their life circumstances, including poverty, poor diet and limited physical activity and access to health services. The study also raises questions about the level of care provided by general health services.

## 2.4 Comorbidity: mental illness and substance use

Many people with mental illness are diagnosed with more than one disorder, and it is not uncommon for this to include substance use disorders, such as alcohol or drug use disorders[6]. Although not considered a disorder, tobacco use is especially high among people with serious mental disorders (Hall, Lynskey & Teeson, 2001). In some cases, such as drug-induced psychosis, there is a causal link between substance use and mental illness, but in many cases, alcohol or other drugs are used as a form of self-medication to address the symptoms of the mental illness, such as anxiety and depression. Mental illness can therefore be said to increase the risk of substance use. The co-existence of these problems 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. As Hall, Lynskey and Teeson state,

> *"[P]eople with psychoses and substance use disorders are more likely to experience a range of negative outcomes including increased levels of medication non-compliance, psycho-social problems, depression, suicidal behaviour, rehospitalisation, homelessness and poorer mental health, and higher family burden" (2001:13).*

## 2.5 Oral health and 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 causes dry mouth

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[6] There is an extensive debate in the literature about the clinical definition of comorbidity. In general medicine it refers to the co-existence of one or more diseases or disorders in an individual. In relation to people with mental illness the term is commonly used to describe the co-occurrence of a mental disorder and a substance abuse disorder (for example Hall, Lynskey &Teeson, 2001; Webster, 2001; Kavanagh, 2001).

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. More specific symptoms may result in extreme fear of the dentist, hallucinations centring on the mouth, hypochondriacal delusions, fear of body secretions, fear of contamination or ritualistic tooth brushing, resulting in abrasions to the gums. Psychiatric medications also have side-effects that compromise oral health. Some anti-psychotics have the side-effects 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).

### 2.6 Mental illness and the risk of suicide

The risk of suicide for people with serious mental illness is significantly higher than for the general population. The death rate for people with schizophrenia is at least twice as high as those in the general population, with suicide or accident the major cause of death (Access Economics; SANE Australia, 2002). Similarly, SANE Australia reports that suicide is the pre-eminent cause of death for people with bipolar disorder, with this group making up 12% of suicides in Australia in 2003 (Access Economics; SANE Australia, 2003). In general, males are far more likely to complete suicide than females. Current statistics in Australia, show that the number of deaths by suicide for young men aged between 25-34 years is the same as deaths due to motor vehicle accidents.

International studies indicate that suicide amongst people with serious mental illness is more likely to occur in those who are not treated or not adequately treated, or have had their care reduced (WHO, 2001). SANE Australia found that people with schizophrenia are most vulnerable to suicide after discharge from hospital, especially in the first year after a stay in a psychiatric ward (Access Economics; SANE Australia, 2002). In the case of bipolar disorder, of those who suicide 60% have had inadequate treatment and over two-thirds have been misdiagnosed (Access Economics; SANE Australia, 2003).

### 2.7 Homelessness, housing and mental illness

One of the key findings of the Burdekin Report was the high level of homelessness among people with mental illness (Human Rights and Equal Opportunity Commission, 1993). Subsequent research has continued to highlight this trend. For example, Robinson (2003) cites research from 1998 that found that around three-quarters of the homeless people within the inner-city homeless hostel system in Sydney had at least one significant mental disorder. People living with mental illness are certainly highly at risk of 'iterative homelessness', a term used to refer to "the repeated and ongoing loss of, or movement through, accommodation in the short and long term contexts of homelessness" (Robinson 2003:3). It explains the tenuous nature of accommodation for many people with mental illness, who often live 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.

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. Yet stable housing is consistently shown to be critical to the effective management of mental illness and enhanced social functioning (Harvey et al, 2002; O'Brien et al, 2002; Robinson, 2003).

Reynolds et al (2003) found that 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. 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.

There is acknowledgement of the issue of the lack of supported accommodation options for people with mental illness in Tasmania. While it is difficult to ascertain the precise level of need, the growing numbers of people with mental illness in the State, combined with the decrease in low cost housing, means that the demand for appropriate housing is unlikely to diminish in the coming years. In 2002, a project funded by Mental Health Services and Housing Tasmania investigated the issues and needs from the perspective of service providers around the State (DHHS, 2003). The launch of the Affordable Housing Strategy in 2003 also heralds a more comprehensive approach to the development of a range of flexible, low cost supported housing options for people with mental illness. In Stage One of the Strategy, four new accommodation facilities will be established around the State, providing housing for 80 people with low level support needs (Housing Tasmania, 2003). However, as a number of national studies have clearly shown, in addition to accommodation, people with serious mental illness in both public and private housing generally require comprehensive support and case management to maintain their tenancies.

## 2.8 Mental illness and prisons

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. For some, the lack of support can lead to criminality and imprisonment. The LPDS 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 disorder (AIHW, 2001: 133-4).

The high prevalence of mental health problems in prison is replicated in Tasmania. While there is currently no data collection to enable accurate measurement, the numbers of people with serious mental health problems are 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, the 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.

### 2.9 Families, carers and the impact of mental illness

Many people with a serious mental illness do not have any continuing contact with their family. A significant proportion of participants in the LPDS (35%) did not have any regular face to face contact with a close relative and 31% were living alone (Jablensky et al, 1999). But in many cases the responsibility for caring for people with mental illness is taken up by their family. 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 Australian Institute of Health and Welfare define ‘informal care’ as help with daily activities, 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). The responsibility for caring for family members with a disability is often not a choice for many carers. While many do so because they see it as an extension of their relationship with a family member or friend in need, others take on the role because there is simply no one else to do it (AIHW, 2003). 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 iterative 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). 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).

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.

Government pensions and allowances are the principal source of income for 40% of carers generally in Australia (AIHW, 2003: 79). In addition to the Family Allowance and Parenting Payment, Centrelink administers special purpose carer payments, such as the Carer Payment and Carer Allowance. These two payments provide financial support for carers of people with an ongoing need for assistance. The Carer Payment is an income support benefit payable to people who, because of their caring responsibilities, are unable to engage in a substantial level of paid work but are not eligible for other income support payments. The payment is subject to an income and asset test. The Carer Allowance is payable when the care recipient requires substantial amounts of additional care because of a disability, severe medical condition or age-related frailty. The allowance is not income or asset tested. Both payments are based on co-residency of the carer and care recipient.

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). As Carr et al conclude, 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 (2002:35).

# SECTION THREE

## THE NATIONAL POLICY CONTEXT: HOW IT AFFECTS THE LIVES OF PEOPLE WITH SERIOUS MENTAL ILLNESS

### 3.1 The National Mental Health Strategy

There are few areas of Australian social life that have such a comprehensive policy context as mental health services. The Human Rights and Equal Opportunity Commission's National Inquiry into the Human Rights of People with Mental Illness documented the impact of mental illness and the requirements for mental health care in Australia. For the first time many Australians were made aware of the lives of people with mental illness in our community and were shocked by the degree of deprivation and abuse of human rights many were experiencing in the psychiatric institutions. Influenced by the lobbying of mental health professionals and international responses, State and Commonwealth Governments commenced the process of mental health service reform in 1993 with The National Mental Health Strategy. Significantly, the reform process placed an emphasis on deinstitutionalisation:  the closure of psychiatric hospitals and stand-alone facilities and placing the residents in the community with the goal of providing a level of care and support to ensure that they could live independent, socially integrated lives.

The Strategy, encompassing the three National Mental Health Plans, provides a policy framework and strategic plans for mental health policy and service delivery. Since then, the First and Second National Mental Health Plans have set out detailed agendas for Commonwealth and State governments to operationalise the broad aims of the Strategy. The Third National Mental Health Plan, introduced in 2003, articulates the agenda for the next five years. The broad aims of the National Mental Health Strategy are:

- To promote the mental health of the Australian community;
- To, where possible, prevent the development of mental disorder;
- To reduce the impact of mental disorders on individuals, families and the community; and
- To assure the rights of people with mental disorder.

It contains a detailed set of principles and key directions for the mental health reform agenda in the next five years, including the need to ensure quality of service, sustainability of effective treatment options, recognition of the centrality of consumer and carers' rights and investment in the mental health workforce. It places significant emphasis on 'the recovery agenda' (Australian Health Ministers, 2003: 10-13). It also highlights the necessity of a 'whole of government approach' to mental health reform.

However, in spite of enunciating a raft of commendable goals, priority themes and key directions, the Third National Mental Health Plan fails to set expenditure goals, define new mechanisms for accountability or prioritise areas requiring urgent attention (Groom, 2003).

## 3.2 Deinstitutionalisation

One of the most significant effects of the National Mental Health Strategy has been to propel the process of deinstitutionalisation. The movement towards deinstitutionalisation began over thirty years ago. The majority of residents of psychiatric institutions in Australia were already living in the community when Brian Burdekin wrote his report in 1993. 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 hospitals to manage acute episodes. Deinstitutionalisation has been predicated on the need to provide a range of community-based services appropriate to individual need with a focus on maximising individual independence. It was also about the need for cost containment and the need to reform institutional care generally (AIHW, 2001: 102-3).

The move towards deinstitutionalisation has been driven by three key factors: the social justice and moral discourse about the basic human rights and independence of people with disabilities; the rapidly improving pharmaceutical management of mental health problems and the conviction of policy makers that community-based care offered a less costly alternative to institutional care (AIHW, 2001; Bostock et al, 2001). It was in the 1990's that deinstitutionalisation and neo-liberalism [economic rationalism] found each other in an 'uneasy match'. (Green, 2003:5). The convergence of the movement for individual rights and autonomy with the economic rationalist agenda resulted in cuts to government expenditure and ultimately saw a lack of support and care for many of the most vulnerable in the community. As Green (2003:6) states:

> *In the past two decades of the twentieth century governments and policy makers confidently assumed most of the functions previously conducted by institutions would be carried out by families, neighbourhoods, local public services and the community based agencies. In this way the complexity and demanding nature of housing, healing, caring and protecting young people and adults in community settings has been consistently underrated.*

Importantly, recent analyses have highlighted the fact that the issue of housing, the type 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. Bostock and Gleeson (2004) point out that the focus 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. Yet as Green points out, 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: 1) an increase in the demand for low cost housing and services; 2) a failure to recognise the necessary functions institutions formerly fulfilled (including the provision of housing) and to fully cost and transfer these functions to community programs; and 3) 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 led the nation with the closure of 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. After a period of gradual downscaling, in 2001, the remaining 70 residents were moved into the community in supported accommodation. 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.

### 3.3 Funding mental health services

In financial terms, the costs of serious mental illness and associated suicides are enormous. An accurate costing of the burden of mental illness in Australia includes both direct costs on the health and community services systems and a range of indirect costs. The latter include the reduced productivity of people with serious mental illness and their carers, including tax foregone; out of pocket expenses of informal carers; costs on the criminal justice system, accommodation costs and costing of volunteer work. It has been estimated that the economic burden of serious mental illness for adult Australians is at least $1.45 billion per annum for government and $2.25 billion per annum in ‘societal costs’ (Carr et al, 2002). Access Economics and SANE Australia estimate that the real financial costs of schizophrenia in 2001 to be $1.85 billion (2002) and the cost of bipolar disorder in 2002 were $1.59 billion (2003).

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 psycho-social 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 rationalisation 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.

While Tasmania has increased per capita funding for mental health services, the increase is well below the national average per capita increase (Commonwealth Department of Health & Ageing, 2002). Furthermore, Tasmania has the smallest clinical workforce per capita in Australia (Commonwealth Department of Health & Ageing, 2002).

In the financial year 2003-04 the Tasmanian Government budgeted $53.5million for Mental Health Services. This figure incorporates hospital-based psychiatric services and components of forensic mental health expenditure. This is approximately 5.6% of the total operating expenditure for the Department of Health and Human Services for that financial year.[7] This percentage is below the national average of state government expenditure on mental health services, which is 7% of their total health budget, according to the Mental Health Council of Australia. 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). Based on the current budget figures, an increase to 7% of health expenditure would require the Tasmanian Government to commit an additional $13.7 to the Mental Health Services budget.

The role of community sector agencies in Tasmania in the provision of support services for people with mental illness is significant. 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 and they are not able to meet the current community need. Mental Health Service funding for community support services is based on annual funding grants and makes up a very small proportion of the total mental health service budget. At only 3.3% of the Mental Health Services budget in 2002-03 and 3.8% in 2003-04, the increasing pressure on these community services is not currently being matched in budget allocation.

### 3.4 Income support and mental illness

The income support system is critical to 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. According to Butterworth (2003) more than 30% of income support recipients in Australia have a diagnosable mental disorder, compared to 18.6% of non-recipients. The figures can be explained by two important factors: that people with mental illness find it more difficult to find and sustain employment due to the effects of their illness (Jablensky et al, 1999) and that living on a low income and being unemployed increases the risk of mental illness (Mathers & Schofield, 1998). More specifically, Jablensky et al (1999) found that 85.2% of people with psychotic disorders receive a government pension or allowance, with 68.3% receiving a disability pension.

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[7] Parliament of Tasmania, Operations of Government Departments 2003-04, Budget Paper No.2 Volume 1, pp. 130-134

Over the past decade, the number of people receiving the Disability Support Pension has increased markedly, as have the numbers receiving the Carer Allowance (Adult) and the various other Carer Payments (AIHW, 2003: 353). In June 2003, there were 412,777 people in Australia receiving the Disability Support Pension, with 25% having a psychological or psychiatric condition (FaCS, 2003). The reasons cited for the rise in the number of disability pensioners include the introduction of the Disability Reform Package in 1991 which changed the eligibility criteria for disability payments; loss of access to other forms of support; the ageing population; and changes to the labour market which have made it more difficult for people with a disability to find or retain work (FaCS, 2003). The Department of Family and Community Services has introduced a number of policies to reduce the number of claims, including the Better Assessment and Early Intervention initiative in 2002.

### 3.4.1 The welfare reform agenda

The welfare reform agenda in Australia was formally introduced in 2000 in the *Australians Working Together* package, although moves towards system change had begun much earlier. The reform agenda 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. The reform agenda is extending across the income support system.

In 2002, the scope of welfare reform was extended under the *Australians Working Together* package to include improved services for very disadvantaged jobseekers including people with mental illness, such as those receiving Newstart Allowance (Incapacitated). This category includes people with a diagnosed mental illness but for whom the illness is not seen to be a permanent impairment. Additional funding was provided for the Personal Support Program to enable those most disadvantaged in the job market to have access to personalised, case-managed assistance.

The Government has sought to change the conditions of eligibility for the Disability Support Pension in a number of ways, including changes in the assessment arrangements of work capacity for Disability Support Pension claimants and those who are temporarily ill or injured. This change, introduced in September 2002, shifted the assessment of work capacity from the treating doctor to Centrelink staff. General practitioners are still required to report on the claimant's medical condition and the impact on the person's ability to function but Centrelink staff along with 'external experts' have responsibility for determining work capacity. FaCS consider the new assessment tool more appropriately addresses the person's abilities (FaCS, 2002).

Reducing the number of people making claims on the Disability Support Pension means that many people with a mental illness will only be eligible for Newstart Allowance which, even with a medical exemption, requires them to meet a number of mutual obligation requirements. 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 reduced eligibility for a range of State Government concessions.

In 2002, the Government drafted legislation which made eligibility for the Disability Pension more difficult by reducing the 'inability to work' test from 30 to 15 hours per week. In the original Bill, these changes were to apply to all new and existing recipients. This Bill was withdrawn and re-presented to the Senate with the proposed changes to apply only to new claimants from July 2003. The Family and Community Services Legislation Amendment (Disability Reform) Bill has subsequently been rejected twice by the Senate (Bills Digest No.125, 2002-03). Although this change has not yet been legislated, disability advocates believe it remains on the agenda. This legislative process has created considerable pressure for Disability Support Pension recipients and their carers, as well as those whose illness may require them to claim this payment in the future. As well as making it more difficult for those making initial claims for the Disability Support Pension by lowering the benchmark for incapacity to work, the proposed changes would decrease the opportunity for existing Pensioners to supplement their low income with some additional paid work when they are capable of doing so. The current penalties for working above the specified work hours are extremely harsh with payments suspended for up to two years.

### 3.4.2 Mutual obligation and breaching penalties

The methods to achieve compliance with the 'mutual obligation' agenda have been widely criticised. 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[8] 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 poor communications from Centrelink and administrative error are factors which might explain this. The subsequent independent review into breaches and penalties in the social security system (Pearce, Disney and

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[8] 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 now 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).

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. A Taskforce formed to review the social security penalty system is due to report to the relevant Ministers in April 2004.

# SECTION FOUR

## LIVING WITH SERIOUS MENTAL ILLNESS

### 4.1 Describing the illness

The burden of serious mental illness on the lives of those who experience it directly and those who love them is so heavy that it is sometimes difficult for people to see beyond it. Confronted with the debilitating effects of the illness, the stress of caring, and the lack of understanding of the mainstream community, those engaged in a daily struggle for survival rarely dare to wish for more than an alleviation of the symptoms.

The predominance of the illness is such that it is almost as if we lose the capacity to speculate how the lives of people with mental illness would be if they weren't also chronically poor and disadvantaged in purely social and economic ways. Would the experience of schizophrenia be different if, instead of the trauma of homelessness, people who are ill had housing they could rely on, housing which was affordable, near to services, and in which they had support to stabilise their health and live a fulfilling life? Would disorganised psychotic thoughts be so overwhelming if you weren't also under pressure to deal with Centrelink forms and the prospect of having your electricity disconnected? Is depressive illness less of a torture in the loneliness and squalor of substandard housing than it was in the confinement of a psychiatric institution?

The people with serious mental illness who were interviewed for this project were all experiencing a significant level of disability as a consequence of their illness. This disability disrupted all their hopes and relationships and deprived many of them of the opportunity to achieve common aspirations such as contributing to the community, having long-term relationships with their children, gaining employment and achieving home ownership. They are the uncelebrated veterans of years of battles with terror, despair, horrific or grandiose delusions, disorganisation and the side-effects of medication.

> *Well firstly I suffered from a little bit of depression before 12 years ago and then the onset of the main part of the mental illness was bipolar and I was very down for the last 12 years ... [A]nd over that 12-year period, I was pretty much heavily drugged and I couldn't do much at all. I was walking around a zombie basically. When I say '12 years' it doesn't sound like very long at all, but when I take 12 years in as many days, in as many hours, in as many minutes and seconds over a 12-year period – that is a real pain in the arse. (Leo, 37, schizo-affective disorder, North-West Region)*

> *I've spent three years in bed, three years in bed. I was knocked out cold. I'd be awake for about two hours a day and the rest of the time I was asleep. So I would just, when I got up I would just sort of clean up and cook tea and eat and go back to bed. Yes, for three years. (Loretta, 39, bipolar disorder, North-West Region)*

Participants were asked to talk about the impact of their illness on their lives. They described the psychoses, hallucinations, delusions, high levels of anxiety or overwhelming depression which they experienced over extended periods. They explained that these symptoms are often combined with extreme difficulty in organising themselves, remembering details and a lack of motivation even for simple things like meeting basic needs for food or hygiene. Some of them reported that the confusion of their thoughts made reading impossible.

> *When I was medicated, heavily medicated, you can't use your mind to think properly. You're alive but you're not alive, you can't plan and you can't think. You can only do short-term stuff. (Leo, 37, schizo-affective disorder, North-West Region)*
>
> *Well I have got psychosis. I hear voices, and I had a hysterectomy about 16 years ago and the chemical imbalance caused them to start and it nearly drives me crazy. It is just a screaming noise that goes louder and louder. So I have been in and out of hospital and have nearly been in every hospital there is to be, Hobart, Wynyard, Burnie, everywhere. (I've) tried every medication. And at the moment I am on another medication that seems to be helping me a little bit ... I mean I can put up with pain, I broke my arm, a gall bladder, a hysterectomy, but it's nothing like the pain I get in my head, because I hear these voices and they drive me mad. And I've had it for 15 years. (Celia, 55, schizophrenia, North-West Region)*
>
> *I have panic attacks too but sometimes with the medication I can get out and do things and feel confident but other times I get high and I just sit at the table and I can't do anything. You feel scared, you lie down and put your head on the pillow and you hear voices and you hear things you've done in the past and they're bagging you for everything and you end up screaming and shouting. (Danielle, 32, schizophrenia, South)*
>
> *I felt like I had nothing to offer anybody because of this damn thing. I was eighteen when I first started getting sick and it wasn't diagnosed until after I had my third baby, which was fifteen years ago. But about fourteen years of it were uncontrolled because of not being able to find the right medication, catch it at the right time, then not being able to tolerate the right medications and things like that. I ended up by just putting my hands up and I gave up and I spent a year in bed finally. And then finally this doctor gave me Lithium and I came down and I was treated for a mental illness after that. But up until then it was just, you know, you are just a loser basically, or a rebel or whatever it happened to be. A loser when you're depressed and a rebel when you're high. (Mandy, 39, bipolar disorder, South)*
>
> *I've been watched, I think I am being looked at. The common things of schizophrenia are, I think I am. I get thoughts in my head, I get messages taken out of my head. I just feel tired and with this condition it does leave my life social wise, it doesn't make me go out a great deal. I stay indoors. If I do go out, it has to be for a purpose. Yeah, I am on medication and that does help a bit, but, being the way I am for so long, it is pretty hard to get out of it. My mother and sister, they are not proud of my condition. It is a pity I turned out like this, but that's the way it goes. Ah, that's about it. (Henry, 51, schizophrenia, South)*

> *And then I felt something inside of me, I was getting scared and I couldn't understand why, and this night I broke down at work and one night I just, it just consumed me. I just got my blankets out of my room, and went on the beach and slept on the beach and ever since then everything went crazy. It stopped me from working and I couldn't work. I was too tired and I was too violent and I lost my car and my housing, my lady through it all, I was just unable to go back to work. I was in and out of psych centres all the time. (Neville, 51, schizophrenia and anxiety, North-West Region)*
>
> *You see it is a chicken and egg problem, alright? If I had a girlfriend I know I would work harder at looking after myself, looking after my house. When I live with people who, who like a clean house, right, I will raise my level because I can't, I can't do otherwise without letting them down. And when I am by myself I don't have any incentive, you know. And the thing is will I ever? Because who is going to want to live with somebody like me? And I don't feel confident about getting a woman that I would feel good with because of the state I am in. The point is that even when I am not feeling that bad I don't feel like I've got much to offer somebody. And yet if I don't find somebody I will never have anything to offer anybody. (John, 28, bipolar disorder, anxiety disorder and substance use disorder, North)*
>
> *I'd had jobs and stuff like that but after I got the mental illness I sort of took overdose after overdose. Couldn't handle living anymore. First relationship I had, that went downhill, second one went downhill, third one I had a child with a girl I was going out with. I just got sick of going to hospital all the time. It's not so bad now, but. It's mind over matter I think ... Yeah, bipolar you just get down and out, you don't want to get out of bed, don't want to do anything. Never want to clean up the house, anything like that. (Hugh, 40, bipolar disorder, South)*
>
> *I was diagnosed at 20 years and I'm 27 now. It's been a long few years. It's been pretty full on and shocking there for a few years until they got my medication right. It was about 12 months before I was diagnosed but all the signs kept coming. They diagnosed me with depression which was the wrong thing to diagnose because they put you on anti-depressants and they make you go up, with bipolar disorder. (Daisy, 27, bipolar disorder, North)*

### 4.2 The impact on carers and families

Twenty-six carers were interviewed in the course of this study. While 11 of the carers interviewed lived with the person for whom they provided care, the pattern of care described were those defined as informal care (AIHW, 2003:66). In addition to providing accommodation at times, the type of assistance given most commonly cited by the carers interviewed were: the provision of food, clothing, transport, paying for medications and advocating for their relative with services. The majority of the carers were the parent of the person they care for.

The impact on a family when a family member develops a serious mental illness is, without exception, profound. The combined effects of deinstitutionalisation and inadequate community support have, in many cases, thrown much of the care of those with mental illness onto their families. In spite of carers feeling locked out of, and discounted by the mental health system (MHCA, 2000), and in spite of operating with little professional support, they are called upon to provide substantial housing, financial and advocacy support. The tensions this creates for families are clearly evident in a range of ways.

When questioned about their reasons for being carers, people in this 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. This mixture of caring, because they do care and because they perceive that no one else does, is an exhausting emotional cocktail.

> *I feel inadequate a lot of the time; I feel I haven't done enough for him. I mean if I could pick Keith up and nurture him again, I would leave home if I thought it was going to work well. Sometimes I think it would be so easy just to leave and get a home and just have a normal home and get the family to understand him and love him for like who he is. No sickness, nothing. Just so when I'm gone he would be right, he would have this feeling of worth, stability perhaps. Even though he's got an unstable life probably. And, this is airy fairy, I know, to try and give him that stability so he can live the rest of his life feeling good. I don't know, I just feel inadequate. I feel I have let him down … It is just devastating. (Bronwyn, 56, son Keith, 33, with schizophrenia, South)*

> *Devastating. Devastating I think. And also I think that you re-run through and think 'if I had done this differently'... I think it is sad that you have to live with regrets as well. I think it is very hard the way you constantly have to think, that it [son's quality of life] might be OK, but it won't be OK for very long. That this is just how it is going to be and it won't be any better. It's very hard. (Meredith, 53, son Donald, 23, with schizophrenia, South)*

> *Yes, it is constant. It's that constant draining that's there all the time. You are always worried, yeah, it's just there permanently, and you never get a break from it. It comes between every relationship in your life, it stands between you and your partner, and it has altered my relationship with my other son; he has been affected, his life's been affected by it. My friends, because you become totally obsessive about them and their illness, that you cut [friends] out, well you don't have time for other friends. (Jenny, 48, son Ben, 19, with schizophrenia, South)*

> *Oh, it created years of uncertainty, we would never say we could go away, or do whatever we wanted to do, because Phil was always there. That was all. We had to be there for Phil ... not that we have any, any regrets about it, we were pleased we were, but it was always there. Well, we aren't unhappy about what we have done. We are happy; we enjoy our lives as I say. But there was always that 'where was he?', 'How was he?' And also our expectations of what Phil was going to be because he was a good student, he was brilliant with his study, he had it in front of him, and he lost it all. (Brendan, 69, son Phil, 39, with schizo-affective disorder and bipolar disorder, North-West Region)*

While the people with mental illness who were interviewed had typically experienced significant breaches in their family relationships, the importance of family and carers was substantial. For those people who have managed to maintain relationships with parents or siblings through years of illness, the security of knowing they have someone to turn to in a crisis, or when there was no response to their needs from community and health services, makes an enormous difference.

> *I just have a sister, who I love very deeply, my two brothers I don't really see that much … But my sister I see heaps. She is my carer. My pension goes into her bank account and she organises my money, my Hydro and when it comes out and my rent and that sort of stuff and she pays my bills and she gives me spending money and all that type of stuff. (George, 38, schizo-affective disorder, South)*

> *I'm one of the lucky ones, though. I've got Mum and Dad and if I get in trouble I know they'll pull me out. I know I have that back-up. (Daisy, 27, bipolar disorder, North)*

# SECTION FIVE

## AFFORDING THE ESSENTIALS OF LIFE

Of the people with serious mental illness interviewed in the course of this project, all but one was dependent on Commonwealth pensions and benefits for their main source of income. Eighty five per cent of the interviewees were in receipt of the Disability Support Pension, with a further 14% dependent on the lower income of Newstart Allowance but receiving exemption from their Activity Test requirements on the basis of illness.

Participants were asked to talk about how living on a very low income affected their mental health. Everyone reported feeling increased anxiety and stress as their money ran out each fortnight and the bills came in.

> *Oh, I get very anxious, yeah, just worrying where your next cent is going to come from before you get paid again…It does impact on your mental health when you don't know where you are going to get the next bit of milk from. (Alison, 37, schizo-affective disorder, South)*
>
> *[Poverty] adds to the depression ... it just adds to the depressive side of it and you can't, you can't see anyway out of it, because no matter where you look, I can't see my way out of it. Am I going to live like this for the next 20 years of my life? I don't want to. What's the use of that? (Denise, 52, bipolar disorder and anxiety, North)*
>
> *I find anxiety to do with finances affects me a lot and really gets me down and I have a friend from work who has helped me out at times, but to go and have to ask family members, 'Can you lend me $20 because I've got no food til Thursday?' is really, really difficult. It's just shame and embarrassment and, oh, it's just horrible. (Dawn, 45, depression and bipolar disorder, North)*

The participants were asked how they managed their finances and specifically how they prioritised their expenditure. As the following comments indicate, for the majority, the fortnightly payment barely covered the essentials.

> *I find that on unemployment benefits, it just covers you enough to, you know, pay for the Hydro and you know, buy your food and that, it's just enough or sometimes it's not enough. (Belinda, 36, bipolar disorder, North-West Region)*
>
> *When you had the heater on you'd run up the power so much, you would have to turn it off and you'd sit down and freeze because you couldn't afford to have it running. (Neville, 51, schizophrenia and anxiety, North-West Region)*
>
> *You just do the best you can, with what you can. I mean you're limited as it is, so like my car – it's the only form of transport I have got and it's a bomb but that's the only*

> *form of transport I'm going to get. If I didn't have my car I might as well be dead. I think because I'm on the dole, I've got nothing to look forward to. Well I get $450 a fortnight, $160 of that goes in my rent. Yeah, you add a car on top of that with petrol, just this fortnight I bought two new tyres. You wouldn't believe what sort of food you live on; tuna and beans, for what was it 3 or 4 months? Every day, tuna and beans. (Alex, 50, bipolar disorder, North-West Region)*

> *If I was living by myself I would definitely have to be thinking, cold water showers. I wouldn't be able to afford any life [laughter] but it's true! You have to be thinking about whether you can afford coffee or not, which most people don't have to think about. (Leo, 37, schizo-affective disorder, North-West Region)*

> *Where I am now [boarding house], I get meals, which is good. When I was living with Pete it was not too good. I always run out of money about 3 days before payday. I've worked it out. The pay is not enough to live on. We need about another $30 a week. When you run out you spend those last few days eating whatever you've got left - usually it's bread or noodles. (Simon, 28, schizophrenia, North)*

> *It sounds like a terrible thing to say but I had to wait until my mother died, a couple of years, before I could get some bedclothes. I slept in a sleeping bag for a couple of years on a mattress. But now I've got a few bits of furniture from that, but also I use the tip shop in South Hobart. And there's been a few old chairs and things left outside the flat, which I've salvaged from time to time, but basically I've never bought much furniture at all. (Robert, 53, anxiety and depression, South)*

But many like Moira, were defiant in the face of such bleak hardship:

> *It's been real cold just lately and my heater's broken so I leave the oven door open. It's just too cold so I said to my budgies, 'Birds! Tonight we will not suffer!' (Moira, 31, bipolar disorder, North)*

### 5.1 Housing: Access to appropriate, secure and supported accommodation

Anglicare's interviews with key stakeholders and service providers in this area consistently identified lack of appropriate housing options for people with serious mental illness as one of the most critical issues for this group across the State. This is strongly supported by the accommodation histories of the majority of participants in Anglicare's research which illustrate the transient and insecure nature of housing for many people with mental illness. Participants were living in a range of tenure types including public housing, private rental, crisis accommodation and boarding houses. Many participants described feeling isolated and insecure, a lack of safety and social discrimination which were stressors exacerbating their mental illness and often precipitated an episode of acute illness, resulting in hospitalisation.

It is difficult to measure precisely the level of unmet need for accommodation types for people with serious mental illness throughout the State (DHHS, 2003). This is largely due to problems in identifying the size of the population group, lack of consistent data collection in existing services and the highly transient lifestyle of many people with serious mental illness. The following issues are indicative of the need for increased housing options which include a range of short, medium and long term tenancies with corresponding capacity to maximise independence, choice, security of tenure and adequate provision of support. The need for appropriate and regular support to find and maintain appropriate tenancies is highlighted in the following examples.

> *The whole thing with housing too, I mean they need independent housing, but they need help with, oh I don't know, there is a whole list of stuff they need help with ... And keeping him at home isn't the answer either, because you imagine it's even harder for him, he is 19 now, for him to be out there on his own. The longer you keep him at home the longer you are making decisions for them and doing things for them and all the rest of it. Whereas they really need to be independent in their own way. (Jenny, 48, son Ben, 19, with schizophrenia, South)*

> *My son is actually in hospital now. They've put him into a housing commission unit because they tried him in all these hostels around the place. [Boarding house], that wasn't too good for him, but you know, and when the [crisis accommodation] was there, and all the hostels and he has been asked to leave all of them. So there is absolutely nowhere. I suppose he should be out at [residential care unit], but there's no room. So they have put him in a unit on his own and he is very bad, he is getting a lot worse. There's a nurse who goes and sees that he takes his medication, and sometimes he slips up and doesn't actually put them in his mouth. And now, 'everyone is conspiring against him'. He is a lot worse, you can't talk to him about anything or anybody you know, they're conspiring against him. And now he is back in hospital but he will have to go back there [to his unit]. But he's not looked after you see, and there is terrific isolation up there. And that's what I am saying, if he was in a situation where he was being cared for, that would be paradise. (Win, 70, son Adrian, 30, with paranoid schizophrenia, North)*

### 5.1.1 Insecure housing or iterative homelessness

Many participants in this research live in a cycle of homelessness with repeated movements through a range of accommodation. The average number of moves for all participants with mental illnesses was 4 moves in the previous 5 years. Twenty of the 52 participants with mental illness (almost 40%) had moved five times or more in the past five years, with one person moving 14 times.

A number of research participants talked about the benefits they saw in hostel or boarding house accommodation. This was often the only way they were able to ensure that their basic needs such as regular meals, personal hygiene and sleep were met. The experiences described below by two young men, both in their 20's and both with schizophrenia, illustrate clearly the pattern of transient accommodation common to people with serious mental illness. As in both these cases, the marginal accommodation available to this group exposes them to risk factors which erode their self confidence and set off episodes of illness.

> *I'm living in [a boarding house]. It's good. It's warm and you get your food. I was living there before but then a bloke that lived there asked me if I wanted to move*

> *into a flat with him. I said OK but I shouldn't have. It was terrible. He was OK to begin with but then he went mental and he couldn't sleep and he kept banging on my door and waking me up. He never used to pay his part of the bills either and he expected me to buy all the food. In the end I couldn't sleep either. So I was really glad when I could go back to [the boarding house] but I still can't sleep because of what happened when I was living with Pete. I used to live with my Gran but after she died my uncle decided he wanted to put tenants in the house and make some money so I had to leave. I moved into my car and I lived in it for a few months until the police found me one day. They were good - they got me into [the boarding house]. (Kim, 28, schizophrenia, North)*

> *The [crisis accommodation] is alright. I came here when I came out of detox because I had nowhere to go. Before I went into detox I was living in the caravan park. I'd got really sick and I was in hospital for a long time and when I got out I had nowhere to go. I wandered around for a while and then I ended up in the caravan park because it was all I could afford. But everyone there was into drugs and drinking and I got into it too because I wanted to fit in. But I've got out now. [Crisis accommodation] is all right but the rooms are real small and I stay inside all day because if I go out everyone I meet wants to talk about drugs. (Justin, 26, schizophrenia, North).*

### 5.1.2 Public housing options

In acknowledgment of the particular and chronic housing needs of this group, current national housing policy stipulates that public housing is prioritised for clients with high and complex needs. Although the existence of a serious mental illness may assist some people to be placed in the Category One high priority group for public housing, it does not ensure it. A number of the participants in this research reported long waits for housing.

> *I'm at home now but I was in hospital for about three months ... and I was sick for a fair while. I'm still just getting better now. Yeah, I moved home but my parents are moving out. They're going to be gone in about three months so I'm hoping to get a place in the next three months. I lived at [Mental Health Service (MHS) inpatient service] for a while, that's near the hospital. I stayed there for a while and then I lived at a hostel and then I went up to [MHS residential rehab/respite service]. I left there. I used to get pretty angry and I was sick and things were a bit worrying for a time but, yeah, I'm getting better now and hopefully I'll get a housing commission house in the next three months, hopefully. Yeah, I think I can [live on my own]. (Jarrod, 19, schizophrenia, South)*

> *I'm living in a shed at the back of [suburb]. I've got a shed up the back there. I'm waiting for housing. I've been waiting for about a year, just trying to be patient. (Russell, 42, depression, South)*

People with serious mental illnesses can be vulnerable to victimisation by other people in an unsupported environment. Findings from Anglicare's research indicate that a substantial minority of participants feel unsafe in broadacre public housing estates. The following examples highlight some of the problems experienced by a number of participants. Neville has schizophrenia and an anxiety disorder and is currently living in crisis accommodation.

> *I lived in a Housing unit in [city] and I had a lot of people using me, borrowing money off me and not paying me back. They was drug addicts, shooting up and smoking dope and cones and all that stuff and I just wanted a unit to be by myself because I couldn't face crowds or anything like that. I was too paranoid. And I just didn't like living in there and I am never ever going to get another Housing unit. I'd rather sleep in the street than get one of them because you get different people and they move in but they haven't got an illness, and they think you should be just normal like them. 'Come down the pub Neville', 'Come over and move the car'. I can't do those things so I get sick and end up in the psych ward. So I was very unhappy living in Housing. (Neville, 51, schizophrenia and anxiety, North-West Region)*

> *I applied for Housing, I went up to [Housing Tasmania broadacre estate] and it was nightmarish. I had domestic violence on one side, and the actual house wasn't that bad, it was the environment. The welfare dependency, domestic violence, the drugs, the burglary, all this sort of thing and I thought I would die up there. I would just get beaten to a pulp. (John, 28, bipolar disorder, anxiety disorder and substance use disorder North)*

> *I got broken into once, got bashed about twice, got the car stolen once from my driveway. I just don't like being there. I'm on the Category One transfer list but nothing's happening. I just don't like being there so I just stay there I suppose. Can't do anything about it. (Hugh, 40, bipolar disorder, South)*

> *I can't go into public housing, there's too much drug abuse and that puts me in the areas of drug abuse and alcohol abuse. And if I go into them areas I get sick as what they're at. So I basically shifted back to me mothers'. And to rent to get away from those sort of areas, ah, I basically can't afford to rent because the rent's too high. A couple of hundred or $220 a fortnight is too much. I can't afford to live like that. (Les, 41, schizophrenia, South)*

In the following example, Gavin describes his traumatic experience of living in a Housing Tasmania unit without appropriate support. Trying to deal with long-running problems with neighbours without any support exacerbated his problems with anxiety and substance use and resulted in him being charged by the police and experiencing a major relapse. A substantial period in hospital was followed by a long stay in mental health service rehabilitation accommodation.

> *I've had previous Housing Department places and even though doctors present Housing with your problems they seem to throw you into a bunch of units. And I found my nerves ended up going, so I ended up in hospital because I'm pretty much on my own. It was a vicious circle for a long time. The original doctor wanted me to go into a quiet area. So it's taken a long, long time and it's also taken a lot out of me, a lot of trips to the hospital, a lot of pain and suffering that I probably need not have gone through. Yeah, I mean I'm usually one to hold things more in and the last place I was at I actually got charged by police. I just couldn't handle things anymore*

> *… Oh yeah, especially when you've got a lot of riff-raff. If they've got an inkling that you're anywhere amongst the mental health profession, the old names come out, and in their imagination you're swinging from the chandelier and stuff. You get harassed a fair bit. I'm probably garbled, but I ended up breaking down too. At the moment I'm at [MHS residential respite/rehab service] for rehabilitation…and we think I'm just about to secure a Housing Department unit over at [suburb]. But unfortunately from previous experiences at the last unit at [Housing Tasmania broadacre estate] I was repeatedly broken into and anything they didn't steal they trashed. So I'm trying to look at ways to rebuild but on a low income it's hard enough to make ends meet normally but trying to rebuild, to find the things you need going into a unit - it's scary, you know. And you know what stress can bring on. [I lost] the lot the second time it happened. It made me lose heart, really lose heart for a long time. It's hard replacing your things. (Gavin, 44, anxiety disorder, South)*

### 5.1.3 Renting in the private market

The current housing boom in Tasmania has dramatically reduced the amount of affordable private rental accommodation in the State. With 61% of Tasmanians in the private rental market in 'housing stress', housing affordability is a critical problem for low income earners (Cameron, 2002). Low income earners are significantly disadvantaged in a housing market in which rental prices have increased between 16 and 79% across housing types (Madden, 2004; Colony 47, 2003). The budgetary crises caused by these increases are revealed in a snapshot survey of people seeking assistance from Tasmanian Emergency Relief services in 2003 which found that rent payments were a significant form of financial stress for people seeking relief. Almost 40% of the private renters surveyed reported experiencing an increase in their rent in the previous year, on average by $30 per fortnight (Madden, 2004). For people with disabilities and chronic illness, living on low fixed incomes with high health costs, housing affordability is a constant concern. As one participant describes, the pattern of homelessness is often determined by inadequate income:

> *I live with my mother. I go there when I've got too many bills. I go to my mother's, pay all my bills off and then I go back and rent again. Ah, the rent's too high and it's hard to get into houses or where you want to go anyway. I don't want to go to [Housing Tasmania broadacre estates]. I'd rather be in the city where I can come here [Non-government (NGO) mental health service] easier and I can go to the doctor's easier. I can't afford to rent out in other suburbs. It's too far out; it's too costly for fuel. It's just another cost that you can't afford. (Les, 41, schizophrenia, South)*

The nature of mental illness means that reducing the costs of private rental by sharing accommodation can be difficult. Difficulties managing sleep disruptions and the symptoms of the illness can be exacerbated by the stress of managing share-house relationships and finances. Half the people with mental illness interviewed in this research were living alone.

> *I was living with some friends, then they decided to throw my stuff out and then I went to my sister's, then I went to [crisis accommodation] for a night and [police constable] organised to ring the Housing and they said 'Well you know, as long as*

> *you get well George, you keep your place. You are not going to do anything stupid no more, we will give you a house in a week to you'. So I got it, up in [Street], just up the road. (George, 38, schizo-affective disorder, South)*
>
> *Now, he doesn't have any friends of his own, that's a bit of a problem. He did move out into a flat with another chap to get away, to try and have his own friends. Phil did get up of a night and sort of not play up, but go to the fridge and have a drink and the bloke didn't like him walking about and making a noise and so it didn't work. So he came home to us again. (Brendan, 69, son Phil, 39, with schizo-affective disorder and bipolar disorder, North-West Region)*

In addition to the problem of affordability, research conducted by Anglicare in 2002 identified the multiple barriers to the private rental market experienced by socially disadvantaged groups such as people with disabilities (Cameron, 2002). Those people living with mental illness are highly susceptible to discrimination by landlords and real estate agents, which often results in their exclusion from this form of housing tenure entirely. The participants in the current research confirmed this to be an ongoing concern.

> *And then trying to find housing. I'm on the private market and I looked at one house and it was through a friend and she said to them I feel that I have to tell you that this person's got bipolar and immediately when I rang them they said, 'I just really don't think that we can help you. I just don't know what we do for you'. And I thought, 'Well you could just rent me your house'… And then we are locked out really because public housing is just so, so, so hard to get. We ended up hanging out, trying to stay at my parents' place, which didn't work and then ended up in my car. (Mandy, 39, bipolar disorder, South)*
>
> *He has lived in the parks on the streets. Anglicare gave him some money to get into a flat but nobody would take him. He couldn't get the accommodation, so nobody would take him, so that's what he done, he just lived on the streets. Or he would stay with me for 3 or 4 weeks and lose the plot and then off he would go, and walk everywhere, walk. So, and not having anywhere for him to be stable, to live, like not being able to get him accommodation ... Even the probation officer took him around to accommodation and nobody wanted to put him in because of his problem. Nobody wanted to give in. It was alright if I went guarantor for it, but I couldn't afford to pay his light bill, his rent. (Pauline, 62, son Jock, 34, with schizophrenia, North)*
>
> *They just have to meet Ben, and he hasn't got a hope of getting anything privately, unless we went guarantor and even then I doubt it. Once they meet Ben they soon twig that he's, I mean he presents fairly well, but he hasn't got a hope of getting anything privately. And you know the biggest issue, too, once they do get something, is helping them maintain it. (Jenny, 48, son Ben, 19, with schizophrenia, South)*
>
> *It's so hard. If people see a slight personality variance, people hone in on that. One poor person [fellow member of a support group] had to write an affidavit that, if she gets violent and that, she can be evicted straight away, and she hasn't got that, she is very, very shy, and very, very depressed. (Bruce, 61, depression, South)*

> *And, that's what I am, you know, I am a mundane schizophrenic. But looking for housing, if you dare tell them that you have got a mental illness of some sort you won't get the house. So when dealing with people in positions of authority you do definitely cop it. (Clare, 35, schizo-affective disorder, South)*

Some people with serious mental illness can function effectively in the private rental market and sustain long-term tenancies. However, in some cases, people with serious mental illness can be challenging tenants and without adequate support and assistance it may be extremely difficult for them to maintain a tenancy. Some people have difficulties with basic life skills such as housekeeping and personal hygiene. People with schizophrenia and bipolar disorder may have problems managing money. In a manic phase, it is not uncommon for people to spend all their money in a spending spree, as exemplified in the following narratives.

> *I'm really lucky. I've been living in my place for 9 years and it's nice. But now I've been given a notice and I'm going to be evicted and I don't know what I'll do. I think what happened is I was sick before and I was really racing around and I didn't pay my rent. I think that's what happened. I've worked it out though - I've paid $32,000 in rent in the time I've been there. And now they're just kicking me out. (Moira, 31, bipolar disorder, North)*

> *I got evicted last year because I didn't pay my rent. I'd got sick. I spent all my money shopping, I guess. I think that's what happened. Anyway I had to leave so I had to move in with my mother. She lives in a little two-bedroom Housing unit so it was really hard. I had furniture and stuff that I'd bought when I was working and I had to take it all with me to Mum's. It was really hard to find a new place because I didn't have good references from my landlord. (Katrina, 32, bipolar disorder and obsessive compulsive disorder, North)*

> *My landlady is in the flat behind. She's quite supportive. I was friends with her daughter so that's how I got the house. Now she knows that I have a problem with maintaining my house properly, she knows also that I'm in a lot of pain and discomfort mentally and physically a lot of the time. I have had problems, not that I don't take paying my rent seriously, it's just a lack, a total lack of organisation. Occasionally the problem being, occasionally I would justify, I would use the discomfort I was in to justify spending my money on something for me which was, often, not necessarily, but often on drugs. (John, 28, with bipolar disorder, anxiety disorder and substance use disorder, North)*

People experiencing episodes of psychosis may damage private property or abandon tenancies as a consequence of the illness.

> *But the last time I rented in [city], I had a bit of trouble I had to go into hospital, I smashed a few windows in the place which I rented so I think it would be hard for me to rent on my own again.  It was something that I wasn't in control of. (Belinda, 36, bipolar disorder, North-West Region)*

> *Well the last time, it was suggested that my son go to [crisis accommodation]*

> *instead of hospital. He did agree at that stage. And that happened many times; in, and out to me, and then to a flat. John would go and get a flat somewhere and then walk out and leave it and everything in it. I'd give him things and he'd just walk out. (Geraldine, 55, son John, 34, with schizophrenia, South)*

Research participants who had private rental housing with sympathetic and understanding landlords were much more likely to have maintained their tenure over a longer period and feel more secure about their lives. However, for many others the expensive and competitive market context and the nature of mental illness made them particularly vulnerable to exploitation by unscrupulous landlords. This situation often leads to people being forced to move on a regular basis and to live in inappropriate or substandard accommodation. As previous Anglicare research found, the most vulnerable groups in the private rental market are the least likely to know their rights as tenants or to pursue them, if they do know them (Cameron, 2002). Richard, for example, has maintained his tenancy for 12 years. Seven years into the tenancy he accepted a drop in rent in exchange for an agreement that repairs to his flat not be done, an agreement contrary to the terms of the Residential Tenancies Act. Five years after this agreement he is scared to negotiate for further essential repairs because of his fears of a consequent rental increase.

> *[I live] in rental, in private rental. And God lives there. I got things both good and bad. A lot of times I have to fix up a lot of things by myself because I'm too scared to ask, like I got my rent reduced by $20 about 5 years ago but everyone comes up and says how dirty the place is and how dirty the carpets are but I read in the Bible how I'll be a repairer of wells and stuff like that. So just lately I've preferred to do my own stuff like coating the wall with putty, but a few things like light switches and stuff like that I can't fix. I don't know whether to try to fix them because I think it's electrical and I don't know whether it's a bit dangerous but I feel like I should because that's what the Bible says. I don't know what extreme to take it to. For $20 I don't know, it seems like a lot of money to me. (Richard, 40, schizo-affective disorder, South)*

> *I'm renting a place. It's really hard to find places. We had to move out of our place suddenly so I saw an ad and I took this place in … St. Ron [NGO housing support worker] said, 'Don't do it, it'll just be trouble' but I said 'Nah I have to'. So I took it and we moved all our stuff in and when we got there, we'd been there one day and I was hanging the washing out. The place didn't have a clothesline so I was putting the kid's clothes on chairs and the landlord said 'You can't put your washing out like that where people can see it' and I said 'I have to, I haven't got a clothesline', so he kicked us out! Just like that! So we had to move again. Ron said 'I told you it would be trouble'. (Rex, 35, depression and anxiety, North)*

### 5.1.4 When living with family is inappropriate

A further concern is the number of adults with serious mental illness who are living with family members in circumstances that are unsuitable. A number of the carers who participated in Anglicare's research recounted experiences in which their adult children were forced to live with them because there was nowhere else for them to go. This often resulted in increased stress and anxiety for the parent, particularly in cases where the adult child was inclined to violent, threatening or otherwise frightening behaviour when unwell. Consistent with the findings of the LPDS (Jablensky et al, 1999), most of the carers living with adult sons or daughters with mental illness were women, most often their mothers. In a number of cases, the carers reported feeling frightened and without support to manage the situation.

> *He is about 6 foot 2, right, so he pinned me against the wall like that and I am black and blue from head to toe, and I accepted that… And it's not very nice but that's what you live with. And then I get bailed up in my own home and he sat at the door and he is so big and he sat like this up in the doorway and then you get locked in a room if you have got a key. You have to hide all keys or otherwise he padlocked himself in the room. How do you feel in your own home being locked outside for about 3 or 4 hours or so? That's what you've got to live with. (Betty, 53, son Mike, 26, with schizophrenia, South)*

Caring for a family member with a serious mental illness can also have a destructive and distressing effect on other family members. In the following example, the mother of a young man with schizophrenia, now in his early 20s, describes the painful choices she had to make about her son living with the family.

> *We hadn't ever encouraged him to come back to our house because his illness, his imaginings, that he really thinks are absolutely part of life, is all to do with vampires and creatures of the night and all that dark side ... And he is paranoid, and he's into lots of blood letting and cutting, and blood and this is all part of his world. He cuts himself all the time and he was getting pictures of the people cutting themselves and people sucking blood and sticking them up all over the bedroom. And at the time his younger brother and sister were much younger than him and we were really concerned about the other children having to live with this. So we didn't encourage him to come home. And he, he has knife collections, lots of knives, and it is all to protect himself and he has knives to protect himself and to protect us. You know, so it is all, it is rather a concern when you have got younger children. (Meredith, 53, son Donald, 23, with schizophrenia, South).*

In another case, a 16-year-old in a psychotic state was living with his elderly grandmother for a period of time because he was exhibiting violent behaviour towards his mother. This situation was deeply distressing for his mother as she describes:

> *He was living with her for 4 months. That was fine, but I always used to think 'Well this is crazy, there's an 80-year-old lady looking after a psychotic teenager'…Yeah, the only reason I was at risk was because I'd reached frantic point and I have been trying to persuade him to see a doctor in the previous 2 weeks. And I had been pushing OK? And you can't push a psychotic. But I had been pushing and I knew that I was pushing too hard and he rebelled ... and so he attacked me. (Emma, 49, son Angus, 18, with schizophrenia, North)*

The findings of this research demonstrate the many problems and barriers encountered by people with serious mental illness in seeking the type of accommodation that meets their needs. 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. The experiences described here highlight the need for a range of appropriately supported housing options with an emphasis on long-term tenancy to maximise security and stability. Research shows strongly that this is the most critical and effective way to prevent repeated and prolonged hospitalisations that are both detrimental to the person with mental illness and extremely costly to the community (Harvey et al, 2002; O'Brien et al, 2002; Robinson, 2003).

### 5.2 Food insecurity

> *I'm on the pension, the invalid pension, and he's on a carer's pension, which is not much, the carer's pension. We don't allow ourselves enough meat, but we try to eat meat once or twice a week or fortnight, which is you know, pay day. We are waiting for pay day now … and it's really hard. When I was in hospital I thought it was marvellous because I had food every meal. And they used to bring me plates of fruit all chopped up. I thought I was in heaven. (Ainsley, 56, schizophrenia, North)*

Food insecurity was a recurrent theme in all focus groups around the State. The majority of participants experienced anxiety about having sufficient food to last the fortnight. Similarly, reliance on Emergency Relief agencies for food was a common experience. Some participants reported being dependent on the additional food supplied by carers. This was confirmed by the carers who reported that supplementing food for their family member was a constant and often quite costly necessity. A majority of the participants in this research told Anglicare researchers of regular food shortages they were experiencing.

A number of interview participants described their reliance on the free day-old bread distribution, which is coordinated by charities. Others had found other sources of cheap or free food, but the following comment from Bruce encapsulates the detrimental effects of this 'scavenging' for food.

> *I find it really demeaning that ultimately I am scavenging for food at my age. And I find it mentally very hard to cope with, but I can't, like I wouldn't be able to afford half the things. And I do know of a couple of restaurants who have got bain maries and at the end of the day I'll visit them and I will get their leftovers and that's how I survive. But I probably only have fresh meat, which I don't really mind, once a week. (Bruce, 61, depression, South)*

> *Donald doesn't cook. I actually said to him recently, 'Have you ever cooked anything since you went into the flat?' And he just sat there and he thought, 'No' he said, 'No we haven't'. They live on bread they get from [a charity], they go there and get the free bread, and if you go to the [Bakery] at 2.00am they put out the pastries very cheaply from the day before, and they take those home. So that's what they live on. (Meredith, 53, son Donald, 23, with schizophrenia, South)*

> *Every second week you run out, you get low on food because you only can afford to buy for the week. And well, there's petrol to get here, and you've got to have petrol to get to [NGO mental health service] every day, and you've got to go to the doctor and things like that. So I reckon food's only, well I reckon, food's only designed for the rich. Food's probably the dearest item. It's dearer than Hydro and Telecom, I reckon it is. (Les, 41, schizophrenia, South)*

> *I mean it got to the stage where I decided I wouldn't have breakfast and I wouldn't have lunch, I did eat at night ... But after a while I got really ill on that. (Robert, 53, anxiety and depression, South)*

Participants also talked about drinking large quantities of tea and coffee when they were experiencing food shortages in order to make their stomachs feel full.

### 5.2.1 Reliance on Emergency Relief

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[9].

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). While researchers suggest that this finding may be distorted by the fact that ER support is given as food, the 2004 survey found that 59% of respondents had gone without meals due to a shortage of money in the past year.

Anglicare's 2004 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).

The experience of hunger and the inability to afford food is the most confronting face of poverty in our community for both service providers and those in crisis. Most ER clients state that they feel embarrassed or uncomfortable about using the services and report feeling humiliated by having to ask for help from a charity (Wolstenholme, 1998). Nonetheless, for the majority of participants in this study, Emergency Relief is often their only option.

> *[The pension] only stretches for the weekend after you get paid and then you have got none. It's so meagre. Then I go to the [ER provider] like everyone else does. (Alison, 37, schizo-affective disorder, South)*

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[9] The following is a list of what can be purchased from a Tasmanian metropolitan supermarket for $29 in April 2004: 1 x 375g Vita Brits; 1 loaf home brand bread; 1 x 150 home brand tea bags; 1 x 450g home brand jam; 1 x 420g can baked beans; 1 x 200ml shampoo; 1 packet plain beef sausages; 2 x 170g Heinz toddler food; 3 bananas; 2 kg potatoes; and 1 x 500g home brand margarine.

> *I have had help from [ER provider] twice. Oh, over the last twelve months. Yeah. I don't really like asking for it. And I have had a lot of help from my parents as well. (David, 38, depression, North)*

### 5.2.2 Reliance on carers

Both individuals with mental health problems and carers described a pattern of reliance on carers for the subsidisation of food costs. All the carers interviewed in this research were involved in regular provision of food for their family member, 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[10] (Madden, 2004). The impact of the subsidisation of an ill family member's costs on the budgets of carers is further discussed in Section 10.

> *When I used to rent out [suburb] I used to buy enough food that would last out the week and my mother would supply the rest of the food. (Les, 41, schizophrenia, South)*

> *And there are times at the end of the fortnight where we literally don't have anything to make dinner with. We don't have a stocked cupboard or anything like that. I don't, I can't afford to buy meat. Oh, I go to my Mum's and Dad's once a fortnight for a meal and that's the only time in a fortnight that we eat meat and that's been going on for 2 years, 3 years. (Dawn, 45, depression and bipolar disorder, North)*

> *Yeah. I've been to the Salvation Army and get help and otherwise, well yeah. I've got a really good family and they'd help me if I was down but you can only ask them so many times and it seems like every second week I'm short. I would rather go and ask the family but you can't ask every week. (Vince, 56, anxiety and depression, South)*

### 5.2.3 Diet managed with support of community service agencies

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

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[10] When looking at who had been forced to repeatedly access ER the survey found that people on the Disability Support Pension due to a psychiatric disability (69%) or those who had someone in their household experiencing a mental illness (62%) were far more likely than other ER clients (56%) to have accessed ER two or more times in the past year (Madden, 2004: unpublished data).

> *I cook for myself now and also receive Meals on Wheels three times a week through the people at the day care centre. They come three times a week which is very helpful. There was a stage when I would just eat noodles and I became quite sick. It's cost and the motivation. (Anita, 39, depression and bipolar disorder, North-West Region)*

> *I have lunch at (NGO mental health service) on Tuesdays and Thursdays and at (NGO mental health service) on Wednesdays and the other days I have lunch at (NGO community service).* [On weekends I eat] *Nothing. On Sunday I go to my church and they have morning tea and I eat that. (Ross, 45, schizophrenia, South)*

### 5.3 The cost of 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). Participants in this research raised similar concerns about clothing affordability. They reported not being able to afford new clothing and having a lack of warm clothes for the winter.

> *I haven't bought clothes in 5 years. These clothes are 5 years old. Suits. I need a pair of socks, I think. What I wear is comfortable but it's not warm. But it will have to do. I've got to save $50 [a fortnight] for the next 6 months [repaying Centrelink advance payment]. How can I afford clothes? (Alex, 50, bipolar disorder, North-West Region)*

> *I haven't had anything new in seven years. (David, 38, depression, North)*

> *This is my winter outfit. This is what I wear every day I go out, every day I come here, every day I go to [volunteer work] which is where I work, this is what I wear. This is op-shop top, op shop pants. (Dawn, 45, depression and bipolar disorder, North)*

> *Yes, well I just can't afford new ones [clothes]. I have to just go without, just go without basically. Maybe I might be able to save a bit of money and get something but I don't know, I just can't afford it. After a few weeks saving I could maybe get something special but most of it is second hand. I would love to be able to go home and throw the lot out. I know there are these jackets they've got, you know, they have in the shops, you know cheap fur jackets that, I can't, I can't afford that. (Rosemary, 53, schizo-affective disorder, North)*

Moreover, the issue of adequate clothing raises specific concerns for people with serious mental illness. The consequences of manic spending episodes, dramatic weight changes due to medication and depression and the symptoms of their illness creates particular problems for this group. Some participants of this research had collections of inappropriately sized and styled clothes accumulated during periods when they were experiencing manic symptoms and spending wildly and some had had the experience of giving all their personal possessions, including clothes, away.

> *I have lots of clothes, heaps of them, because when last year when I was high I would go shopping but they're not necessarily the right clothes. I don't have a coat. All I have is this, and it's not a coat it's a shirt. I am cold actually. (Katrina, 32, bipolar disorder and obsessive-compulsive disorder, North)*

> *I find it all so difficult. What happens I find with your medication is you go and get a pair of jeans and your weight fluctuates and you're gone and you've got to wait for ages ... and I mean that's why I've got trackies on today, but tracksuits are viable things. (Gavin, 44, anxiety, South)*

In the course of the interviews, conducted through winter 2003, participants were asked if they had a second set of clothing in addition to those they were wearing, including a second pair of shoes and a warm coat. While most reported that they had a number of t-shirts, a majority of the interviewees did not have a warm coat for the winter, many only had one jumper and a small number only had the clothes they were wearing. One interviewee had no shoes, only thongs.

A common response from the participants with family support was their reliance on their parents for their supply of clothing. Parents and charitable second-hand clothing shops were the main sources of clothes for all interviewees.

> *My mother buys me clothes for my birthday and Christmas and I still have to buy a certain number of clothes and I usually have to lay-by them and you have to wait 3 months before you get them, it takes about 3 months to pay for them. Um, sometimes I go to Salvos and places like that. (Les, 41, schizophrenia, South)*

Many low income earners routinely use second hand clothing shops, particularly those run by charities. In Tasmania, people in financial crisis contacting Emergency Relief services can receive free clothing if they identify this as an area of need. Apart from this system there is little discounting for Health Care Card Holders or Pension Concession Card holders in the charities' shops. The main providers of charitable op-shops use the income raised from these shops to cover operational costs and fund the provision of food to people in crisis through their Emergency Relief operations. The price of clothing in op-shops is substantially lower than in most first-hand retail outlets but these prices can still represent a financial impost which can be beyond the means of people on low incomes. A number of participants raised concerns about the prices charged by charities.

> *Often it's hard to afford the things in the op shops. I just found a coat there today for $3 – what a bargain! So I snapped that up. But often the prices are more than you can afford. I don't understand it – mattresses from the [charitable op shop] are $200 - $300. How can that be? They've been donated to them for free so that they will give them to people who need them. What are they doing making money out of it? (Lee, 39, depression, North)*

> *But op-shops have become very expensive now. You can't go into an op-shop with $2; I mean you are looking at $7 - $8 for an article. (Denise, 52, bipolar disorder and anxiety, North)*

Being dependent on donations, op shops also do not necessarily hold the stock required by all people. A number of participants commented on the particular difficulties in getting access to shoes and clothes for men.

> *I went to the op shop and walked in and first thing you notice is that it's nearly all women's clothing and I said 'Where are all the men's clothes?' And they said 'Don't you wear your clothes until they fall to pieces?' And I said 'Yes'. And they said 'So do most men'. And so that's why there's not much selection at all, in terms of size or whatever (Robert, 53, anxiety and depression, South)*

> *I didn't have warm clothes but [NGO counsellor] took me to the [charity] and got me fixed up, so I'm good now. My biggest problem is shoes because my feet are shaped funny so I wear shoes out really fast. Plus, I walk everywhere so I wear a pair of shoes out every 3 months or so. I buy first hand shoes and I like to buy boots that last a bit but I still wear them out every 3 months. That's a big expense, because it's $60-$70 a time. (Kim, 28, with schizophrenia, North)*

### 5.4 Access to transport

The very nature of the illness means that people with serious mental illness are often isolated from the community. 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).

The participants in this research indicated that access to transport was a highly problematic issue for them. Few could afford to own a vehicle and the lack of affordable, accessible transport had increased their sense of social isolation and exacerbated the symptoms of social withdrawal many of them were experiencing.

Anglicare's 2004 survey of emergency relief agencies also 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 (Madden, 2004, unpublished data).

A minority of participants in this research owned a vehicle and for this group, the costs associated with running a car were a significant impost on their budget.

> *I have my own car. But the petrol bill! I'm borrowing money all the time and you have to pay it back pay day until you get another bill. Fuel is basically pretty expensive. I reckon I borrow up to $50, $60 a fortnight just to run the car and then I've got to pay that back every fortnight. (Les, 41, schizophrenia, South)*

> *I've got a car ... the only reason it's still on the road is because my brother-in-law is a mechanic and he can keep it going. But if something bigger happened to it, well I'd be out. (Vince, 56, anxiety and depression, South)*

The majority of participants in this research were dependent on public transport and for them there are critical issues with availability, particularly when they are living in Housing Tasmania properties on the metropolitan fringe or in non-metropolitan areas.

> *Like go to some other place like Risdon Vale the buses are so infrequent you have got to go in to [town] and you spend the whole day and you don't want to spend the day waiting for a bus to go home, and if it's in the evening, you can't go out in the evening. So you really are living in, really, like ghettos in a way. (Bruce, 61, depression, South)*

> *It's really difficult here if people don't have their own private transport. The bus service runs at really obscure times. It only runs once a day and so if you want to make appointment, you've got about an hour before it comes back, so if you are reliant on the public transport you have to make arrangements to stay overnight because there are not too many people can get to their doctor, see their doctor out and get back on the bus within an hour. There's the community bus that takes people up for the day and brings them back for $20 which is okay but you have to have a disability. You have to be on a disability pension to use that bus. (Loretta, 39, bipolar disorder, North-West Region)*

> *I feel the previous mental health centre was easier to access for that and also it is very frightening walking to a doctor, walking all that way when you are not well, say you need a doctor or the psychiatrist or a nurse or community mental health team. And there are no buses on the weekend. I've currently applied for community transport for a disability allowance for taxis. More people in mental health should be made aware that they can apply. (Anita, 39, depression and bipolar disorder, North-West Region)*

Many of the participants in this research also stated that they found using public transport difficult. The reasons they cited 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. Many of the people interviewed went to great lengths to avoid using public transport.

> *I tried to catch the bus and I got lost, I didn't know where I was, timetables and all that sort of thing. I ended up out Lutana that time. Yeah, you get confused, you get confused and you can't ask anybody because they'll think you're a nutter and so it's a Catch 22. (Vince, 56, anxiety and depression, South)*

> *I walk everywhere now. There are some buses but not many and anyway I don't like buses. If get on them and I can forget where I'm meant to get off. I get really scared. (Katrina, 32, bipolar - obsessive compulsive disorder, North)*

> *Well I couldn't catch public transport at the moment because I am too scared of confined spaces ... [W]hen I lived in [town], and I used to live in [suburb], I used to try to keep taxi money on me but most of the time I didn't have it, and I used to have fear attacks and I'd seem somehow I'd get paranoid and I'd have to get from [suburb] to [the hospital] and I'd walk all the way and I had to cross some bridges and I was totally terrified. And I'd hope to God that it wouldn't rain and I'd get soaking wet. By the time you get to the hospital they'd see you, well wait you'd sit there for hours. I'd walk up and down panicking and that and they'd say 'there's nothing we can do just give him another tablet' and then you'd go home again and you got to walk all the way. (Neville, 51, schizophrenia and anxiety, North-West Region)*

As these accounts clearly illustrate, the combination of cost and fear meant that people with serious mental illness may find themselves walking long distances and placing themselves at risk. This can make accessing clinical or support services unnecessarily difficult for them. As Anita pointed out, there is a scheme in which people with disabilities are eligible for a taxi allowance but workers report that it is difficult for a person with mental illness to access it as the assessment process appears to prioritise people with physical mobility impairment. In addition, few of the participants in the research were aware of it. Those people with serious mental illness who were Health Care Card holders were doubly disadvantaged by being on jobseeker allowances which are a lower level of income than pensions, and at the same time 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.

### 5.5 Access to telephones

Telephone debt is a significant problem for people in financial crisis generally (Griffiths & Renwick, 2003). Recent surveys of Emergency Relief clients in Tasmania indicate a very high rate of phone disconnection due to a shortage of money (Madden, 2004). 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). Telephone debt was identified as another cause of financial concern for the participants in this research. People with mental illness are necessarily very reliant on the telephone for emergency contacts, for support and counselling and for companionship.

> *With a mobile phone – there are times when I use the telephone a lot when I am depressed and I ring my friends all the time because I get confused and I've got insomnia. (Anita, 39, depression and bipolar disorder, North-West Region)*
>
> *He has got his own mobile and I can't say no, but it's there for when I'm away and he can get on the phone all night. And that bill has run up too and I'll end up having to pay it. (Sue-Ellen, 56, son Luke, 32, with schizophrenia, South)*

> *And everything else, I can't afford petrol, films anything like that. Telstra especially, the telephone bills I can't afford that. Just have to forget about Telstra. (Rosemary, 53, schizo-affective disorder, North)*

Access to telephones is an important safety issue. The following narrative illustrates the risks for a single woman with mental health problems who has no access to a phone. Moira has bipolar disorder and experiences periods of feeling depressed and suicidal. At those times she seeks support from Lifeline but since her phone has been disconnected, calling Lifeline means walking to the nearest pay phone.

> *This can happen at any time of the day or night. Yeah there was one night I went down to the phone to talk with Lifeline. It was 10 o'clock and there was this man near the phone doing this [indicates masturbation]. It was a bit scary but I had to talk with Lifeline. (Moira, 31, bipolar disorder, North)*

A number of the participants in Anglicare's research indicated that they currently, or had in the past, used mobile phones. Like consumers across all income groups, people on low incomes are making greater usage of mobile phones, at times in addition to land lines. Reported telephone debt among people in financial crisis is divided evenly between land line and mobile phone. Lack of payphone access has contributed to a shift to mobile phone use, along with homelessness, outstanding debts for landlines, isolation and a need for social contact (MacNeill, 2002). Although low income people may own and use mobile phones for emergency access and for short phone calls, without easy access to payphones many are unable to maintain essential connections within family, social, government, educational and community networks (Consumers Telecommunications Network, 2003). However, mobile phones present particular problems for disadvantaged people: an apparent lack of credit checks before contracts are entered into, the unusual nature of contracts for mobile phones, the speed with which significant debts can be accrued and the possibility of dealing with multiple providers, making the negotiation of payment agreements more difficult (MacNeill, 2002). Clearly mobile phone service providers need to more closely assess the ability of consumers to service their debts before entering into contractual arrangements.

### 5.6 The costs of gambling

A significant minority of participants, both people with mental illness and carers, discussed times when gambling, particularly an addiction to poker machines, had been a problem in their lives. The problem was self-defined and is indicated by its impact on their level of disposable income and their families. The participants talked about gambling in terms of winning, but they also valued it as a social activity, an escape from loneliness and often their only chance for social interaction. As the following narratives demonstrate, gambling in all forms had a huge impact on their limited budgets.

> *I was really hooked on gambling for a while. I liked the pokies, I don't know why, I think I liked the noise they made and I liked winning. I used to play the pokies a lot. (Kim, 28, schizophrenia, North)*

> *The pokies suck [people with mental illness] in. That and the psychological gain of intermittent reinforcement - that just sucks them in no worries. And I have met so many and I'll say 'How well did you do?' and they lost but they cannot, intellectually, get their head around probability. You know it is a 1 in 10 million chance that they'll actually get anything out of it, they cannot understand that. And my son is the same, his girlfriend is the same and the people I [know]... It's the same stuff, they have no understanding. It's the intermittent, intermittent reinforcement schedule that pokies are programmed with. The gambling crowd know what they are doing. (Merrin, 51, son Anthony, 23, schizophrenia, South)*

> *I had a big gambling issue up until about February this year. Since I split up with my husband I just used to just go gambling every fortnight. Most of my money went on that, the pokies…When I was gambling I was just not having any furniture in the house, having nothing for my kids when they turned up. (Narelle, 45, depression, South)*

> *Oh, well, when I was living in [town] if I had money on me, I would spend it in the TAB all day. I've got to learn how to budget my money. And I can't go every day down the races and the pub, spend it, live the next fortnight with nothing. The person I went to at [ER provider] and got a food order and when I went the next week, she said 'You can't come back for another three months'. And they got it on the computer so you can't go to [other ER providers] or anything like that. I'd be paid tomorrow and I'm a bit frightened of going to the pub and gambling. (Neville, 51, schizophrenia and anxiety, North-West Region)*
> *Melissa will go to an Oasis, or one of the gaming groups, I don't know their proper name. Anyhow, yeah, she goes there and she'll, she'll spend heaps, she'll put it through the pokies or, she'll gamble on keno, keno tickets. She absolutely loves keno. Absolutely. (Frank, 57, daughter Melissa, 26, schizophrenia, South)*

The manic phase of bipolar disorder is commonly characterised by excessive spending. Gambling can therefore have an immediate and devastating effect on the lives of people with this disorder. Two narratives in particular dealt with this issue when the individuals concerned had access to unusually large sums of money: one from an inheritance and one, a divorce settlement. Both these sums of money were spent on poker machines in short time frames.

> *Lana has been addicted to alcohol at different times and gambling, to poker machines. They like, they hypnotised her. They stop their mind from thinking. They mesmerise them I think, and while you are playing poker machines you don't think of anything else. One of the things that she did when she was really manic, she had $20,000 in the bank. And during that fortnight Lana put $20,000 through the poker machines…I couldn't believe it. And then for about a month after that, or even longer, she was so depressed that she felt as if somebody had stolen the money, and she would cry daily. (Ada, 74, daughter Lana, 41, bipolar disorder, South)*

> *I had a lot of money and because I was manic, I did get a lot of money from my settlement but nobody told me there was a tomorrow and I got addicted to gambling machines and gambled a lot of my money, probably $100,000 away, and lost a lot*

> *of money. Whereas today I should be living quite wealthily, I am struggling on the pension. And I am finding it very hard to come to terms with. (Denise, 52, bipolar disorder and anxiety, North)*

Tasmanians lose approximately $80 million each year on poker machines in pubs and clubs. There is no research available which confirms the anecdotal evidence from support services that people on low incomes are especially vulnerable to high losses from gambling, however, the connection between mental illness and gambling is illustrated in this research. Clearly this group is extremely susceptible to the appeal of poker machines for a range of reasons and the social impact on them is catastrophic.

# SECTION SIX

## GENERAL HEALTH AND SERIOUS MENTAL ILLNESS

### 6.1 General physical health

The participants in this research mirrored the findings of other Australian studies (eg Lawrence et al, 2001) in that they had very poor general health. The participants in the research discussed quite serious but often neglected health concerns. Some participants reported that general health concerns were neglected because of the dominating nature of the mental health problem or because of self-neglect.

> *My body has been alright really. I had knee surgery about seven years ago and my appendix blew up and stuff and that took away some of my energy you know but I haven't been to the doctor much because I haven't had much. I mean your body's one thing but your mind is more important. I'd rather have an aching knee and a happy mind. (Russell, 42, depression, South)*

> *It wouldn't enter Don's mind to go to a dentist or a doctor. No, he doesn't worry about that. He doesn't sort of worry about anything like that, and the same with other health issues. They are just not a priority. He doesn't seem to be aware of things and that lack of a bit of planning that goes with something like that, it's not there. He hasn't got that sort of mental ability to do that any more. (Meredith (53) son Donald, 23, with schizophrenia, South)*

### 6.2 Access to general practitioners

The pivotal role of general practitioners (GPs) in the care of people with serious mental illness is widely recognised. The National Mental Health Strategy identifies access to GPs as critical to improving opportunities for diagnosis, early intervention, treatment and referral. The development of better linkages between mental health services and GPs is articulated in the key directions outlined in the current National Mental Health Plan 2003 - 2008. However the findings of this research suggest that people with serious mental illness and their carers have mixed responses when asked about access to general practitioners. While many did not attend the doctor regularly for the reasons described above, others cited cost as a barrier.  Participants had mixed levels of access to a GP who regularly bulk-billed. For those who did not have this service, the co-payment represented a significant barrier to access.

> *They don't bulk bill any more. Like my doctor won't bulk bill any more, which means that if I get sick I have to make sure I get sick when I have got enough money to pay, to pay for the doctor's bills. It is ridiculous, because all this doesn't work to my financial calendar you know. It's just stuffed. (Clare, 35, schizo-affective disorder, South)*

> *I have a very, very good GP. But no, I stopped going because it was just too expensive and because then you've got some drug recommended on top of the visit and so on. I should go - I need testing for prostate cancer and all those sorts of things you should have after you're 50. (Robert, 53, anxiety and depression, South)*

> *And when it comes to doctors, we have to pay the gap and that really, out of the fortnightly pension, is a huge amount of money. And my daughter is anorexic now and so she has to go to the doctor. And she is on Newstart because she had to leave Uni and she can't afford to go to the doctor. And she should be going to monitor her anorexia. (Dawn, 45, depression and bipolar disorder, North)*

> *Well the trouble with GPs is it is hard to find a bulk billing GP so that's probably the big issue for a lot of people I guess. In terms of that, unless you are lucky enough to live nearby somewhere you might have to make long trips. Even sort of getting in to see someone is quite difficult at times, if you want to see someone sort of fairly quickly. So I often end up with the after hours doctor, you know waiting for hours to see someone. So, yes, it can be difficult. (Bill, 33, partner Briony, 19, with schizophrenia, South)*

A substantial number of the participants, typically those on the Disability Support Pension, did have access to a doctor who bulk-billed. In several of those cases, the GP provided very supportive primary health care and there was a high level of satisfaction with this arrangement in preference to other specialists, as reflected in these statements:

> *He will squeeze me in in an emergency, if it's really full on, because he likes to send me up with a letter because it affects the reactions a little bit in the hospital. Because I can actually be right off the show and look like I've got it together and sound like I've got it together but I am really right off. And he is very good with that and he understands it. He knows that I know what's happening. This particular GP, his books are closed because he is just overworked to blazes. (Mandy, 39, bipolar disorder, South)*

> *But now I just even have gone out on a limb, I've just got my GP now and my medication. I have stopped seeing my psychiatrist in [town]. You just go down there, 'Oh, hello, Neville. How are you? All right?' 'Yeah, not bad.' And he'd just give me my prescription and 'See you later'. He didn't ask me anything, see if I was having attacks and seeing things and hallucinations, paranoia. He didn't ask me nothing, just hands me my 'scripts. (Neville, 51, schizophrenia and anxiety, North-West Region)*

> *Seeing I've had it for 12 years I know myself, I know the ups, the downs, the in betweens, and I have my own injection ampules at home so if I broke down … I could just go to the hospital and get an injection. So, I manage it really well. Yeah and that's thanks to my GP, and not so much the people from up the coast, but it was from the local GP. He allowed me to go off one of my medications because I thought and my husband thought and my doctor thought that I was being overdosed, so I have learned to go off one. And I am still okay after three or four weeks. (Loretta, 39, bipolar disorder, North-West Region)*

However, some participants reported that they prioritised treatment for their mental health over treatment for their physical health or chose not to discuss physical health issues with their GP.

> *That's where I find it really, really hard. My GP has for years probably pretty much done all of it. He is probably pretty much my psychiatrist. [I] tend not to go to him with a health problem. I just put up with it because, just within yourself, after seeing him a lot whether he'll think it's in the mind or something you need a tablet for. (Gavin, 44, anxiety, South)*

### 6.2.1 The role of general practitioners

The support provided by the GPs visited by the participants in this research varied significantly. It ranged from providing advice on medication, referral and counselling to direct assistance with financial management. One participant, who has experienced regular extreme manic episodes which include spending sprees followed by periods of deep depression and despair, reported that her GP is now co-signatory on her accounts and, with her agreement, disperses her money to her in instalments. Stacey was very positive about this arrangement, pointing out that this enforced budgeting has resulted in improvements in her mental health, her diet and her confidence and self-esteem. While the level of support is clearly valuable in many cases, this arrangement is one that places the GP in a potentially difficult position.

> *I have got a fantastic doctor who I could ring 24 hours a day. I see a private dentist and I went recently. But I am fortunate enough that I can afford to do that because my GP helps me with keeping to a budget and I sort of leave my cheque book with him and leave my key card and I do that to get so much money out each Wednesday and then split it up and pick up some money on Friday and again on the Monday... [My GP] has gone co-signer on my accounts, because I have got 2 accounts, 1 for the bills and so therefore it is guaranteed he couldn't take my money, he needs my signature as well. But it means that when I am manic I need his signature and we have to discuss why I need the money. For me, I pick up $30 from the surgery, that supplies my petrol and food for those 3 days, so I do that Mondays, Wednesdays and Fridays. So that's, I find that I have actually got money left over when the next time to pick up the $30 comes around. [Before] I was often going to the Salvos to get my food. (Stacey, 28, schizophrenia, South)*

The important role of GPs in the care of people with mental illness is evident. There is a need for specific education and professional development for doctors to work effectively with this group. Commonwealth funding has been allocated through the Divisions of General Practice in a variety of packages including the Better Outcomes in Mental Health to achieve this end. The National Comorbidity Project also directs the focus of care onto GPs. Participation in these professional development programmes is voluntary and currently approximately 15.6% of general practitioners have registered nationally. In Tasmania, 95 of the 615 general practitioners in the State have registered for the level one training in the General Practice Mental Health Standards Collaboration Programme which is consistent with the national level of registration[11]. However, the limited time and remuneration available to general practitioners in dealing with people with serious mental illness means that significant barriers to access remain.

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[11] General Practice Mental Health Standards Collaboration GP registration data, April 2004, unpublished data.

## 6.3 The cost of medications

All the people with mental illness interviewed for this project were on multiple courses of medication, with a number prescribed medications for both their mental illness and other physical ailments. In the context of general budget management, participants were asked whether they could always afford their prescription medication. There are many reasons for non-compliance with medication, although the cost was consistently raised as a concern in this research. Those who took prescribed medication for physical disorders as well as a mental illness reported severe problems with affording all their prescribed medication.

Under the Commonwealth Pharmaceutical Benefits Scheme (PBS), concession card holders are currently charged a co-payment of $3.80 on each prescription. All co-payments on further PBS prescribed medicines for the rest of the year are removed once a concession card holder reaches a Safety Net Threshold of $198 or 52 scripts within a calendar year. In addition, all pensioners receive a Pharmaceutical Allowance of $5.80 per fortnight in addition to their pension to help cover the cost of pharmaceuticals (DoHA, 2004).

While the Government subsidy covers the real and substantial cost of the medication, the cost of regular psychiatric medication can make a significant impost on the budget of a pensioner or allowee. The respondents interviewed for this research typically indicated that they were regularly 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 the cost.

> *I couldn't afford my meds last year when I was sick. But generally I make sure that I've got the money for those. (Katrina, 32, bipolar disorder and obsessive-compulsive disorder, North)*
>
> *It is a real struggle. If I have got $10 left in my purse at the end of pension day that's wow! And that's only because I probably haven't bought 40 prescriptions. Most of my money goes on food and prescriptions. (Denise, 52, bipolar disorder and anxiety, North)*
>
> *And, you know, I've done silly things like reduced the dosage of my medication because it was costing too much to pay for it and that sort of backfired a bit. Then I thought it was good and I stopped altogether but then I fell in a hole and then I went on new medication and stronger dosage, which was more expensive, so it backfired. All these lessons you learn after a while. (Robert, 53, depression and anxiety, South)*

Other participants had made an effort to ensure that money was prioritised for their medications or had organised ongoing credit arrangements with their pharmacists, but they reflected on the negative effect this had on their overall budgets.

> *Sometimes I haven't allowed for it and I have to use my food money for it. So therefore I would go without food to buy it, yeah. (Stacey, 28, schizophrenia, South) [before GP assisted with budgeting]*

> *It's pushing it with everything else you've got to do and medications aren't cheap. It takes a lot out of your fortnightly pay. See because of this depression and the triple bypass I'm on 8 tablets. I've got to take them for the triple bypass just to keep me alive and then probably another 2 or 3 [medications], so that's a lot of expenses over the counter. (Vince, 56), anxiety and depression, South)*

> *I usually end up wondering if I've got enough [medication] for the next three months but getting up to there [saving the co-payment] in the first place is almost impossible, you just do it by living on bread and vegemite for a week. (Alex, 50), bipolar disorder, North-West Region)*

> *With my medication I pay at the hospital $14.60 a month plus I have five other medications that I get from the ordinary clinic as well. So, that does make it expensive, especially if I have got to get my medication from the hospital at the end of the fortnight and I haven't got the $14.60 to buy it. Then they'll put it on the account at the hospital and then I have to find somewhere else down the track for that money while at the same time I have got to pay for the current medication. I just have to. Well they send me, you know, a letter from the hospital to pay the bill otherwise they will initiate legal proceedings to get it. So you have got to pay it, but then at the same time you have got to pay that particular month's medication as well, so it's like you are always chasing your tail. (Dawn, 45, depression and bipolar disorder, North)*

> *I generally book that up at the chemist but they took my Medicare card. So, I've got to pay tomorrow. It's pay day tomorrow. I've got to go and get my medication and then pay them, [then] they'll give my Medicare card back to me. Umm should I say this? I owe about three or four chemists in [town] where I booked my medication up and I haven't paid for it. Well I'm willing to pay it and I'll go back there one day and … It really frightens me if I've got no money to get my medication til I pay the chemist because I am terrified of being dead and I need my medication. (Neville, 51, schizophrenia and anxiety, North-West Region)*

In the wake of the 2002-03 Federal Budget, which introduced cost cutting measures across the health budget, the co-payments charged on pharmaceuticals for concession card holders were increased. The Pharmaceutical Benefits Scheme and co-payment arrangements continue to be under threat from Government concerns about the rising costs of health and aged care and from the implications of the Fair Trade Deal with the United States (Lokuge & Denniss, 2003). The effect of any increase in the cost of prescription medicine would be 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.

## 6.4 Oral health

People with mental illness have a high risk of oral disease which increases the need for oral health care including gum treatment, restorations and extractions. The issues confronting concession card holders in accessing the public dental health care system are compounded when people have complex needs such as mental illness. In addition to the health issues which act as barriers to this group accessing dental services, the financial barriers and waiting lists faced by all Tasmanian low income earners are significant concerns for people who have the additional burden of mental illness. A simple example of how the tools used to manage over-demand for the dental service effectively bar access to those with multiple disadvantages is the current practice in the south of the State of requiring patients in need of emergency treatment to ring the Dental Service at 8.30am. All emergency appointments are routinely filled by 9.30am. To compete in this flurry of activity would be enormously difficult for a group characterised by lack of access to telephones; difficulty organising thoughts and activities; difficulties with motivation; and a tendency to sleep through the mornings due to the side-effects of medications.

The carers who participated in Anglicare's research identified oral health as a major problem for their family members and friends. While displaying clear visual evidence of substantially decayed teeth and partial and broken dentures, none of the people with mental health problems interviewed in the research were accessing regular or preventative dental care. A minority was attempting to access emergency care and there was also evidence of an excessive use of tooth extraction as the common response to dental problems. For those who had attempted to access dental care the multiple barriers (the charging of co-payments and the existence of an extensive waiting list) had exhausted their motivation to pursue this assistance.

> *I've got a mouthful of teeth that are just shot to pieces because of years of depression and not caring and also probably because I live too much ... (Mandy, 39, bipolar disorder, South)*
>
> *So, dental care is hopeless and they do forget to do their self-care stuff, that's quite common. All that, they forget to brush their hair, that's an indicator, if they forget to brush their hair they are not likely to be doing their teeth or perhaps having showers and wearing clean underwear. So that's just part of the condition, they forget to do it. (Merrin, 51, son Anthony, 23, with schizophrenia, South)*
>
> *I was real lucky. I got all my teeth out ... you know, what happened was it was my birthday and my sister took me down the casino and I got 7 numbers out of 8 on the lotto and they give me $800 and it only cost me $1, the ticket. So, I just got all my teeth fixed [extracted]. (Vince, 56, anxiety and depression, South)*

### 6.4.1 Access barred by illness

Clearly a lack of interest or concern about oral health was the principal reason for most of the research participants not pursuing oral health care. For example, a participant missing all his teeth and having broken dentures explained that 'he had had no reason to go' to the dentist. Other participants explained:

> *Yeah I got sore teeth at the moment. I don't know what to do about them 'cause most of them are hurting. I don't know whether to go to the dentist, 'cause I just don't know how to go about it, mainly. I suppose if it's free you just get a filling, or*

> *something like that, but I need a lot of work done to them. (Richard, 40, schizo-affective disorder, South)*

> *I don't even bother going to the dentist. No. I haven't been to a dentist for 15 years. (Alison, 37, schizo-affective disorder, South)*

The carers also noted that the symptoms of mental illness itself contributed to the poor oral health of their family member. They cited lack of motivation, lack of appetite and/or disinterest in a balanced diet, disordered thinking, lack of interest, poor memory, lack of forward planning and the way these symptoms contributed to poor financial management skills. Another significant barrier was fear of the dentist. In this, as in other areas of their health care, the pressing concerns of their mental illness made other health needs of secondary importance.

> *But I've got no bottom teeth. I used to be scared to go to the dentist but I'm not any more. I've got to go to get my teeth. I don't find that a problem. So it's all right. (Neville, 51, schizophrenia and anxiety, North-West Region)*

> *Oh well I am a drug addict and used to take speed and amphetamines and I didn't take care of my teeth. But they've done good though and ... I'm scared of them. I don't like them. I fear that needle, mate, they have to knock me out. (Ron, 44, schizo-affective disorder and substance use disorder, South)*

### 6.4.2 Access barred by cost

Both participants with mental illness and carers identified cost as a barrier to oral health care. For most of the participants the Public Dental Service is their sole option for oral health care and the associated costs, including the co-payment fee, represented a major disincentive to seek treatment. Their concerns are exemplified in these statements:

> *Oh, I'm putting it off because I know basically all my teeth need pulling out and I don't know whether it's vanity, or I'm just trying to hold onto my teeth for as long as possible because I don't really think I can afford a false set and it's going to be a long process and you've got to have the money. I mean it's deep down in the nerve. I'd rather buy panadol for the pain and that makes me able to eat. I think it's a combination of how to get there and the money thing even if you only need a quick fix. (Gavin, 44, anxiety, South)*

> *No, this is a big problem, a big problem, it is costing him hundreds of dollars and we are footing a lot of those bills for his dental problems. He hasn't got a lot, but he went to a dentist here the other day, because he has got an ache in a tooth. Now the dentist said 'I will have a look at it' and I think took an x-ray, gave him a bill for $120, come back next week for another $120. Now he can't, he can't do it, and it is possible that his medication could even be causing some problems. There definitely should be some compensation there to help him through. There's no way he can pay his dental bills. (Brendan, 69, son Phil, 39, with schizo-affective disorder and bipolar disorder, North-West Region)*

Belinda's story illustrates the consequences of poor oral health particularly poignantly. At the time of the interview, Belinda felt that her mental health had improved sufficiently for her to return to the labour force. She had just gone back on to Newstart Allowance and was looking for work. In addition to overcoming the barriers presented by a chequered work history due to her mental illness, she also was facing a highly competitive job market with teeth that were in such a poor state that her speech was difficult to understand. The opportunity to fix her teeth would greatly enhance her chances of finding work and a path out of poverty.

> *I don't really go to the dentist a lot because it costs too much but the last time I had to save up for a while. I had to go without a partial denture so I had a few teeth missing, until I saved up. I couldn't just, you know, give them the money straight away for it. [I have to wait] a few months. Yeah. But that's not too long though. But it is expensive and you don't get any help with dentures to pay the bill off. (Belinda, 36, bipolar disorder, North-West Region)*

### 6.4.3 Access barred by waiting lists

Clients and carers also cited the extensive waiting lists that exist for the Public Dental Service as a barrier to pursuing dental care.

> *I had a broken tooth last Christmas and I phoned the dental clinic and they said 'Well we will put you on the waiting list'. I had a broken tooth and it was 3 weeks for the broken tooth. I put myself on the waiting list for just general dental check up 4 years ago. And my daughter is now out of the school dental service. She is 20 and she can't get to the dentist either. (Dawn, 45, depression and bipolar disorder, North)*

> *And I have never been able to get him to what is supposedly the free dentist, but I understand the waiting list for that is 30 years now. (Win, 70, son Adrian, 34, with paranoid schizophrenia, North)*

Charlie is a volunteer carer who works through an NGO befriending scheme, a program which links volunteer carers with people with serious mental illness. He described his attempts to help his frail elderly 'mate', the resident of a boarding house, who suffered from a mental illness and had extensive physical health problems. Charlie's 'mate' had a cracked dental plate which made it impossible for him to eat the special food his medical condition required.

> *He had had a colostomy, and nobody could take him and no family would sort of look after him and he had a cracked top plate. [When I was introduced to him] I thought 'Well I had better get this teeth problem sorted', so I went up to the State teeth ... and they made an appointment for me about three or four months down the line – with this cracked plate and this man has a colostomy, mind you! And I explained to them about the cracked plate. But unfortunately he died [before the appointment].*

Many of the carers were themselves living on low incomes and were eligible to use the Public Dental Service. They noted that even without the complicating problems of mental illness they could not get affordable or accessible treatment from the Public Dental Service. This contributed to a sense of hopelessness about the crisis in the public dental system ("none of us can afford the dentist") which undermined their motivation to advocate for access to existing services for their family member with mental illness.

### 6.5 Comorbidity

A number of the participants in this research experienced comorbidity, or the presence of two or more diseases or disorders. These included mental disorders (eg bipolar disorder and anxiety), mental and physical disorders (eg schizophrenia and multiple sclerosis) and mental health and substance use disorders. This reflects the very high prevalence of comorbidity for people with mental disorders, for whom it has been described as the rule rather than the exception (Teeson & Byrnes, 2001).

The co-existence of other disorders in addition to the distress and confusion of serious mental illness makes a punishing double burden for people and raises significant issues for their carers and services. Comorbidity generally is often associated with poor treatment outcomes, greater severity of illness and high service utilisation (Teeson, 2001). Where the comorbidity is of psychosis and substance use disorders people are more likely to experience a range of negative outcomes such as increased levels of medication non-compliance, psycho-social problems, depressions, suicidal behaviour, re-hospitalisation, homelessness, poorer mental health and higher family burden (Hall, Lynskey & Teeson, 2001).

The consumption of alcohol or drugs is defined as a substance use disorder if it is "causing damage to [an individual's] health physically or mentally to the extent that they had impaired control over their use or that obtaining, using or recovering from alcohol or drugs was taking up substantial amounts of their time" (Teeson & Byrnes, 2001:101). The following comments are from the carers of people who have received treatment for substance use or whose pattern of substance use was consistent with this definition. They are indicative of the ways in which the comorbidity of mental and substance use disorders results in poor health outcomes, increases burdens on carers and exacerbates social disadvantage as well as the symptoms and behaviours of the existing condition.

> *I used alcohol for food. Unfortunately where I was I was under so much pressure I actually turned to alcohol and would not eat because that was like a blockage of everything around me. And I can remember once I didn't eat for a month and it just seemed that I had nowhere to turn to at the time, so I would just drink cheap wine or something like that. I had to go to rehab to learn how to readjust my lifestyle to try and learn nutrition out there. But I don't know, it seems as though when I go to the [Housing Tasmania] unit I won't have that amount of money to spend on food. Whether I will be able to stick to it or not, I'm not sure. Money scares me. (Gavin, 44, anxiety, South)*

> *Actually, the police were good with him but there was one occasion when I though it was a bit difficult. I was woken up at night and the police asked me if I would come*

> *and get him, he was in the cell, for his protection, and he was really, really drunk, and I thought 'Well if he's really, really drunk how am I going to get him into the car with me?' And the policeman said 'Oh but he was alright for us' but there were two of them, you know. (Geraldine, 55, son John, 34, with schizophrenia, South)*

In response to the complex treatment and management issues and the significant disease burden raised by high rates of comorbidity, there is a policy shift towards a more collaborative response from mental health services and drug and alcohol services. But the implications of this are still being explored and issues still exist in the delivery of separate services from agencies with different service cultures. For example, a number of the family members of younger people with mental illness reported highly judgmental treatment of young people by psychiatric staff during early episodes of psychosis where there is an assumption that the psychosis is drug induced.

> *That's actually what they were saying, that it is his fault he's on marijuana, so we don't want to know. Except that I kept on saying 'No he's not, he's got no access to it. No, he's not. He can't even get into town on his own'. They think it's his age group. Maybe that's the easy way out. Somewhere between the ages of 14 and 20, and they just make the assumption. But what I don't understand is why then, why don't they want to do the diagnosis in the first place? Is there some government policy where we don't want to diagnose this age group because we might have to fork out money for them? (Emma, 49, son Angus, 18, with schizophrenia, North)*

Other examples illustrated the problems arising from the separation of mental health and drug and alcohol services.

> *I needed a safe place, these suicidal feelings were just overwhelming me. I always look better than I feel and people are blown out when I say I feel like shit, you know I feel like shit, the gnomes are back sort of thing, you know. They said 'No, she's just' (and they always talk about you like in the third person), they say, 'She's just had a bad week or maybe she has drunk a lot of alcohol or something, Yeah, you know we can't admit her at the moment'. (Alison, 37, schizo-affective disorder, South)*

> *But the day they transferred him I said 'Well what about some drug and alcohol counselling and what about this, and what about that?' Well they hadn't thought about any of that practical life things that you teach people, so, they phoned somebody in from the drug and alcohol people, they got them to come in the day he was being discharged. (Jenny, 48, son Ben, 19, with schizophrenia, South)*

The most common form of substance use by people with mental health problems is nicotine use. The LPDS found that nicotine was the most commonly used drug among individuals interviewed (67%), with lifetime diagnosis of alcohol use disorders in 30% and cannabis use disorder in 25% (Jablensky et al, 1999). Cigarette smoking is the most common form of substance use for people with schizophrenia, with a prevalence rate of 3 to 4 times higher than the general population (Access Economics; SANE Australia, 2002). However, while smoking has negative health impacts, many people with mental illness find that smoking has a positive effect on the symptoms of the illness. This can be an additional barrier for people with serious mental illness to give up smoking and budgeting for cigarettes becomes an important part of their financial management. Many of the participants in this research stated that their cigarettes were a high budget priority.

*When I have got the voices bad I smoke because it relaxes me, but I can remember one day I was so distressed I had a smoke and I was crying and I said, 'I am so scared I'm going to get cancer with all this smoking' and [Dr] said 'Listen if you have got those voices for hours and hours every day you need something, just try and cut down a little bit.' (Celia, 55, schizophrenia, North-West Region)*

# SECTION SEVEN

## SOURCES OF INCOME

### 7.1 Centrelink

All but one of the participants with mental illness interviewed were dependent on Commonwealth pensions and benefits administered through Centrelink as their sole source of income. The exception was a self-funded retiree whose income was close to eligibility for a Centrelink benefit. The participants who were on the Disability Support Pension were generally satisfied with their dealings with Centrelink. Typically these respondents reported far lower levels of anxiety about the reliability of their income than those who were on Newstart Allowance. They also expressed greater confidence that any issues they had could be talked through with the Centrelink staff. The availability of Centrelink Community Officers visiting mental health services was clearly an important factor in allaying anxiety about filling in forms or dealing with enquiries from the agency.

However, some participants and their carers reported significant concerns about their dealings with Centrelink. These participants were characteristically those in receipt of jobseeker allowances but temporarily exempted from mutual obligation requirements (Administrative and Activity Tests) because of mental illness; and carers of young people with psychosis who had experienced great difficulties in getting access to any form of income support. The issues reported by these participants focused on: the complex requirements Centrelink place on income support recipients and the penalties imposed on people who failed to comply; the level of administrative errors made by Centrelink; the difficulty getting income for young people experiencing their first episodes of psychosis; and the poor interface between Centrelink and mental health services.

Some participants had difficulty getting access to Disability Support Officers for front desk interviews. As the following comments demonstrate, the lack of understanding of mental illness and the stigmatising attitude of some staff were deeply distressing for some participants. Similar responses were reported by people with mental illness in recent Victorian research (Zigarus, 2003).

> *That is one area they need a lot of work on, they need someone in the mental health area, someone who can show a bit of compassion and take a bit of extra time to listen and not speak in riddles and don't blame the computer every time. (Gavin, 44, anxiety disorder, South)*
>
> *Well they don't know what you're talking about if you're answering one of their questions. They say 'Well, why can't you?' or 'Why couldn't you apply for that job?' And you say 'Because on the day I felt like I should be going to the hospital, not for a job' but they don't understand. Yeah, one guy said to me, he said 'Oh' he said, 'You haven't signed your form and we can't put it in'. He said 'Do you mind signing it now,*

> *if you can, otherwise leave a mark'. And I eyed him down and I said 'You know what? I'm going to do my best to get your job and put you where I am right now, because you have made me feel so small.' (Vince, 56, anxiety and depression, South)*

The complexity of Centrelink forms and requirements and the difficulties this presented to people experiencing mental illness was commented on by numerous interviewees.

> *It's like anything, you know, when you're unwell – I mean I'm rational but I'm heavily drugged that's what I describe as being unwell – everything is so much harder. You have to be very patient with yourself; your mind doesn't work well, you've got to take someone with you because you can't follow a form. I made sure last year that [my father] came to all of them to work things through. But my father and my mother are pretty incredible, pretty amazing. They never gave up. (Leo, 37, schizo-affective disorder, North-West Region)*

The anxiety experienced by many income support recipients when dealing with Centrelink has been reported in previous research. For example many of the participants in recent Tasmanian research describe feelings of being under constant surveillance and threat of loss of income (McCormack, 2001). These experiences are heightened for those people with serious mental illnesses the symptoms of which may produce strong feelings of dread and threat. The current shift in policy towards tightening the eligibility criteria for the Disability Support Pension has increased these problems as the following remarks illustrate.

> *I was frightened, like Centrelink is a pretty imposing place, and I was scared when I was going for the pension and I felt guilty and maybe I wasn't sick enough to qualify for the pension and that I was putting it on or something, and I wasn't. But it turned out I had no problems at all. (Clare, 35, schizo-affective disorder, South)*

> *It's so cruel. When we were trying to get him on the Disability Pension Centrelink rang him and told him he'd have to have another medical assessment with a doctor appointed by Centrelink. Well, I think that's what they told him. What he understood was that he had to 'score a number of points' or he would be in trouble. At the time he was being constantly told by doctors that he was too sick to return to work or study, it was very confusing for him. He became extremely fearful and he crawled under a house and hid in a dirt hollow. We were frantic; it took hours to find him. He was rehospitalised because of that. (Meredith, 53, son Donald, 23, schizophrenia, South)*

### 7.1.1 Providing income support after the onset of illness

For young people with mental illness and their carers the onset of illness might also coincide with their first encounter with Centrelink as families try to negotiate some financial support. For those entering the mental health system for the first time, this is an intensely traumatic period and one in which people are often not given the information they need to navigate the health and income support system.

The parents of young people who cannot participate in education or training because they are experiencing serious mental illness may find themselves in a bureaucratic tunnel of eligibility criteria. The average age for the onset of schizophrenia is the early 20s (Access Economics; SANE Australia, 2002). Since the introduction of the Youth Allowance in 1998, Australians under the age of 24 who are students and jobseekers under the age of 21 are subjected to a parental income and assets test to determine their eligibility for Youth Allowance. Currently individuals whose parents have a joint income of $28,150 or more are not eligible.[12]

Parents may be unable or unwilling to pay the full costs of board and independent accommodation for adult children, but the option of having an adult child with serious mental illness boarding at home, particularly if there are younger children present, may be untenable. The only income support payments potentially available to these young adults who are unwell are Youth Allowance at the independent rate[13] or the Disability Support Pension. Although young people experiencing exceptional circumstances should be eligible for Youth Allowance, the fact of homelessness or even substantial evidence of a parent's unwillingness to support or house a young adult does not ensure their entitlement (Welfare Rights Network, 2002; 26-27). At the same time it is very difficult for young people experiencing their first episode of psychosis to be assessed as eligible for the DSP as it is not possible to diagnose schizophrenia until a second episode of psychosis. The pension is also designed to support people with profound health problems over long periods and health professionals are unwilling to predict at first presentation that a mental illness will be long-term.

The Government's stated intention in the legislative change to Youth Allowance was to encourage young people to stay in education and avoid unemployment and to compel families to support their young family members until they have achieved financial independence (Ruddock, 1997 in Welfare Rights Centre, 2002:12). But the result of these discrepancies is that carers of young adults who are ill, who may require substantial periods of care and rehabilitation and who may never be financially independent, can get no income support for them. Furthermore, young adults (under 21 years) in receipt of the Disability Support Pension are not eligible for Rent Assistance if they live with their parents, although they would be if they lived in any other care arrangement.

The cost of this hole in the safety net is the havoc it wreaks upon both people who are ill and their carers. At a traumatic time for their family, carers are often unable to ensure their adult child is provided with stable housing, decent nutrition or even a regular income. If the young person does have problems with drug or alcohol usage the carers may find their relationship shifting from being focused on trying to stabilise their child's health to engagement in conflict about money.

> *It is the wording of things too, like to get on the pension, on the disability pension. There are a couple of category things. Like are you well enough to work for 2 hours a week? And there was a question like in the future, like 6 months or 2 months, I forget the way it's worded, 'Do you think this person will be able to work more than 6*

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[12] Eligibility criteria for family with 1 child. Cut off increases with family size.

[13] It must be established that it is not reasonable for the young person to live at home. This requires the young person to be living independently.

> *hours a week?' And if you get a tick in the wrong box, they'll just rule it out. That's what happened a number of times with Ben until I begged them to do something, because he was getting to the point where he was smashing things because we had no separate, he didn't have any independent money. We were told he was dependent on us until he was 25 so we were supporting his drinking and drug problems as well as his other problems. But he, he had no dignity, he had no independent money whatsoever, and it became a huge issue. One of the hugest issues, apart from his mental problem, was him not having any independent money. (Jenny, 48, son Ben, 19, with schizophrenia, South)*

### 7.1.2 Centrelink and clinical mental health services

The experiences described by the people in this research strongly suggest that Centrelink and mental health service providers do not liaise effectively to ensure that income and personal support is given to people who are eligible for it and who require it. Participants reported examples of hospital staff who were unable to assist them with Centrelink requirements. In a number of cases this worked to the clients' social and economic detriment (see the Case Study p7). Examples were also given of psychiatrists making decisions about eligibility for the Disability Support Pension based on their personal judgements about its purpose, particularly if there are issues with substance use.

Similarly, there were instances where the level of error and mismanagement of client information by Centrelink suggested that, in spite of reforms, vulnerable clients who are not clearly flagged through their status as Disability Support Pensioners remain at risk of unfair treatment. Participants gave examples of people with serious mental illness required to provide multiple health certificates when Centrelink refused to accept those from Government mental health service providers and mental health service workers taking unacceptably long amounts of time to fill in Centrelink forms essential to secure income for clients. Emma's story here conveys the level of effort, stress and desperation this process exacts on the carers in these cases:

> *Well I knew they [forms of income support for people incapacitated by illness] were out there, but you go and ask the people at Social Security and they seem to be ignorant of them. And it was quite interesting actually, because one day when I finally got through all the forms and the psychiatrist at the hospital hadn't signed his bit and he'd had it for 6 weeks and he still hadn't signed it. We were finally getting to the point where my son would at least have a financial backup, even if he wasn't going to have a medical backup, and it wasn't coming through because the psychiatrist hadn't signed the form. I mean he was just basically being slack. And I just cracked up. I, for months I fought for that. For 2 years I fought for his pension (I don't get an allowance) and a bit of recognition that this person actually is ill. And so I, I just stood there in front of all these people and howled. And the poor guy behind the counter was so distressed and embarrassed, he immediately went and got the social worker at Centrelink and she took me into the little private office and sat me down, and solved the whole problem. She phoned up the hospital, abused the psychiatrist I suspect, and it was all solved within 3 days. (Emma, 49, son Angus, 18, with schizophrenia, North)*

While people over the age of 24 do at least have the safety net of entitlement to income support payments, the assessment process is still lengthy and distressing.

> *When I was first starting off I did [have problems]. They'd put me on Newstart at first because I didn't go on the pension, and I was on that for ages and ages and ages until the pension come though and I seen so many doctors, I'd been to 2 government doctors, psychiatrists, my own GP and it was ages until I got it. All the doctors said the same thing, that I should have it, there's no, not my own fault, I should have it, and I eventually got it, but it took a long time… when I had to start putting in for jobs I just go to pieces, I'd drop everything, or cut myself, or I just felt incapable of doing it, and there was no way I could hold down even a part time job. (Ainsley, 56, schizophrenia, North)*

### 7.1.3 Poverty traps: The hazards of coming off the Disability Support Pension

For many people with serious mental illness access to the Disability Support Pension is their only means of a stable and secure income. Some recipients move from this form of income support to jobseeker allowances, which are subject to the mutual obligation regime of activity and administrative tests. Failure to comply with these requirements results in financial penalties, with significant reductions in payments. As described in Section 3.4.2, people with mental illness were identified among the highly vulnerable groups who were least able to comply to the requirements and most likely to be breached (ACOSS, 2001; Pearce, Disney & Ridout, 2002). The number of jobseekers receiving third breaches (100% loss of income) has reduced since the independent review into the social security penalty system, however breaching rates remain high, particularly for Youth Allowees (Welfare Rights Centre, 2002). Problems such as transience, disordered thinking and episodic illness means that people with serious mental illness on jobseeker allowances will continue to be highly susceptible within a complex system.

As these stories indicate there are a number of factors which drive people from the disability pensioner to jobseeker category, including their own desire to join the paid workforce, but also the tightening eligibility criteria for DSP. The combined pressures of the mutual obligation requirements, the breaching regime and the stress of managing a mental illness can readily result in the deterioration of mental health without adequate support. This process inevitably produces a cycle of illness and income support changes that is detrimental to the individual and resource-intensive and inefficient for both the social security and mental health systems.

> *Everyone keeps telling me I should be on the Disability Pension but I'm now back on Newstart. I was on Newstart Incapacitated but as soon as I started looking for a job they put me on Newstart and I've had a few people say to me 'You should be on a pension' because if you get a part-time job you're allowed to earn more in that fortnight than if you're on Newstart. (Daisy, 27, bipolar disorder, North)*

> *They're alright but it's hard to remember what to do with all the forms. One time they stopped my payments and I went in and said I wanted them back and they said they'd sent me forms and I hadn't returned them but they never sent them. Sometimes, though, they send the forms and I put them down to fill them in and I*

> *just forget, or I put them some place special to deal with and I forget where I've put them. Sometimes I go into Centrelink and they say 'What are you doing in here Rex?' and I say 'Have you sent me any forms lately?' But they haven't so they just say 'Don't worry about it, go home'. They're alright. (Rex, 35, depression and anxiety, North)*

### 7.1.4 Poverty traps: disincentives to family formation

One of the most fundamental problems faced by people with serious mental illness is loneliness and social isolation. For example, the LPDS found that over 63% of the participants were single and had never married (Jablensky et al, 1999). Longing for a partner, for companionship and a 'mainstream life' was a common desire reported by the participants in this research. In this context it is ironic, if not tragic, that those individuals with a serious mental illness who are fortunate enough to have a partner are then penalised by a reduction in their income support payments. In circumstances where the level of income is already at a minimum, further reductions could be a real barrier to forming a relationship, and certainly reduced income contributes to stress and anxiety, aggravating the symptoms of mental illness.

The following comments exemplify the frustration felt by participants in this study about this situation:

> *When you get married and, you are on the pension, you lose money. And I find that very hard to understand because you have still got the same bills. And Centrelink agree with us but they never seem to do anything about it. (David, 38, depression, North)*

> *Yes, well, and it [income] diminishing as well with being partnered now, like being with Briony, my girlfriend. I have dropped I think around $200 a fortnight and she has dropped about $80 a fortnight and that's like a massive amount ... because we are now partners, so that's made life hell. Well, the Centrelink lady that I spoke to who made the decision that we were de facto said that we should have looked at the financial implications before entering the relationship. (Bill, 33, partner Briony, 19, with schizophrenia, South)*

## 7.2 Financial Management

Living on a very limited income is extremely difficult for most people. When the demands are further complicated by the effects of serious mental illness, the careful and conscientious management of finances required to survive is often almost impossible. Disordered thinking, confusion, lack of motivation and the capacity for planning are some of the characteristics of these disorders which make even basic budgeting difficult. Many of the participants in this research spoke about the difficulties of managing their finances, particularly during episodes when they were severely ill.

> *I lost control of it and spent an awful lot for a long time and had to pay it back for a long time. And I had to get help and I am still paying it off. So credit cards are a horror show. (Anita, 39, depression and bipolar disorder, North-West Region)*

> *I got my credit card a $1000 limit. And I bought, instead of buying clothes I bought a CD and a TV. I went $200 over the limit, and now they are taking it out and I only get $250 each pay day instead of $446. I need someone to make a budget out for me, so I can try to save and I can try to stick to it. Because my money's gone in a couple of days on the horses but I'm, being on a pension, disability support pension, I'm not working, I've got nothing to do with my time. (Neville, 51, schizophrenia and anxiety, North-West Region)*

The symptoms of mental illness can also make it difficult for people with serious mental illness to organise nutritious or regular meals for themselves. The suppression of hunger, difficulties managing money, lack of motivation and co-morbidity can all make the routine tasks of securing regular meals difficult.

> *I get too lazy and I can't be bothered cooking so I just have a tin of baked beans or a tin of rice cream or something like that. Yeah, I lack motivation. Most of my money goes on the horses. … Baked beans, spaghetti in the cans, and rice cream and that's about it, I didn't eat very much. But I'd drink a hell of a lot of tea. And smoke a lot, thirty a day and … No just probably milk, tea and sugar. It's what I used to live on. As long as I had milk, tea and sugar and a packet of smokes, I'm right. I didn't worry about food, that's not beer, it's milky tea and sugar. (Neville, 51, schizophrenia and anxiety, North-West Region)*

The options for obtaining assistance with managing finances are very limited for people with serious mental illness. Some of the participants interviewed indicated that they had formal or informal arrangements with family members, boarding house managers or mental health services and, in one instance, with their general practitioner. However such arrangements can place additional strains on personal and professional relationships.

The Guardianship and Administration Board is able to order the appointment of an Administrator to make legal and financial decisions for an adult with a disability who cannot make reasonable judgments about financial or property matters because of their disability. An Administration order is a last resort option to be used when no other realistic alternative is available. The Public Trustee receives State Government funds to act where clients do not have another person who is willing or able to take on this role.

Community Service Obligation (CSO) clients administered by the Public Trustee have assets to the value of less than $100,000 and are among the most disadvantaged people in Tasmania. They are on very low incomes, have few or no assets, their disability means that they are unable to manage their own finances and they do not have anyone else who is able to look after their finances effectively.

In addition to the State Government funding, the Public Trustee covers its costs through the imposition of client fees and charges. A review by the Public Trustee of the fees charged to CSO clients found that the monthly cost to clients represents about 8.5% of income for a single person relying on the Disability Support Pension as their sole source of income. At $550, the Establishment Fee represents more than a full fortnight's income for this group. While the Establishment Fee can be paid off over time, a client relying solely on DSP will be paying more than 10% of their income to the Public Trustee during this period.

Where the client has debts accrued prior to the Administration order to be paid off, as is often the case, the combined impact of debt repayments and Public Trustee fees can leave the client with very little income remaining for their living expenses.

The current fees and charges act as a significant disincentive for people who might otherwise seek the services of an Administrator or for family members or service providers who believe Administration would otherwise be in the best interests of a person with a disability. For example, Max was diagnosed with schizophrenia 10 years ago and experiences chronic and regular psychotic episodes which lead to periods of hospitalisation. He is unable to work, finds it difficult to organise his thoughts to undertake self-care activities, to cook or maintain a tenancy. He is constantly concerned about his financial state and regularly runs out of money. As a consequence of his inability to manage his finances Max experiences substantial periods without shelter and often runs out of food before his next pension is due. Max is aware of the Public Trustee's Administration service but said he did not think he could afford it.

> *Well [my friend] Jason, Jason went on the Public Trustee program you know, I, I actually asked about it when I went with him to pick up his food, you know he goes every Monday and Tuesday and picks up a load of groceries and that. The only thing is they charge you $500 a year to do it … I wondered if [a charity] had a service that was, that didn't cost so much to run. (Max, 41, schizophrenia, North)*

The prohibitive costs associated with the Public Trustee's Administration service have led to a range of other more informal arrangements for clients who are willing to have service providers manage their finances. However, such arrangements are labour-intensive for the services involved, may compromise client relationships and may involve risks of perceived or actual impropriety. The main reason cited for not referring these clients for formal Administration orders is the high fees and charges imposed by the Public Trustee.

### 7.3 Employment and training

Employment is the pathway out of poverty but it is a difficult route for people with serious mental illness. The illness itself, the side-effects of medication regimes and the difficulties in finding appropriate work all combine to make lifelong unemployment the reality they face in the current employment environment. Some of the people with mental illness interviewed had histories in the workforce, others had developed their illness before finishing their education. Despite this, nearly all expressed a desire to one day be well enough to be able to do meaningful remunerated work. But, as the following remarks indicate, people with a serious mental illness would have to overcome the major obstacles they confront through daily living before they are able to meet the requirements of paid employment.

> *Of course I have thought about going back, but look those things are pointless at the moment. I have to stop taking drugs, I have got to eat properly, to do my washing up. I mean frankly going back to school or working or whatever, it is not a priority. I have to live first or I will not be able to sustain it. (John, 28, bipolar disorder, anxiety disorder and substance use, North)*

> *You have to go to work every day of the week, no matter how you are feeling. I personally am absolutely scared to death of having to ever go to work. I am truly petrified of ever having to go to work. I can do my voluntary work because I love the people that I work with and I think that's my passion, to work with people, but to go to a job — I would be terrified and I have absolutely no confidence I could do it. (Dawn, 45, depression and bipolar disorder, North)*

> *And I've been too frightened to go back to work. I get nervous around violent men and I couldn't hold a job down. I've been too sick. I did a bit of work in the day centre making things with my hands and all that sort of stuff, did clay work and all that. I just think I'm too sick to keep a job. And now I'm coming right I've been, well I'm fifty-one now, so I don't know if I could get employed. From '84, to now, I'm fifty-one, I lost all that life. (Neville, 51, schizophrenia and anxiety, North-West Region)*

Training and education is another area which is difficult for people with mental illness. Just as many aspire to paid employment, they also want to increase their education and gain qualifications which will help them to find work. A number of the interviewees had accessed the Pensioner Education Supplement to attend TAFE. However, in addition to the symptoms of their illness and the side-effects of medication, which can often produce drowsiness and problems with concentration, the episodic nature of mental illness can make completing courses of study difficult. A number of participants had commenced study but none had completed for a range of reasons, some of which are described below.

> *So I went to Uni and studied sociology and history just part time, and did alright, got sick, ended up in hospital, and came back. And then I had 6 weeks of work to catch up on, caught up on that, did that year, passed the exam, started the next year, got sick, found I had 6 weeks of work to catch up on, caught up, passed the exams, looked at the 3rd year and thought God this is a bad pattern. I'm stressed. Yeah, I might, I might give it a rest for a while, maybe go back one day, but the thing is I have forgotten everything I learnt anyway, so it's just pointless. I mean, I might, I might have good marks on paper, but in my brain I don't know what I learnt. So it's futile. (Clare, 35, schizo-affective disorder, South)*

> *I went to TAFE and everything was going really well and then six months down the track I crashed. I went into a depression and I couldn't go back to work and in terms of family and jobs I suppose it's the stigma that you've got mental illness. People don't really understand. I think give people half a go and that's the biggest confidence booster sometimes. (Daisy, 27, bipolar disorder, North)*

> *Everything I accept to do, like seriously I was going to do the Adult Ed overlocking course, I was so wrapped in it. Two days later my life had seeped away and I had to ring up and say I can't do it. (Denise, 52, bipolar disorder and anxiety, North)*

### 7.3.1 The need for supportive employment environments

People with serious mental illness also face extreme difficulty in getting paid employment, as they often encounter discrimination in the workplace, with employers unwilling to take on someone with a diagnosis of mental illness. There is a growing recognition of the support needs in training and employment programmes for people with disabilities, including psychiatric disabilities (Frost, Carr & Halpin, 2002; Shankar & Collyer, 2003). A number of participants reported very positive experiences in training and rehabilitation environments. However they do highlight that the labour market is not so supportive or accommodating of the employment needs of people with a serious mental illness.

> *CRS [Commonwealth Rehabilitation Service] they spent about $10,000 on me to qualify me up for work. I've just did Security, Crowd Control and Security 2. And I've finished that now. Now I'm working with Dave here to get a job and I'll see what happens now. But TAFE is good to me, CRS is good to me. Yeah, they're very dedicated at CRS, they're very good. But the biggest problem is my schizophrenia 'cause as soon as the employer finds out you've got a pension card they want to know why you're on the pension. That's the biggest problem that I face at the moment getting back into full-time work. I've put in for something like 500 jobs and no interviews. I just don't get interviews. And as soon as you say schizophrenia they more or less finish the interview and you never hear from them again. It's just, it's very hard for me to get back into the workforce. (Les, 41, schizophrenia, South)*

> *With Adult Ed it was the expense as well as becoming unwell. With the TAFE course, the people were great but expense was a problem as well. The CRS was good, they helped me to find work with the art works and he gave me a subsidy through Centrelink. But I thought if they could provide work for people which is suitable, where staff may be made aware that a person is becoming unwell and might need to take time out. But casual on-call work is just not ideal. Your sleep pattern goes out of whack amongst other things. Part-time permanent work, I think, is more or less ideal. (Dawn, 39, depression and bipolar disorder, North-West Region)*

> *No, I wasn't able to do my job [as a housemaid] and so I had to see the doctor and I went into hospital. When I get sick I go into hospital and I leave work and then. No I couldn't do the job and I just got sick and went to hospital. (Belinda, 36, bipolar disorder, North-West Region)*

Supported vocational rehabilitation and employment programmes have been demonstrated to be effective in assisting people with serious mental illness to enter the workforce (Frost, Carr & Halpin, 2002). However, there is insufficient access to these programmes nationally due largely to the historical focus of Commonwealth Government supported employment programmes being predominantly limited to people with intellectual disabilities. The majority of participants in this research strongly articulated a desire to engage in meaningful and satisfying activities including study and paid employment, but to achieve these goals requires a substantial support structure commensurate with their needs which might include flexibility of work hours, suitable physical environments and intensive mentoring. As Shankar and Collyer (2003) point out, in addition to support for the client, the support network should extend from the vocational rehabilitation program to support and education for the employer and strengthening social networks. Notably this study found that strong emotional support was a key determinant of successful employment for people with mental illness. They argue for a much broader approach to vocational rehabilitation for this group.

# SECTION EIGHT

## OVERCOMING THE BARRIERS TO SOCIAL EXCLUSION

### 8.1 Social isolation, mental illness and poverty

The participants in this research reported a quality of life which was, in most cases, very poor. They were largely isolated from their communities, with lives characterised by extreme loneliness, boredom, financial crisis and shortages of essentials such as food and power. The absence of community support – rehabilitation programmes, non-clinical community-based services providing opportunities for social and professional support, accessible and affordable housing, supported vocational and employment training, and accessible transport – means that many people are at best experiencing what the Mental Health Council of Australia has described as 'institutionalisation in the community'. This means that people with mental illness are 'contained' by the limited service response of mental health care providers, rather than having recovery and quality of life promoted (Groom, Hickie & Davenport, 2003). At worst, the support and service system is so deficient that many people are caught in a constant cycle of poverty and ill health. The stress of life in constant financial crisis exacerbates their mental illness and this perpetuates the cycle of poverty. Neville's description of this life encapsulates the loneliness and dreary hopelessness of his daily life:

> *Some days I would just spend it walking around town asking people for money and cigarettes and go in the Christian bookshop and get a cup of coffee. Just wasting my life, just did nothing, just wandering around or stay home all day and watch the soapies and all that. Just lost motivation, get upset with myself. Yeah that's how I spent my days. When I was broke I used to sleep in late and take some extra medication to bomb me out again so when I woke up the day would be over. (Neville, 51, schizophrenia and anxiety, North-West Region)*
>
> *Oh, just the isolation you know. [It is] mainly the loneliness you know. And you know, and it is difficult on your own because you try, but at this place with no phone on, it's awful. Sometimes you know, you can only watch so much TV, you can only read so many books, you can only read so many papers and then what do you do? Nothing. (Rosemary, 53, schizo-affective disorder, North)*
>
> *I used to go to the Bible Study but I don't really do anything else other than that. I could be doing more. Often I feel I should be doing more. I spend a lot of time at home. It's a bit different when I am on my own. When I was living in [town] I hardly knew anybody, you know, and I used to not get out at all really. (Belinda, 36, bipolar disorder, North-West Region)*

People also reported social isolation caused by lack of income. As these two narratives suggest many people felt trapped in their homes, unable to afford the cost of any social activity that required them to pay for transport or purchase anything, even a cup of coffee.

> *One of the biggest things is not being able to get out of your flat. I mean you can get out and walk. But to do the things you used to do is the hardest thing. You know you think to yourself 'I used to go down the casino' and all that sort of stuff. It's sort of 'Oh I'm stuck in the flat all the time' and it does get to you and that's when it starts to play on you inside. But as far as putting money aside, you never get to. (Vince, 56, anxiety and depression, South)*

> *Watch TV, read books. The only thing I do is watch TV and read books. I hardly ever go out my front door, for just that reason [can't afford to]. (Alex, 50, bipolar disorder, North-West Region)*

### 8.2 Breakdown of family relationships

While close interpersonal relationships can be a protective factor with mental illness, many people find themselves alone because of the illness, which can create significant conflict and problems in relationships with partners or families. Many participants in this research had little or no contact with their own children or their parents or siblings. The following narratives illustrate clearly the human and social cost when people with serious mental illness are not provided with adequate support to maintain family relationships, even with their children.

> *But I don't see them [2 teenage children] very much, so it's not such a great effect. I think they would be much happier if they could see you clean shaven and well dressed ... they just want to see you looking after yourself. It's that simple. Yeah. They want to see you shine. Especially as they get older. And this is why the ex's don't want me around them because as far as they are concerned I am not showing the right example. (Max, 41, schizophrenia, North)*

> *I ran away from home at 16 and didn't have contact with my family until last year. And I turn 29 tomorrow, so, yeah. So for all that length of time I didn't have contact with them. But mental illness runs through the family and I had depression and so did both my parents so I just grew up in that sort of environment. I didn't have the life skills that I should have had because my parents were too sick to teach me that sort of stuff. (Stacey, 28, schizophrenia, South)*

> *And the only other thing I want is, I would give anything to see my grandchildren. But I can't because they said, you're – what did they call me? When other people are being nasty, and they call you manic, or something like that, and you are not coming near the children. Their mother keeps saying that, yeah. (Ainsley, 56, schizophrenia, North)*

Both the people with mental illness and the carers described a chronic lack of support for the families of people with mental illness. The potentially devastating impact on children of living with a parent with serious mental illness was described by a number of participants. Without adequate early intervention and parent support programmes, these children are at risk of developing mental illness and of being trapped in a cycle of disadvantage (Raphael, 2000). A number of the research participants described the devastating effects their illness had on their children. For many it was a great source of guilt and grief.

> *My daughter has talked to me on several occasions about what it was like going through my depression for her from in Grade 6 upwards and she had to take the responsibility of me because I had left her father and there was the 3 children and me. Some days she would come home from school and I would be in hospital … Yep, or I would be there in a pool of blood or I spent days and days and days in bed … And what angers me now is that there was never a recognition by anybody of what is this doing to your children. Are your children being supported? (Dawn, 45, depression and bipolar disorder, North)*

> *My son turned into a heroin addict and he … I mean he is a lost cause. He is sixteen you know, and his father is saying 'Well I don't really care about it' you know, and I am saying 'Well I love him. I worry about him'. This is what is making me sick, I can't sleep. And he has just gone down again. And I know it was me, it was him having to grow up [too fast]. (Denise, 52, bipolar disorder and anxiety, North)*

> *My eldest daughter started a psychology course and did it for two years and she said 'I understand your illness now', so it doesn't bother her. My youngest daughter, she has got, she tried to commit suicide a day ago … And that to her, she can't deal, see she thinks that it's, she blames herself, that I've got bipolar and we've tried to tell her that it had nothing to do with you at all, and it could happen to anyone. [She's] sixteen yes. (Loretta, 39, bipolar disorder, North-West Region)*

> *My grandson locks me in my bedroom and tells me 'Stop being retarded' and bangs the door on me and says 'You've got to sit there until you come out of your dither'. I get into a dither. But that was, that was the best medicine for me. If he says 'Stop being retarded' and shuts the door, that's my medicine. (Elaine, 59, bipolar disorder, North)*

Faced with major impediments to maintaining friendships and family relationships because of the shrapnel effect of their illnesses, the participants in this research also reported that poverty itself created tension and aggravated their family breakdowns.

> *I have a 4-year-old as well. It's hard when she comes round. I've got TV but I haven't got videos or things like that. She says 'How come you haven't got it, Dad?' and I wonder that myself. You think before you got sick all the money that you did waste that you could have, you know. (Vince, 56, anxiety and depression, South)*

> *I do have 3 children by my first marriage who unfortunately I don't see very often because the illness has a stigma. I have got a 7-year-old daughter from a de facto relationship and sometimes going and picking her up and walking her to school is my outing. It is hard when it's their birthday or Christmas coming up or Easter and you need to get presents. And children expect a lot these days and you can't get it. So I lead a very lonely life and that sort of pins me in myself and it makes me ill again because it makes you spend too much time by yourself getting your old ticker ticking over and it makes you think you're going to die a lonely old man. (Gavin, 44, anxiety, South)*

## 8.3 Breaking the cycle: the role of community-based support services

The policy of deinstitutionalisation is based on the fundamental premise that people will be supported to live sustainable and meaningful lives in the community. As this report has documented, adequate support in the community presumes a range of services to support a range of needs. These include assistance with life skills and tenancy maintenance, budgeting advice and vocational support, as well as providing information about services to both people with mental illness and their family members. The participants with mental illness and the carers described a state mental health system locked in a pattern of crisis response. They identified a critical shortage of supported accommodation options, rehabilitation services, community drop-in centres, medical support and access to information. Yet the provision of these services is the fundamental element in an effective framework of community support.

In the following quote, Bronwyn describes the cyclic experience of many people with chronic mental illness. Her son Keith experiences patterns of homelessness brought about by the lack of support he needs to manage his daily life. His life, like the lives of the majority of participants in this research, is a constant cycle of psychotic episodes and hospitalisation brought about by the failure to support his recovery in the community.

> *Well, he has been at [NGO residential rehab. service], he has been on his own. Out on his own he is fine for a while and then he just goes downhill. He has had where he owes a lot of money in the end, you know, because he doesn't pay his bills. He can't maintain his money properly, he doesn't eat properly, then he gets into bad company because they are the only ones who will accept him, and so it is a merry-go-round with him. And we were hoping it is broken now, because he seems really good and has been good for a few months now, but I am waiting for the crash. You know, you wait. (Bronwyn, 56, son Keith, 33, with schizophrenia, South)*

The experiences reported in this research strongly confirmed the value of a range of support service options and the positive impact they can have on people's lives and mental health. Where people did have access to services they valued them highly. While different models of services suit different clients, where people had found a model which was available and which suited them, they praised the support they received.

As the following narratives illustrate, people attended and valued support services for a range of different reasons. A number of participants viewed the social interaction as the most important aspect of the service.

> *I've been around here [NGO mental health service] backwards and forwards for about six years … and that's the good thing about being here, that sense of acceptance no matter where you are and if somebody else hasn't been through it, someone has you know and you don't feel judged. (Mandy, 39, bipolar disorder, South)*

> *At the support group … we had a guy there who pulled his curtains back for the first time in 3 years, and he used to sit on the end of his bed day in and day out. So I just think all these support groups are very, very, very valuable, and they should be*

> *really, really encouraged and funded. It all comes down to the funding. (Bruce, 61, depression, South)*

A number of the participants had established a very structured schedule for each day of the week which they felt was vital to maintaining stable mental health. The valuable role provided by mental health services and non-government organisations is evident in these comments.

> *I started full-time [at TAFE] and I have gone down from 3 days now to 1 day, and at the moment I am finding it hard to, to go, I'm not very well. So, that's 1 day a week on a Monday, on a Tuesday I don't have anything on, on a Wednesday I have yoga in the morning and in the afternoon I have a spinners group which is run by [Mental Health Service], and then on Thursdays I have spinning in the morning, and in the afternoon I have art group at [Mental Health Service] and then Friday I see my GP. So that's all and then Sunday I go on a bus trip with the [Mental Health Service]. (Stacey, 28, schizophrenia, South)*

> *I go first to the [charity] and do voluntary work 1 day a week. I don't get any help with petrol for that. Oh that's good, being around people. I enjoy that. And I have a [NGO befriending scheme] mate that comes and sees me one day a week. Yeah, and Saturday me and my wife will always do something with our son. And I go and play bowls one day a week. Sometimes I find that hard, if I haven't got the money but I really like my bowls. Yeah and I go to [Mental Health Service rehabilitation service] one day a week as well. (David, 38, depression, North)*

People also reported different concerns they have experienced with different services. This reinforces the need for a variety of service options and activities to meet the wide range of needs and expectations of people with mental illness.

> *[Mental Health Service] assumes that if you have a mental illness, you also have very low intelligence. There is no, yeah I mean OK, I did woodwork, I did the communal cooking, I can't remember what bits I did, but there is no intellectual part to their addressing of issues that you have or of content of courses that they could provide, and yet people with mental illness aren't necessarily underachievers. (Dawn, 45, depression and bipolar disorder, North)*

Service providers and users all report that there has been a gradual downscaling and withdrawal of these services on the ground. Given the essential role to be played by community-based services, it is a matter of great concern that community mental health services, the services provided by the Tasmanian Mental Health Services and the non-government sector, are critically under-funded resulting in severely limited staff and service options.

In many cases, when questioned specifically about the events of the first years after the first psychotic episode, younger people and the carers of people with mental illness under the age of 25 reported difficulties across the whole spectrum of care. They reported obstacles to getting access to information, appropriate referrals, rehabilitation services, regular appointments with psychiatrists, proactive community support, secure accommodation or income support (See Case Study p7). This is particularly alarming given the findings about the need for early and active intervention in the critical period between two and five years after the first psychotic episode, when most of the impairment and disability arise (Access Economics; SANE Australia, 2002). The absence of early intervention clearly has the impact of determining a future of illness and disadvantage.

> *Yes, because up until then his psychiatrist kept saying 'No I am not putting him on the Disability because I feel I am just feeding his drug habits, and it is his drug habits that are the problem, not his schizophrenia'. So the psychiatrist refused to. But then, once he was admitted into the hospital and I spoke again to the psych team, they agreed that he has schizophrenia, it was a long term mental illness, and they organised his benefit on the condition that they would put all these things in motion. But they didn't, nothing happened. (Jenny, 48, son Ben, 19, with schizophrenia, South)*

The policy framework developed in the National Mental Health Plan clearly articulates 'recovery' as a guiding principle which supports the objective of independent living in the community. State Mental Health Services are required to implement these policy objectives through governmental services and non-government organisations. However, despite increasing demand for services, community-based agencies report that there has been no corresponding increase in funding to meet the needs of this growing client group. Some community services report that they are inadequately funded to cover core operational costs, let alone maintain staffing levels at a level which meets basic worker safety requirements. Other small support services describe the stress of having to constantly reapply for core funding without certainty that the service will be continuing. Government mental health services present as similarly under-resourced and as a result are not providing the range of support in the community which is so essential to helping people to stabilise and recover. A more detailed discussion of mental health service funding in the State is provided in Section 3.3 and Section 9. However, it is important to note here that the catch-cry of the National Mental Health Plan, State Mental Health Plan and the conversation of mental health service staff at all levels is to increase the role of non-government organisations in the care of people with mental illness. It is critical therefore that the community sector is funded accordingly and appropriately to provide services at a level which can meet the high level of need.

# SECTION NINE

## MENTAL HEALTH SERVICES AND THE CYCLE OF POVERTY AND MENTAL ILLNESS

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 was of acute clinical services in a hospital setting. As a result, when asked about mental health services, people responded with descriptions of hospital services.

The intention of this research is to focus on the interaction between poverty and mental illness, not to evaluate hospitals or mental health services generally. For this reason, the section reporting on acute care services is presented within the context of poverty and the social conditions of people's lives. 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.

### 9.1 The revolving door of acute care services

This section examines the 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 recurrent theme emerging from all the group discussions was the oft-repeated cycle of episodes of illness triggered by the unrelenting difficulties of life on a low income. Participants described in detail how trying to survive the disarray of mental illness in the context of the stress of living on 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 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 Dawn succinctly points out:

> *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, North)*

All the participants in this research reported a pattern of repeated hospitalisations in acute care psychiatric services. For many the hospital represented a refuge, a safe place where they could be relieved of the burden and fear of the symptoms of psychosis, as well as receive regular meals and be warm and clean. The system is not working when the most vulnerable members of the community are forced into hospital to find sanctuary from the combined effects of their illness and their poverty.

### 9.2 Admissions

A strong theme of the focus groups was people's difficulty in gaining admission to hospital when they were feeling extremely unwell. There is considerable pressure on psychiatric beds across the State, with a consistently high occupancy rate. As Neville describes below, the rigorous triage assessment combined with the paucity of community follow-up or support options can result in frightened, unwell and lonely people 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.

> *I go to hospital. Yeah, they made me wait for hours, because it all depends how sick you are who goes in first. If they see you and they think you've got nothing wrong they will just leave you sitting there until last. Yeah, and panicking, not sitting, walking up and down, walking around panicking. You're hearing voices and that...I've been out to the hospital and they don't do anything. They just say 'There is nothing we can do. Best to just go home and take your medication and have a cup of tea'. (Neville, 51, schizophrenia and anxiety, North-West Region)*

Participants also told of being refused admission because no psychiatric registrar was available and of long, distressing waits in the Department of Emergency Medicine cubicle dedicated for people presenting with psychiatric symptoms. These cubicles are intended to provide privacy and security, however, as the comments below indicate, the perceptions of people confined in this situation differ significantly from those intentions.

> *This is what they do with mental patients. So that you are not mingling with the normal patients, they take you away. But because they are very busy in Casualty, instead of waiting your six hours out in the waiting room along with everybody else, you spend your six hours in the waiting room locked in with a security guard at the door. And every now and then if you are lucky, someone pokes their head in and says 'Do you want a cuppa? I thought, the first time I went in there, there was blood on the wall. It was terrifying. (Clare, 35, schizo-affective disorder, South)*

> *I was brought in when I was really ill or bad. We call it 'the box', down there in DEM [Department of Emergency Medicine]. You're placed in this box and a security guard will come up and stand next to you because you're in there for a mental problem. Because you've got to see a doctor to get into the ward, they'll ring the DEM nurse and there's all this glass, plate glass, and you'll be in there for 5 to 6 hours and then you've got to wait for hours until a psychiatrist comes down to evaluate you.*

> *And in between that time everybody knows that you're there for mental health problems so they look at you, the other users of DEM, and at the crisis that you're in. It's the most uncomfortable, unbearable… [A]nd when you do actually get admitted, which is lucky nowadays, you'll be in there for one night, usually, and released without even seeing a psychiatrist. The mental health system has really collapsed. I mean that. (Gavin, 44, anxiety, South)*

### 9.3 In-patient care

There was also a perception among the participants 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 expressed concerns relating to the limited time spent on the wards by the nursing staff, what they saw as cutbacks to in-patient recreational and rehabilitation services, and their perception that the length of stays in hospital were being determined by budgetary concerns. Australia-wide there are difficulties in attracting allied health professionals such as psychologists and occupational therapists to work on psychiatric wards because the average length of stay does not allow for effective therapeutic interventions.

When discussing the therapeutic response provided in acute care services, a number of participants expressed concerns about the lack of interaction between patients and hospital staff.

> *I've been at the hospital and can't talk to anyone, you may as well be at home or that's how I found it when I was there. Other people might be different but no one talked to me or said anything and the only time someone talked to me was when the psychiatrist said 'You can go home'. And I hadn't spoken to anyone and I really wanted to talk. They only kept me in there three days, you know. You're in and out quick. (Ray, 56, anxiety, South)*

> *There's a distinct breakdown in communication between nurses and clients… You see, the problem is the nurses don't spend enough of their time out on the wards, sort of doing the rounds asking, 'What's going on here? Have you got any problems?' More and more you have to go them and they're doing what seems to be reams and reams of paperwork and that's what they say, rather than actually them coming and spending time on the wards, which you would think a nurse would be paid for. But I mean there aren't enough nurses. I don't know where they have all gone. (Leo, 37, schizo-affective disorder, North-West Region)*

> *[Time in hospital] was time out more than anything else. It was waiting for the drugs to work and being in a safe place while I was waiting for the drugs to work. The hospital didn't used to be as bad as it is now. The hospital is awful. The nurses don't want to be there, and the patients don't want to be there. There's nothing to do, there's no activities. When I first went to hospital we had a meeting every morning. And you could compare notes and get to know each other and stuff. There were craft activities, there were games, you know like lawn bowls, or carpet bowls, or whatever, just things like that, and music, and I think they brought dogs in that you could pat. But now all you do is you sit in your room and feel like shit. (Clare, 35, schizo-affective disorder, South)*

The heavy reliance on acute care mental health services resulting from a lack of community-based services means that the only type of treatment offered is not the optimal option in many cases. For example, participants who are the parents of young people with emerging psychosis were concerned about their treatment in the acute care system. These concerns are reflected in research which shows that treatment through early intervention programs in the community is a more effective response for young people with this condition (for example Access Economics; SANE Australia, 2002).

> *The psychiatrist at the hospital kept saying, you know hospital is a bad place, it's not a nice place for teenagers to be in. But that's all very well, but this teenager was already living in a fully psychotic state, it wasn't nice regardless. (Emma, 49, son Angus, 18, with schizophrenia, North)*

Jenny's description of her son Ben's first admission highlights a number of the problems raised in the course of this research. Ben was initially admitted with a drug-induced psychosis. His experience in the hospital and the combined effect of poor communication, inadequate rehabilitation, and premature discharge resulted in a very rapid re-admission. Jenny and Ben's experience illustrates the frustration felt by many of the carers who participated in this research.

> *... the staff were very half-hearted about Ben. You know they said 'Oh he'll be one of these people who will come back and back. We'll see him again in a month's time.' I organised for him to get his pension. But while he was in the lockup ward for 12 weeks or something, I stipulated that he would need a social worker to help him do his banking, and they promised me that they do put all that stuff in motion. They said they would get an occupational therapist for him to do things during the day. Well they just handed him his money, and they put him in [Mental Health Service supported accommodation], gave him a private room, but there was nothing for him to do, apart from playing scrabble with a couple of older people with mental illness. So his mates just turn up at the door, take him out and he'd be drinking bottles of whiskey. He went through his whole pension, and then he would go back there and they would give him his medication and off he'd go to sleep for the night. They were quite happy with that. And what skills did they teach him about life and living on medication? And it was his first time on medication. That's how he lived for a couple of weeks until he disappeared one night and he actually tried walking in front of a car. And he ended up in such a mess that in the end he went back to the lockup ward. So yeah, he was just so lucky that he survived that. (Jenny, 48, son Ben, 19, with schizophrenia, South)*

### 9.4 Discharge Planning

The discharge of patients was another key area of concern for the participants in this research. Effective discharge planning is particularly 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. The key components of effective discharge are: the assessment of patient physiological, psychological, social and cultural needs; the development and implementation of an integrated care plan; follow-up post-discharge and the evaluation of the discharge strategies (DHS Victoria, 1998). In the case of people who have been hospitalised 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. These fundamental elements of discharge planning are particularly compromised for people who are living on low incomes.

This research identified 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. The participants in this research recounted numerous stories of being stranded by the discharge process. Participants told of being left in the foyer of the hospital with no transport to get home, or of being discharged from hospital to situations of insecure housing and poverty.

> *Oh yeah, they discharged me from hospital into my car. No, I am not joking, that's what they did. That's what they do. It's hard to believe but that's what they did. (Mandy, 39, bipolar disorder, South)*
>
> *[Do they check you have got somewhere to live when you get out?] No. [Do they check to see you can get home safely?] No! It's not the bloody Hilton! Usually I'd have my car because I'd have driven there, so I'd come out pumped up to the eyeballs on drugs and get in the bloody car and drive home! (Rex, 35, depression and anxiety, North)*
>
> *They don't care. No, I mean once you are out, you're out. Yes. Yeah, you take your bag and piss off, that's it. They say 'if you are waiting for someone, pack your bag and put it in the office and wait in the lounge room, we need the bed'. (Stacey, 28, schizophrenia, South)*
>
> *They don't ask you if you've got someone to pick you up and you don't have 5 cents to get home. They don't care... Sometimes I've walked, sometimes I've had to make a reverse charge phone call if I can track down my mother and if I'm lucky enough I'll have a fare. (Gavin, 44, anxiety, South)*
>
> *I don't know whether it is still the same, but when Donald was in hospital you just knew that they were pushing to get them out for weekends. Like on Friday they could be as sick as could be and they would say to them 'You would like to go home, wouldn't you?' And they would say 'Yes', and you would go in and either they had already toddled off with their plastic bag full of gear, or they were seated on the bed to be taken. That happened to him a number of times. (Meredith, 53, son Donald, 23, with schizophrenia, South)*

It is hospital policy that no patient should leave acute care without an appointment with a GP and a referral to community mental health services. However, participants reported a lack of follow-up care within the community. This may be because this group are leaving hospital with illnesses that are characterised by disorganised thinking and poor short-term memory retention, who may have insecure housing and poor access to transport and telephones. When faced with a long waiting period for a service, they may find it difficult to continue contact with mental health services.

> *You just go home. There is no follow-up. You go home with a bag of pills and nothing. (Denise, 52, bipolar disorder and anxiety, North)*

> *Well coming out, the other thing is follow-up. I was in there over a 12-year period and follow-up probably happened twice in those 12 years. I don't know what follow-up is. (Leo, 37, schizo-affective disorder, North-West Region)*

> *Go home. Go home and cry and cry and cry and cry. My last one, after my last admission I was dropped home to an empty house on my own and all I did was cry. (Dawn, 45, depression and bipolar disorder, North)*

But, as Clare's story highlights, planned continuity of care in the days after discharge can have a very beneficial and ongoing impact.

> *Well for the first time ever, I was assigned a case manager last time I was in, which was Christmas time last year, and she's great. And she is really good at keeping me on track, and it's the first thing they have done for me ever. We just talk. Yeah I go and see her when I want to. It's once a fortnight now or when necessary. (Clare, 35, schizo-affective disorder, South)*

### 9.5 Information and referral

The mental health system is extremely complex and service provision in this area is multi-dimensional. For family members and for people who are ill it is almost impossible to absorb an overview of the services available to them on entering the system for the first time. However, without an effective community-based approach to early intervention, hospitals will continue to be the first point of contact for many people and they are therefore critical in the initial assessment of clients' needs and the provision of information. In spite of this a significant number of participants and their carers reported that even after a number of hospitalisations they still have been given little, if any, information on important services, including clinical, accommodation, rehabilitation and support services.

> *I've had to find it out in dribs and drabs along the way. Nobody pointed out to me all the facilities. When I was first diagnosed and came out of hospital and needed all these things, when I was at a crucial point and needed them I wasn't told. I found out about them in dribs and drabs along the way and found out somehow. I think they should have, all hospitals or psychs, should have a list of all the services. Probably they do but they don't give it to you. (Daisy, 27, bipolar disorder, North)*

> *Well you get a pamphlet, a couple of pamphlets telling you about schizophrenia and that's it. (Sue-Ellen, 56, son Luke, 32, with schizophrenia, South)*

Being in hospital for a psychotic episode or having a family member hospitalised for that reason is a time of tremendous stress, anxiety and confusion. It is well recognised that in this situation, people may find it difficult to absorb information given to them. It may be that in some cases, people with mental illness and their carers are told about service and support options available in the mental health system. It is possible that when they say ‘we weren’t told about any services to help us’ they are actually reacting to the paucity of services offered. What this research clearly demonstrated is that most of the participants felt that they were not told anything. This suggests that the information needs to be provided in a variety of ways, including verbal and written information, as an essential component of any effective discharge plan.

### 9.6 Access to Community Mental Health Teams

After discharge from hospital, people with mental illness should be offered a referral into the care of community mental health services for ongoing support and treatment. As discussed above this is of critical importance for individuals and their families after their first admission. Both the research participants and service providers consulted in this research report that this is not happening effectively. State-wide, people emerging from hospital who are barely well, are 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 critical time is inappropriate and potentially tragic.

Research participants with mental illness also reported patterns of interrupted contact with community mental health services which they could not account for. This loss of contact could be explained by a number of factors including the difficulties people with serious mental illness may have remembering to keep appointments or their lack of motivation to stay in touch. This suggests that case workers need case loads set a level to allow them the time to follow up clients. People might also lose contact because of the high levels of staff turnover in the teams, their case manager’s heavy workloads or funding pressures that limit the backfilling of positions when workers take leave.

> *I had a case manager for a while but I don’t know what happened to him. I haven’t seen him for months. I could talk to him and we could talk about stuff but I haven’t seen him for months. Oh, I’m thinking about ringing him just so he can see how I’m going and stuff like that. (Jarrod, 19, schizophrenia, South)*

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 this research was conducted, a Community Mental Health Team worker had not visited the West Coast for many months as the service did not 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.

> *No one’s been since [Community Mental Health Team worker] went. It was really good. With the illness and that, you never ever can mention it and that, and he would sit there and listen. That’s what I thought was good about him. Yeah. I liked him, yeah. (Brian (33) schizophrenia, North-West Region)*

There is an inherent contradiction in the areas of policy development and service funding in the mental health system. The policy principles indicate strongly that the emphasis should be directed to the prevention and early intervention of mental illness, which includes supportive community-based case management to alleviate the risk of high cost acute episodes. However the limitations imposed by the mental health services budget increasingly means that service provision is managed through the strict application of diagnostic criteria, with only those clients with serious mental illness receiving assistance at most services. Known as the 'perverse incentive' (ie. the incentive to be very sick, because it is only the very sick that receive clinical care), this process results in poor outcomes. It is detrimental to the health of people with serious mental illness and resource intensive in the high cost acute care end of treatment. As this research demonstrates, the impact of a restricted budget profoundly affects the people in the community who are so reliant on the support these services should be providing.

> *Well I was on community care for a long time because, as I said, I've had 26 manic admissions. She [Community Mental Health Team worker] went on holidays on the 12 December and it must have been a long holiday because I haven't heard from her since [over six months]. Yeah, and she was coming on a weekly basis. I mean this is what my GP said to me 'Denise, they are not looking after you.' (Denise, 52, bipolar disorder and anxiety, North)*

> *I've phoned them in desperation and they said 'What would you like us to do for you?' And I said,' I don't know that is why I am ringing you, because I don't know what to do'. And they said 'Well what do you think we can do?' And they said 'Well I'm sorry we can't come out'. It's just been hopeless. (Dawn, 45, depression and bipolar disorder, North)*

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.

> *When Simon first came home on his first few weeks in, I thought 'Oh my God, I can't handle this'. He wasn't, he wasn't right at all. So I think they are let out too soon, before they're ready to go. (Gail, 62, son Simon, 25, with schizophrenia, South).*

> *Particularly, the frustrating part was when we had been chasing him around for days and they chased him and got him to a hospital and then let him out the next morning. That was terribly frustrating. (Lois, 67, son Phil, 39, with schizo-affective disorder and bipolar disorder, North-West Region)*

> *And recently Don, I mean this is his story, so I presume it's right, he was suicidal and they thought he might hurt other people and he was in the cells that they have got now, and so he wasn't in the normal ward, he was in the mental health lockup ward ... And he was strip searched and he was put in there and he was in there two days I think, 2 or 3 days, and then they more or less said 'Well, you know, you are fine now', and let him go home. And that seemed an odd thing to me, to not have some interim measure between if you were that sick and that much of a worry, to not have somewhere. (Meredith, 53, son Donald, 23, with schizophrenia, South)*

# SECTION TEN

## THE COSTS OF CARING

### 10.1 The financial costs of caring

> *Oh, I guess devastating is a word. Just from where my life was going to and where it is now are just poles apart. So it affects absolutely everything, every aspect of your life, social and work, study, just everything you can probably think of, financial. So it just yeah, totally turns you all around, I guess. That's my experience anyway. (Bill, 33, partner Briony, 19, with schizophrenia, South)*

In addition to the emotional consequences of the illness, 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 this 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 (42%) and their estimates ranged from $10 – $125 a week. On average carers estimated that they spent $50 per week.[14] While it is not possible to generalise from these responses, they are indicative of the level of direct financial support flowing from carers to their relatives. The majority of the respondents to this question were dependent on Commonwealth income support (Aged Pension, Disability Support Pension or Newstart Allowance). Their level of income may have determined the level of financial support they provided.

> *Oh, well, on our budget, we are people that live very carefully. My husband's a carpenter, and he's had years of unemployment but it took us a long time to get wise. I mean, I was shelling out money and it just meant that, well, we never had a holiday. I mean for a long time we didn't have a viable car, and still we had to shell out for Adrian, because there was nothing else we could do. Now I have come to see*

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[14] For those carers who were dependent on Disability Support and Aged Pension or Carers Payment, this represented 22% of their income (at an income level where income=expenditure). 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).

> *that whatever I do I mustn't give him money and so if he gets himself in debt because he bought a compact disc player, I can't do anything about it. Once I would have done, you see. (Win, 70, son Adrian, 30, with paranoid schizophrenia, North)*

Merrin describes the rationale behind her decision to limit the financial support she provided for her son with schizophrenia. Her description exemplifies poignantly the tensions inherent for carers as they respond to the financial, physical and emotional needs of their sons and daughters while wishing and needing them to be independent adults.

> *Financially it has been huge and I have lost double figures, thousands, to my son, although when he turned 21 I said 'OK you are an adult now and I'm not going to keep on giving you money and rescuing you from your debts and etc, etc, etc'. However I still had recently put him into a flat and I paid the bond and the up front fee, otherwise he just wouldn't have got in, because they cannot, he cannot save money on the DSP. Because part of the condition of schizophrenia is that for some of them it is very hard for them to have a goal in mind and plan to be able to do such things, to do, to get there. Parents will be forking out money to pay for the Hydro because you don't want to see them without power, because then they can't cook any food. And when they can't cook food they have to go and buy take-away and of course that costs too much money. So you think OK I might save more money if I pay the Hydro bill than paying for them to get take-away, you see. He once copped a $300 phone bill on one phone call, which is the kind of thing they can do when they are ill. He wasn't aware that it was $4.95 per minute, was he? One of these 0055 numbers, heart to heart calls. She must have been having a good day. (Merrin, 51, son Anthony, 23, with schizophrenia, South)*

### 10.1.1 Covering the debts

The carers interviewed outlined a range of direct costs they incurred as a result of their family member's mental illness. As discussed in Section 5.1, people with serious mental illness are highly susceptible to unstable tenancies and patterns of homelessness. With their family member receiving minimal support to maintain tenancies or manage their finances it is often their families who are compelled to supply money for new 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.

> *Certainly over the years, I reckon we would nearly fill a removalist van with the things, the bedding, the junk, he [has lost]. There is always some convoluted story that may or may not be true: he has never got it, because he loses the flat, the landlady doesn't like it, the landlady took it all to the tip and there is just nothing left. Or he has moved out and moved in somewhere else and he can't get access to go back to get the bed. He just hasn't got the organisation or the nous or whatever, to plan ahead. (Meredith, 53, son Donald, 23, with schizophrenia, South)*

> *When he was psychotic and slightly on the mend, he wasn't full blown psychotic, he was actually, I thought he was well but I now know that he was just better than he had been, he smashed our house up. The insurance company refused to do*

> *anything, they didn't want to know about it. They wouldn't pay. It's a family member - that's what they call vandalism. Once again we were let down by the mental health situation where there was no acknowledgement [diagnosis] that there was a mental illness. It was about between $7,000 and $10,000 worth of damage done to the house. (Emma, 49, son Angus, 18, with schizophrenia, North)*

The ease with which people with a history of serious mental illness and debt can enter into credit arrangements was commented on by a number of carers. Of particular concern were mobile phone and credit card debts.

> *It's just the whole financial system is geared at the healthy and they can fall through the cracks very, very, very easily. It's bad enough for me, I can make financial errors and stuff, but it is even harder for them because they just have that cognitive challenge which is part of their disorder. OK, I don't think that is fully recognised either by Centrelink or phone companies or banking companies. And all the regulations in our society are geared at functional people like you and me and it is very easy for them to make mistakes. Like credit cards, oh my God he has got about 3 credit cards and they are all chasing him. I have nothing to do with it. I wouldn't come near it, and I'm not going to support that. I don't have enough money to, I just get the mail and I just pass it on. (Merrin, 51, son Anthony, 23, with schizophrenia, South)*

A number of carers interviewed had repeatedly paid court fines, parking fines, credit card debts, hire purchase debts and phone debts to try to ensure that their son or daughter was not prosecuted or forced to live without essentials such as food or power. When asked about the major expenses incurred, the following comment reflects the general concerns:

> *Oh, if I thought about it, the food and the phone and the heating. I loaned him $500 to get his car and it was such a good deal he said. But now that's been run into the ground and fined and everything else and it's just a mad world, it's chaotic. I paid to have his car repaired. I mean it's just an endless job because he doesn't care. (Sue-Ellen, 56, son Luke, 32, with schizophrenia, South)*

### 10.1.2 Providing board

The following narratives illustrate the desperate anxiety faced by low-income carers confronted by the direct costs in supporting adult children who have fallen through the holes in the safety net and received no financial support whatsoever. The difficulty in getting support for young people experiencing their first episode of psychosis was discussed in Section 7.1. Faced with the bureaucratic conundrum created by non-attendance at school, no diagnosis and no income support, Emma's family had to struggle to look after their son.

> *For some obscure reason you don't get a Youth Allowance if you are not at school, so if you can't prove that you are sick and you are not at school, then you are just absconding, so you don't get any financial assistance whatsoever. So that went on for 2 years [until Angus was assessed as eligible for a Disability Support Pension). Yeah, so that 2 years we funded him fully, and except for the fact that he was bedridden so he didn't really cost anything anyway, but he ate continually during that*

> *stage, because he would get up, go to the fridge and eat. So food expenses were very high. (Emma, 49, son Angus, 18, with schizophrenia, North)*

Pauline's son Jock was continually receiving breaches to his Newstart Allowance because of his inability to meet his Administrative or Activity Test requirements and consequently he had no income. Jock experiences a serious psychotic illness which limits his ability to deal with Centrelink or medical services. Although he has had repeated hospitalisations the only consistent psychiatric treatment he has received has been during his stays in prison. Attempts to get Jock to appointments with psychiatrists for assessment for the Disability Support Pension or an Administration Order under the Guardianship and Administration Board have been unsuccessful due to Jock's unwillingness to attend interviews. He is very transient, living mostly on the streets with no income. At the time of this research Pauline was fully supporting Jock out of her own Disability Support Pension payments.

> *And who's expected to care for him? I even took him into Social Security trying to get [help] ... I did meet a good lady in there and she tried her best to try and get him some money for him to keep him in food. That's all that worried me, because it cost me a fortune for food. And I am a diabetic so I had to have different food to him, but it didn't matter to him though, he still ate mine. It was just like hitting my head up against a brick wall. (Pauline, 62, son Jock, 34, with schizophrenia, North)*

Having adult children living at home who are experiencing mental illness can place a significant and unplanned burden on the family budget. Impulsive spending and excessive use of phones and showers are characteristic of certain types of mental illness for which the carers literally pay the price.

> *Well usually in the first week he'll spend the lot and then he's poor. And if I don't drive him where he wants to go, he's very abusive. He runs up huge phone bills and doesn't pay any rent and has never got any money, he gambles and things, and it is like...I could never control him. (Sue- Ellen, 56, son Luke, 32, with schizophrenia, South)*

> *Ben, my son, is managing at the moment, but that's because he is not paying for food, he's not paying any rent, he's not paying for phone calls. That's another thing, like he is just so impulsive, the days when he is not well and feels that, if somebody isn't there, it is nothing for him to make 20 phone calls, he just keeps ringing. I got a $400 bill for a month. (Jenny, 48, son Ben, 19, with schizophrenia, South)*

> *With my Aurora account ... if you analyse this account he has used most of it in hot water because he would not get out of the shower and because I live in the country, to add insult to injury, I have to buy the water and have it delivered because I'm on tank water. So you live on a pension and you have a $600 Aurora account and then the telephone bill comes in and it has gone up to $250. But then when you get a $410 bill, and you are owed $600 and another $400 for registration and you are on a pension, and then you have got to put food in the cupboard, and buy the petrol. (Betty, 53, son Mike, 26, with schizophrenia, South)*

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 this research who reported feeling physically intimidated were more likely to be older women who were living with their middle-aged sons.

### 10.1.3 Subsidising groceries

Carers whose family members were living independently reported a substantial and ongoing financial burden caused through the need to regularly subsidise their household expenses, particularly groceries. Some carers chose to subsidise groceries rather than cover the costs of other debts in an attempt to manage continual debt crises while still ensuring their family member was eating regularly.

> *He struggles to be able to have accommodation because he is trying to run a car, which I had to go guarantor for. And then to rent or buy, and then all the day running sort of thing, it's just too hard. The pension doesn't cover it. And we come to the party a lot financially. We still probably supply a lot of food for him. I mean we buy our own groceries, we buy double that. Not that we can afford to, because we are on a pension too. But he struggles so much. It's just a struggle. And he doesn't waste his money. And we gave him $420 for his bond, you see for his unit. There's never enough money for it, to just get ordinary things. Not anything extra, just the ordinary running of things. He's not wasteful, but over the years he hasn't been able to control or look after money. As part of the illness. Oh, yes, it's part of the illness. (Brendan, 69, son Phil, 39, with schizo-affective disorder, North-West Region)*

> *Another thing with Adrian is that he cannot manage money at all. Because he just gets his pension and busts the lot on fags and Coca-Cola and food. The food runs out and so, if we don't drop in and give him some food, he has got no more food. Yeah, we go a few days before the pension has run out and I take him meat and food and bread and things. I've got to the stage I don't give Adrian money, because I know it will go on fags, so I take him down a joint of meat and things like that, and he'll cook it or something like that, yeah. (Win, 70, son Adrian, 30, with paranoid schizophrenia, North)*

## 10.2 The financial hardship caused by caring

### 10.2.1 Marriage breakdown

Providing care for a family member with a mental illness can have impacts across the carer's life which leads to a spiral of financial crisis. Carers described the pressure that caring for an ill relative had placed on their marriages. Some of the participants felt this was the primary cause of their marriage breakdown. As Jenny explains, responding to the constant demands and concerns about a son or daughter with a serious mental illness can become all-consuming. Along with the difficulties of dealing with a frightening illness and complex mental health system, many parents reported experiencing guilt and even shame about the illness of their son or daughter. This can place relationships under considerable stress and the resultant marriage breakdown increases financial hardship, particularly for the female partner.

> *Me and my husband split up for a period because of the dramas, the dynamics of it all. Because he just couldn't live anymore and he actually moved out, and it was just me and Ben, because it was the only way we could survive. And all I needed, some of the time, was just somebody to come in and take him for a walk, take him, do something with him, even just for a couple of hours in the day. (Jenny, 48, son Ben, 19 with schizophrenia, South)*

> *Oh, OK, second marriage break-up. I left friends, financial hardship, depression, my depression. Yeah, that's enough. My self-esteem has gone down the tube. I mean I'm coming up now, thanks to good friends and [support group] but still I am still watching my back and everything and what I am doing. (Geraldine, 55, son John, 34, with schizophrenia, South)*

### 10.2.2 Difficulties in continuing in employment

The responsibilities of caring for a person with chronic illness can have a clear impact on the carer's ability to maintain employment. According to the Australian Institute of Health and Welfare, carers are less likely than non-carers to be in paid employment or full-time employment although their patterns of participation in part-time work are similar (AIHW, 2003:102-5). The inability to undertake full-time paid employment clearly has a detrimental effect on the financial status of carers.

While a number of the carers interviewed were struggling with the problems of providing financial support while themselves living on pensions, others described the difficulties of combining their responsibilities with paid work. In addition to their distress at seeing their son or daughter ill, carers faced the stress of living with someone experiencing sleep disturbances, unpredictable behaviour and disorganised thinking. They reported that this had a significant impact on their ability to work.

> *For me, I mean the hardest part I think, looking back when he was unwell, was going to work and not knowing, and having to leave him. Yeah, I mean I took days off and juggled things, but yeah. I am holding down my job but only just at the moment, but it has, I have been lucky in that, my boss has been lenient at times. So I am lucky I still have a job though. I mean I have come that close to being sacked for getting phone calls at work constantly from my son when he has been unwell. (Jenny, 48, son Ben, 19, with schizophrenia, South)*

> *And I'm very worried about him, I mean when John was living with me I was so close to going under. I was, I was really agitated for a long time, trying to hold my job down and having all these strange friends of his come in and that sort of thing ... [Y]ou know it was just all crazy and all over the place. (Geraldine, 55, son John, 34, with schizophrenia, South)*

Carers generally are disadvantaged under the superannuation system, which is based on the premise of long-term continuous employment, when caring responsibilities have meant that many have had a discontinuous work history. In addition, carers in the focus groups reported a significant loss of savings as a result of paying debts incurred by their ill relative. The following carers are now dependent on Commonwealth income support (Disability Support Pension and Aged Pension) without the buffer of even a small pool of savings.

> *I've gone through all of my money. About 3 or 4 years ago I would have had enough money to do a trip to England. Ah, I have got nothing now, it's all gone. I have put money into all sorts of things. Now I haven't got anything. (Ada, 74, daughter Lana, 41, with bipolar disorder, South)*

> *Here are the bills and accounts I've paid, and if you add it all up it comes to $16,000. They come under the heading of the car loan, the pager, the bank loan, fines, cash loans from people, fines for abuse in Court, and just things like parking fines ... I had a bit of money, a nest egg that I had to retire on but it's all gone now. It's all gone. (Betty, 53, son Mike, 26, with schizophrenia, South)*

### 10.2.3 The loss of housing

Some carers reported acute disruptions in their own housing in order to provide accommodation to their son or daughter with mental illness. In a number of cases carers reported moving in order to find accommodation suitable to share with their adult son or daughter or to be able to assist in the care of their grandchildren. The reasons they cited for moving included needing more bedrooms, greater accessibility to services or less access to gambling venues. In one case, a carer forfeited her public housing tenancy to find a house more suitable for her daughter and grandson and several reported losing housing after marriage breakdowns. Pauline had to find alternative housing for herself where she could accommodate her son Jock because of her husband's difficulties in coping with his son's illness.

> *I mean it's even got as far as, it's broke my home, my husband didn't want to accept the fact that Jock was like he was, and I got kicked out and then I had to go and get myself a unit. But it's just that Jock will walk all night, he won't go to bed, he'll walk all night. I had him at home, backwards and forwards, backwards and forwards, stuffing food into his mouth, so there's nothing left. (Pauline, 62, son Jock, 34, with schizophrenia, North)*

### 10.2.4 Caring for grandchildren

Increasingly, children under care and protection orders are placed with family members rather than in foster care with non-relatives and there are also a significant number in informal care arrangements. It is estimated from Centrelink data on recipients of Family Tax Benefits that, in Tasmania, approximately 7% of primary carers of children are grandparents. In June 2002 there were 51 children under care and protection orders placed in kinship care and a further 174 children in informal care arrangements in the care of relatives receiving the 'relatives allowance' (Joint Standing Committee on Community Development, 2003). The significant financial concerns that this responsibility poses for older people has been well documented (COTA, 2003). The responsibility of caring for grandchildren on a formal or informal basis was also discussed by the carers interviewed in this research. The nature of their illness can make caring for young children extremely difficult for parents experiencing mental illness. As a consequence, some carers in this research had responsibility for their grandchildren in an informal part-time role and in one case, full-time formal care. The constant anxiety that parents described in relation to their son or daughter with mental illness is multiplied when there are grandchildren involved. As these accounts illustrate, the emotional and the financial costs increase dramatically for the carers.

> *When Lana was on her own with Josh [her son], I know that sometimes I would go over there and I would wonder what on earth they were going to eat because Lana was just a bad organiser. I think that was one reason why they both moved in with me, because I could feed them. She never has been organised as far as food is concerned, and I think while she was using, I think Josh would come home and there'd be nothing. (Ada, 74, daughter Lana, 41, with bi-polar disorder, South)*

> *Well my husband and I are the main carers for our daughter. She comes and goes and sometimes she lives with us sometimes she doesn't but when it is all boiled down whenever there is an emergency, we are the ones she calls. Every time the phone goes I think 'Is she in trouble or has something happened?' If it doesn't go I worry that she hasn't rung us, so it is that constant worry. We are actually custodial grandparents for her first little daughter who is almost four now. So it has altered our life slightly. (Norma, 62, daughter Melanie, 29, with schizo-affective disorder, South)*

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.

### 10.3 The physical and psychological cost of care

The physical and psychological cost of care described by the carers in this research was high. A number of the carers interviewed reported that the stress of care had caused mental health problems for themselves and their partners. A significant number of carers described major episodes of depression resulting from a lack of support, the instability of their relative's illness and the overwhelming sense of frustration and hopelessness.

> *The trouble is there is no one between the carer and the full blown psychosis, there's no one to step in and help you deal with it. And this is another point I would like to make about mentally ill people, that I have suffered from major depression and anxiety and my husband has spells with the psychotic depression, and yeah, lots of things we should complain about, that we have had to overcome. (Win, 70, son Adrian, 30, with paranoid schizophrenia, North)*

> *I started thinking that he was playing games. That he wasn't as sick as he made out, but I was probably wrong. I was really feeling quite unsettled and trying to cope because it was like a whirlwind. I would be away at work, he would be sleeping all day, and I would come home, he would greet me before I got in the door, 'What's for tea?' And he would be up all night, and then I would be up all night. Everything would*

> *be going. Yeah, it would be the microwave, the radio, on the phone, and what happens is the carer becomes quite sick. I ended up seeing my doctor and being put on anti-depressants because I was depressed and upset and my doctor knew the story ... And it is also very important for us to look after ourselves because I ended up at the stage where I was crying all the time. Not in front of him but in the shower crying and I felt resentful and guilty and angry and, I felt awful, unnatural. (Geraldine, 55, son John, 34, with schizophrenia, South)*

> *It is very hard to get care from your family. I mean they think that you can always do what you have done. To do everything. I feel like I am some super-duper appliance. And I think, and then I get really, really depressed, really depressed. I wanted to have something wrong with me. When I used to go and have mammograms I used to hope to goodness they would find a lump so that I could go into hospital and have somebody look after me, and that I would be, I would be looked after, and they would care about me. And that was really, I was really disturbed. (Ada, 74, daughter, Lana, 41, with bi-polar disorder, South).*

Some carers reported that they had themselves had suicidal thoughts as a consequence of their caring responsibilities.

> *I would say with my second marriage, it's caused a lot of problems there. He blamed me for it, my son's illness. It's just ongoing and there is nowhere to go with it. It's frightening looking at his future, it's frightening looking at mine. I don't want to die at my son's hands and have that on him really. But I would be glad to die sometimes, I just think oh I have had enough, enough. (Sue-Ellen, 56, son Luke, 32, with schizophrenia, South)*

> *No, I think one thing is I felt that I was, oh, on my own. Like nobody wanted to listen and help. I'd hit my head up against the wall and think, 'Put myself out of my misery'. That's what I used to think. Like I used to think 'Oh, is somebody going to listen? Is anybody going to listen?' (Pauline, 62, son Jock, 34, with schizophrenia, North)*

## 10.4 Support for carers

### 10.4.1 Financial support: Carer's Payment and the Carer's Allowance

While there is a community presumption that carers will provide ongoing emotional and financial support to people with serious health problems the aspirations of carers often differ markedly. Carers Australia reports that some carers feel resentful of their role, believing that they should be better remunerated for the work they do, aware that the level of work they provide saves the community large amounts of money. Others report feeling exploited by Governments "as a source of very cheap labour in order to give effect to community care policies" (CAA, 1998:7).

Carers receive limited financial support to reimburse them for the cost of care. The major causes of financial hardship for carers have been identified as: limited access to social security payments, the inadequacy of social security payments, having to give up work to care and incurring extra costs due to their caring role (CAA, 1997). As discussed in Section

2.9, the special purpose carer payments administered by Centrelink are the Carer's Payment and Carer's Allowance. The former is payable to individuals providing constant care in their home to a person with a severe disability or medical condition. The maximum rate of this payment is currently $464.20 per fortnight for a single person and $387.60 (each) for a couple. The Carer's Payment is income and asset tested. The Carer Allowance is paid in addition to other payments if the care recipient requires considerable additional care and attention. Eligibility is assessed by Centrelink using the Adult Disability Assessment Tool (ADAT). This allowance is non-taxable and is not subject to an income and asset test. It is $90.10 per fortnight. As well as being a relatively limited amount of income, the Carer's Payment is also difficult to obtain. Frost, Carr and Halpin (2002:23) suggest that this may be because the assessment protocol disadvantages people with a mental illness by not addressing the particular support needs associated with severe episodic conditions.

The vast majority of participants in this research received no specialised income support. Only one of the carers interviewed received the Carer's Payment, only two received the Carer's Allowance, and one received Relative's Allowance, (a discretionary State government payment of $14 a week for people providing permanent care for a child who is a relative). As the comments below illustrate receipt of these payments can be both a complex and inadequate process.

> *The one thing that was very, very difficult for me was when I was in hospital we got this call after I come home, like I was meant to be home, and after I come home we got a call at 9.00 at night and we thought that couldn't possibly be Centrelink because they don't work at night time and they said to the carer, 'Ainsley has been in hospital and you didn't tell us' and the carer said 'We didn't know we had to tell you'. And they stopped my money, they stopped the carer's money and for as long as you are in hospital, and you are not allowed to be alone, you've got to be at home. We thought it was a hoax, but we found out they [Centrelink] said they can take it and showed us and next time I go in I must tell them. (Ainsley, 56, schizophrenia, North)*[15]

> *[The Carer's Allowance] was $80 a fortnight or something like that but the fines and the whatever to bail him out would not have gone anywhere near it. But you can't do anything about it, I mean there's nothing. (Brendan, 69, son Phil, 39, with schizo-affective disorder and bipolar disorder, North-West Region)*

### 10.4.2 System and service support

Consistent with the findings of the national Mental Health Council of Australia report (2003), the carers in this research reported that there was very little support available to them. The findings of this 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 a serious mental illness. Nor do there appear to be discussions with mental health service providers and carers about alternative care options, although this may be a reflection of

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[15] Carers Payment is payable for 63 days in a calendar year during a period of respite or while the care receiver is in hospital. If the period of hospitalisation exceeds 63 days the payment can be cancelled.

the lack of support services available. Generally carers interviewed in this project had little access to mental health services and no access to in-home support. The carers of younger people experiencing early episodes of psychosis tended to prioritise practical support to meet their son or daughter's immediate needs for income and housing over emotional support for themselves. Carers of older adults commented on the lack of respite care and rehabilitation services. Limited access to residential rehabilitation services was also perceived as a significant problem. While most of the carers in this situation would have preferred their son or daughter to be living in independent accommodation with appropriate support, they indicated strongly that, failing this, they needed more support to care for their family member at home. Home visits, someone to take their son or daughter out for social activities, support in crisis situations and counselling and support for themselves were some of the needs they identified.

Carers reported feeling unsupported by a system which they see as unresponsive and overstretched. Those who had engaged in active advocacy for their children were particularly anxious about what would happen to their ill family members without their persistent support. Their anxiety focused on how their son or daughter would be able to actively pursue their rights to services when they, as people who were mentally well, found it psychologically and emotionally draining. They expressed deep concern about access to stable, accessible and affordable housing for their relatives and an abiding apprehension about what would happen should their relative's entitlement to the Disability Support Pension change. The lack of support and understanding of their situations is evident in the comments of these carers.

> *Now I feel like I'm 90% there. Originally I felt like I was imagining it because I was told that (a) I was imagining it, that (b) that it was my fault anyway, because if it was a mental illness it was brought on by the fact that he was a disobedient child. Yeah, the inference was that it's your fault. And then basically you don't want to go and talk to people about it, because you feel like a criminal. And you can't really blame the kids for feeling they are like a criminal, because you, as an adult and a parent trying to get all these services for someone, feel like that. (Emma, 49, son Angus, 18, with schizophrenia, North)*

> *What happens when Jock comes out [of jail]? He'll come to me, I know he will, and I can't turn him out, he's my son, and I can't say 'No Jock you can't come here'. But that's what [peer support group] were telling me that if he wouldn't come to the party then they say 'No you are not allowed here. Out!', or call the police and have him put out. But I couldn't do that, unless he was violent, and then I would have to. And I mean mentally it is more distressing than being violent. I think the hardest problem with Jock was not being able to help him, and not being able to communicate with him. Trying to talk to him, that's the hardest thing. And the other part was trying to get help for him and there was nothing there to help him. So naturally you are going to worry about what you are going to do. Where are you going to find him? And when you are going to find him? And how you are going to find him? (Pauline, 62, son Jock, 34, with schizophrenia, North)*

It is estimated that supporting carers through the provision of education and training is a very cost effective way of reducing psychotic symptoms, episodes and relapse rates for people with mental illness. The associated reduction of stress and poor health outcomes for carers is an additional saving. The cost-benefit ratio has been estimated to be in the order of a saving of $34 for every $1 spent (Access Economics; SANE Australia, 2002: 33).

### 10.4.3 Emotional support: carer groups

Mental illness isolates carers just as it isolates the people experiencing the illness. Carers reported enormous difficulties in maintaining social and family relationships over the years of the illness.

> *I don't have a social life. I haven't had one for a few years now, so in terms of friends, really no support there. (Bill, 33, partner Briony, 19. with schizophrenia, South)*

A national survey of carer services conducted by the Mental Health Council of Australia (2000) identified a range of functions delivered through a range of agencies. The agencies surveyed were generalist carer and support agencies and mental health agencies which focused on both carers and consumers focus or carers exclusively. The services available to carers through these agencies were diverse and included in-home and out-of-home respite, home help, transport, advocacy support, counselling, emotional and social support, emergency financial /material assistance, and education, training and information provision. The range of services available to carers in Tasmania is nowhere near so comprehensive.

In Tasmania, formal support for carers of people with mental illness is thin on the ground and focussed in Hobart. It is primarily available through ARAFMI (The Association of Relatives and Friends of the Mentally Ill), which, limited by very small budgets, provides some education, information and group support in Hobart and Launceston. ARAFMI has no presence in the north-west. In Hobart, ARAFMI provides individual counselling, but can only do so on a user-pays basis. The Mates program run by the Red Cross provides support for carers through the provision of 'volunteer mates' for people with mental illness. However, at the time of this research, the volunteer mates, many of whom are also on very low incomes, reported a critical lack of funds in this programme to facilitate social encounters. Mates operates in Hobart, Launceston and Burnie. In Hobart, there is also a resource centre managed by TAMH (the Tasmanian Association of Mental Health Inc).

There are also a very limited number of respite beds provided in the mental health system[16], with a further three unfunded beds provided in a non-government service in the North-West. Family Based Care in the North West provides home-based support for people with mental illness and by extension, their carers, including in-home respite. This program operates in a referral partnership with mental health services.

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[16] Mental Health Services advises that there are 24 beds in the Mistral Place & Tolosa Street facilities but they are used in various configurations including residential, rehabilitation, also 'step up' and 'step down' as well as respite. These facilities service the State. This means, according to non-government sector services, that there are actually 6 respite beds which are largely unavailable.

Participants in this research had diverse contact and experience with the agencies providing carer support. Many had found the group peer support model valuable.

> *But that's where support groups come in to help, because you are with people who understand where you are coming from and you are able, you can talk about it with someone. I think that really does help. (Gail, 62, son Simon, 25, with schizophrenia, South)*

The experiences described by carers through this report illustrate the extensive demands and expectations they face in providing care for a relative with a serious mental illness. From the financial pressure placed on their family budgets through to the time required to negotiate and advocate for their relative through the mental health and income support systems, the burden of responsibility placed on them is great. As described in this final section, the emotional and psychological toll it takes is equally heavy. Carers throughout Australia have identified similar themes of the lack of support available to them. Carers particularly identify support for their own mental health and wellbeing as an important component of the range of support they need.

# SECTION ELEVEN

## CONCLUSION AND RECOMMENDATIONS

Living with a serious mental illness on a low income in Tasmania is a difficult, lonely and frightening experience. This research has clearly identified the powerful link between mental illness and poverty and the ways in which these two factors feed off each other to create a cycle of illness, loneliness and despair. The daily existence for many participants was a constant struggle to meet their basic needs. In some instances the people who participated were destitute. Participants in this research reported on a range of areas in which their poverty forced them into a position of profound social exclusion. Poverty and hopelessness characterised the lives of many of the carer participants as well. The research highlighted how failures in the income support system, the mental health and housing systems and the lack of social support compounded the financial and emotional hardship they faced 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 in 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 a neo-liberalist agenda of cutting public expenditure across all public services including health and human services, resulting a significant decrease in availability of public housing and mental health services. Finally, the concurrent welfare reform agenda further exacerbates the vulnerability of people with mental illness, increasing pressure on them to meet requirements and failing to provide safety nets when they cannot.

The National Mental Health Strategy sets out highly commendable goals and a framework for the optimal care of people with mental illness. Sadly, as this research has demonstrated, the experiences of people with serious mental illness has lagged far behind the innovative policy directions. The failings of the National Mental Health Strategy lie in a lack of funding commitment 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 mobilisation of the population, enable this to persist. Other societies would not tolerate this. (Groom, Hickie & Davenport, 2003: iv)*

The major conclusion of this report 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. Clearly the most pressing objective is the injection of substantial new and recurrent funding into the mental health service system.

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 jurisdictions. However, as the most recent Australian Health Care Agreements demonstrate, this cannot be assumed. Notwithstanding this important point, the Tasmanian Government has a responsibility to address this grave lack of funding to services for people with mental illness and their families and carers.

In the financial year 2003-04, the Tasmanian Government spent $53.5 million on Mental Health Services. This is approximately 5.6% of the total operating expenditure for the Department of Health and Human Services for that financial year and well below the national average of 7% of state health budgets (Groom, Hickie & Davenport, 2003: 10). Based on the current figures, a commitment of $13.7 million in recurrent funding to mental health services would ensure that Tasmanian mental health expenditure is equivalent to the national average.

**Recommendation 1**
**That the State Government allocates $13.7 million in additional recurrent funding to Mental Health Services.**

**Recommendation 2**
**That the State Government makes a commitment to maintaining the Mental Health Services budget at no less than 7% of the total State health budget expenditure.**

### 11.1 Support in the community

The research has documented the severe lack of services in the community to support and assist people with serious mental illness. This research has 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.

People with serious mental illness in Tasmania and their carers have identified support needs across a range of areas of daily living which are not being met. These include:

- 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.

Many people with serious mental illness require comprehensive support in a coordinated case management model. This support needs to be provided by a partnership of community mental health teams giving clinical support and non-government organisations giving non-clinical community support. This partnership requires adequate funding in order to ensure that services meet clients' needs effectively and proactively.

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. This 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.

Currently non-government organisations in Tasmania receive 3.8% of the mental health services budget. Along with the recommended increase in the overall mental health budget, Anglicare further recommends a substantial increase in the proportion of the funding allocation to non-government organisations 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 and this demands a substantial investment of funds. There is no funding model which provides an evidence-based framework for the most efficacious resource split between clinical mental health services and non-clinical support services. It is therefore of critical importance that the impact of any increased funding to community-based non-clinical support services is fully evaluated as a basis for ongoing funding plans. Therefore in recommending a recurrent funding allocation of $9.7 million to non-government community-based mental health services, Anglicare further recommends that the impact of this funding split is fully and regularly evaluated. The funding increase to the NGO support services represents 14% of the increased mental services budget and Anglicare recommends that this proportion of funding is the baseline for future increases.

**Recommendation 3**
**That the State Government directs $9.7 million in recurrent funding from the Mental Health Services budget to non-government organisations to deliver a range of community-based support, respite and recovery-based services for people with serious mental illness and their carers.**

**Recommendation 4**
**That the State Government adopts the proportion of 14% of total mental health services expenditure as the baseline for future increases for non-government organisations to deliver a range of support, respite and recovery-based services for people with serious mental illness and their carers**

**Recommendation 5**
**That the Department of Health and Human Services conduct regular evaluation and review of the cost-benefits of increased mental health expenditure to non-government non-clinical community-based services.**

## 11.2 Affording the Essentials

### 11.2.1 Housing

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.

Participants with serious mental illness and their carers identified the lack of appropriate accommodation as a critical concern. There is a demonstrated need for a range of appropriately supported and flexible housing options which enhances the opportunity for long term tenancy and maximises security and stability. In-home support is required for people with serious mental illness who are living with carers. Community support services should be funded to provide this. Anglicare recommends that in addition to the establishment of boarding houses committed to in the Affordable Housing Strategy, the State Government develops the following housing options.

**Recommendation 6**
**That the State Government directs that Affordable Housing Strategy funding be allocated for the capital cost and operating budgets for cluster style two bedroom units in a supported community housing model in each region.**

**Recommendation 7**

**That the State Government allocate $344,000 per annum to fund programmes which provide personalised and intensive support for people with serious mental illness who are living independently either in Housing Tasmania properties or sustainable private accommodation. This costing is based on: one support worker to provide support and assistance in the North to 10 people at a cost of $114,000 per annum, two support workers to provide support and assistance to 20 people in the South at a cost of $230,000.**

### 11.2.2 Food, Clothing, Transport and Telephones

People with serious mental illness have the right to a life style which is consistent with the values and standards of the community as a whole. This would mean that they are assured of the type of diet, participation in the activities and have the living conditions and amenities which are considered reasonable by the rest of the community.

A majority of the research participants reported regularly going without food, of frequently running out of food with in the pay fortnight and relying heavily on emergency relief services for food. They talked about eating 'duck bread', the day-old bread donated to community agencies, scavenging for food at the close of business, even relishing being in hospital because of the meals provided. Similarly, the vast majority of the participants reported being unable to afford new clothes. Rather, the common experience was to purchase second-hand clothes from op shops. Many of the participants could not afford such items of clothing as would be deemed essential for life in Tasmania: a warm coat or polar fleece, a couple of woollen jumpers, or even a second set of basic clothing. This is not an acceptable life style for any Australian and the stress it causes only aggravates the effects of living with a mental illness.

There are a number of factors which should be taken into account when considering this situation. First, the level of income support payments is not adequate to meet the rising costs of living. Second, people with serious mental illness often experience disordered thinking and confusion and have an inability to manage their limited budget effectively. In many cases, psychotic episodes may be characterised by periods of extravagant spending. Third, as discussed in the previous section, there is a lack of services to support and assist them to manage their budgets more effectively. This includes support from case workers and also, where appropriate, the capacity to use the services of the Public Trustee to help with the management of their finances on a regular basis. As reported in the research findings, the fees and charges imposed by the Public Trustee on its Community Service Obligation (CSO) clients were a major disincentive for many people with a serious mental illness to use this community service. Furthermore the fees paid by Tasmanian CSO clients are the highest of any state. This situation is neither equitable nor appropriate; the State Government should meet the full costs of providing these services to low income clients through its CSO allocation. Therefore, Anglicare recommends an increase in the income support payments of jobseekers through their indexation to 25% of average male total weekly earnings, which is the basis for pension payments. Also, Anglicare recommends that the problems confronting CSO clients be addressed.

Finally, the issue of affordability of essential items such as clothes requires a systemic response. While charities would distribute goods free of any charge to a client identified as being in a crisis, they require a process of client assessment. Reliable 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. Anglicare recommends that, in addition to the system of offering free goods through the Emergency Relief system, essential items such as trousers, jumpers, coats and shoes in good quality condition cost no more than $4 for any person on a concession card. The Salvation Army has begun to address this issue through their system of offering 20% discounts to concession card holders on one day each month.

**Recommendation 8**
**Anglicare supports the recommendation of the Australian Council of Social Service that the Commonwealth Government progressively increases allowances up to the level of the pension and indexed to 25% of Male Total Average Weekly Earnings.**

**Recommendation 9**
**That the charities which run opportunity shops and recycling centres adopt the practice of offering 50% discount on prices to people holding Health Care Cards or Pensioner Concession Cards.**

**Recommendation 10**

**That the State Government provide additional funding to the Public Trustee to meet the costs of financial administration for Community Service Obligation clients. This would enable the abolition of establishment fees and ongoing charges for Administration clients relying on Centrelink pensions and with assets of less than $100,000.**

Access to transport is critical to social participation for people on low incomes. People with serious mental illness have particular problems both accessing and using different forms of transport. This research has shown that affordability of both private and public transport is a barrier to this group. The state concessions system is an important mechanism for targeting assistance in key social policy areas to those members of the community who are most in need. However, the concessions system is poorly targeted and inequitable, with transport concessions in particular privileging aged pensioners over other income support recipients. Anglicare recommends that the concessions on motor vehicle costs and driver licenses be reviewed and extended to all Pension Concession and Health Care Card holders.

Because of their anxiety about using public transport, a number of participants in the research are dependent on 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 to have ‘independent access into the community’. However, participants in this research indicated little awareness of the scheme. Anglicare recommends that this scheme is actively promoted and advertised widely throughout the Tasmanian community and specifically to Centrelink, as well as GPs and other health practitioners who are required to complete the application.

**Recommendation 11**
**That State Government extends eligibility for all motor vehicle and driver licence concessions to Health Care Card and Pension Concession Card holders.**

**Recommendation 12**
**That the Department of Infrastructure, Energy and Resources actively promote the Transport Access Scheme to the Tasmanian community.**

**Recommendation 13**
**That the Department of Infrastructure, Energy and Resources collect data on the type of disability of people eligible for the Transport Access Scheme to evaluate the access of people with psychiatric disabilities to this concession.**

This research has highlighted that the high cost of telecommunications has detrimental effects on people with serious mental illness. Participants in this research consistently reported that access to a telephone was vitally important to them, for social support and in emergencies. 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 the 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. For people whose 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.” This 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 14**
**That the Australian Communications Authority ensures that people with a disability have satisfactory access to payphones.**

**Recommendation 15**
**That the Australian Communications Authority investigates breaches of the Telecommunications Act particularly in relation to mobile phone contracts.**

### 11.3 General health and serious mental illness

People with serious mental illness have poor general health and high levels of co-morbidity. In response to this the National Mental Health Strategy and subsequently the Third National Mental Health Plan recognises 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 this 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, the cost of pharmaceuticals and the fact that the burden of mental illness was so great that it tended to overshadow all other health issues.

Anglicare commends the Commonwealth Government investment in the Better Outcomes in Mental Health initiative, the 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 the incentive offered to general practitioners in the Medicare Plus package does not guarantee Health and Pension Concession Card Holders access to local bulk-billing general practitioners.

### 11.3.1 Oral health care

Along with poor general health people with serious mental health problems have particular and pressing oral health needs. They also face multiple disadvantages in trying to access the Tasmanian Public Dental Service. The symptoms of mental disorders cause poor oral health both directly and indirectly and make the organisation of personal resources required to access preventative or emergency dental care almost impossible.

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. Programmes to maximise 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 the issues of client anxiety and fear, access, and consistency of treatment in ways which have maximised usage of dental appointments and reduced problematic behaviour.

Exemption from co-payments is critical to access for people with serious mental illness. Yet, in spite of many years of lobbying by community services about the impact of co-payments on their client group, in 2004 the Tasmanian Government increased co-payment charges at the Public Dental Service to $30 a visit.

Anglicare recommends the development of a prevention and treatment service targeted at this client group. The pilot project would include the development and trial of a multi-disciplinary dental programme for adults with low prevalence mental health disorders living in the community. Anglicare recommends further that concession cardholders with serious mental illness be exempted from the co-payment system.

**Recommendation 16**

**That the State Government removes the upfront $30 fee for the Tasmanian Dental Service for adult concession card holders. This could be achieved with the addition of $1.17m recurrent funding based on 2000-2001 estimates and other improvements in the public dental health scheme.**

**Recommendation 17**

**That the State Government allocates $100,000 for a 12-month pilot project to increase access to dental health services for people with serious mental illness.**

### 11.4 The income support system

The majority of people with serious mental illness are dependent on Centrelink payments as their sole source of income. The participants in this research reported mixed experiences of Centrelink. Those people in receipt of the Disability Support Pension generally reported higher levels of satisfaction with the agency, particularly those whose contact was through a Centrelink Community Officer at a community-based mental health service. 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 emerging from this research is 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 income support is dependent on assessments by health professionals and failure to provide 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 income support system and in particular the requirements for assessment for the DSP. Centrelink, on the other hand, fails its clients by administrating a system of fines and penalties widely criticised as harsh and punitive, administrative errors, a level of bureaucratic inflexibility and a trend towards increasingly harsh assessment measures for people with disabilities. In a number of instances, the narratives of the participants demonstrated that inadequate interaction between these two systems resulted in them being left without any income, reliant on relatives and charity. The stress this caused was recounted by the carers.

The research also revealed a number of anomalies in the income support payment system which 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 income support. The cases documented in this 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 means 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 this research had sufficient income to support a second household. These families reflect the fears held by a broad alliance of community organisations who campaigned against the changes to the Youth Allowance on the grounds that it “increased financial burdens for struggling families” (ACOSS, 1998). Young adults with serious mental illness for whom it is inappropriate or impossible to live at home must have access to the Youth Allowance (Incapacitated) 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 the concerns raised in this report 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 18**
**That the Commonwealth Government lowers the age of independence for income support purposes from the current 21 to 18 years for unemployed people in order to remove the financial burden on families of unemployed or ‘incapacitated’ young adults.**

**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.**

**Recommendation 23**
**That Mental Health Services and Centrelink develop formal protocols to ensure that income and personal support is provided to people with mental illness who are eligible for it.**

## 11.5 Employment and training

The current Commonwealth Government has placed a high expectation on participation in work and education and training by all Australians. Like other Australians, people with serious mental illness express the desire to engage in meaningful and properly renumerated work. However the barriers to them achieving this goal are substantial. This research has documented the disadvantages experienced in an education and employment system which does not respond to the episodic nature and particular symptoms of serious mental illness. To facilitate the participation of this group in the workforce, Anglicare recommends that a specialist and supported vocational educational and employment programme be developed.

**Recommendation 24**

**That the State Government and the Commonwealth Department of Family and Community Services (FaCS) provide funding to develop educational and vocational rehabilitation programmes for people with serious mental illness which would also provide expert assistance to employment services and educational institutions. This needs to occur in consultation with Mental Health Services and non-government service providers.**

## 11.6 Mental health services

The conclusive findings of this research indicate that 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 mental health services. Tasmania has the lowest mental health workforce per capita in the nation. Difficulties associated with the recruitment, retention and remuneration of staff need urgent attention. This 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. Research participants and NGO service providers reported 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 does play an important role in the treatment of serious mental illness, even with fully resourced comprehensive and effective community-based mental health support services. The participants in this research in all three regions of the State reported similar concerns about their hospital stays. These included lengthy delays prior to admission, lack of communication from staff during hospitalisation and premature discharge when they, their carers and support service staff considered that they were still unwell. In keeping with the focus of this research Anglicare has developed a series of recommendations which address the issues which are specific to people with serious mental illness and who are experiencing socio-economic disadvantage.

**Recommendation 25**
**That Mental Health Services allocate additional funds to address mental health workforce issues throughout the system, including recruitment, high staff turnover, and to ensure positions are filled when staff leave is taken.**

**Recommendation 26**
**That Mental Health Services ensure that their effective discharge planning protocols include the following strategies specifically relevant to people experiencing socio-economic disadvantage:**

- **Ensure accommodation arrangements are in place at least one day before discharge;**
- **Ensure that in instances where a patient is being discharged to a carer's home, an assessment is made of the carer's capacity to provide care;**
- **Confirm transport arrangements from hospital to home at least one day before discharge;**
- **Contact the family/carers, GP, and, where relevant, Centrelink social workers and other community providers at least the day before discharge to confirm that the patient is being discharged and to ensure that services are activated or re-activated; and**
- **Ensure that an information kit outlining the mental health services system be distributed to patients and carers as part of a discharge kit.**

**Recommendation 27**
**That Mental Health Services implement a comprehensive professional development programme for all mental health workers to ensure that contemporary models of best practice are adopted in all settings. This professional development should cover:**

- **The social determinants of health, and in particular the causal factors for people with mental illness;**
- **Protocols for effective referral and discharge planning;**
- **Protocols for admission of people with serious mental illness;**
- **Management of people with co-morbidity;**
- **The principles and procedures of family sensitive practice; and**
- **Models for inclusion of carers in care plan development and management.**

**Recommendation 28**
**That Mental Health Services review the strategies used to provide information about the mental health service system, including community support services, to people with serious mental illness, their families and key support people on first presentation with a mental illness. Specifically Anglicare recommends that Mental Health Services develops a service directory to be distributed as part of a discharge kit.**

### 11.7 Supporting Carers

The carers of people with serious mental illness provide the community with substantial and largely unremunerated community care services. Carers across the age spectrum articulated similar concerns about the advocacy, housing, support and financial needs of their relatives. This 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, Anglicare recommends the development of a comprehensive and co-ordinated system of community-based services to assist people with serious mental illness which includes a range of programmes to meet the needs of carers and the families, both siblings and children of people with serious mental illness.

**Recommendation 29**
**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.**

**Recommendation 30**
**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 31**
**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, socio-economically disadvantaged and from linguistically or culturally diverse backgrounds.**

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