Odysseus' Labours

A Rehabilitation and Recovery Guide for Those Who Have a Mental Illness and Their Carers

Dr Paul Kauffman and Rupert Gerritsen

Grasp with both hands

Gift of time

Spin dreams

Wonderful dreams

From the poem 'Trapped' by Mary Kirkland Wilson

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Dr Paul Kauffman and Rupert Gerritsen

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Rupert Gerritsen is Team Leader, Community Information and Education with the Mental Health Foundation. He hails from Western Australia where he worked with Aboriginal and non-Aboriginal young people, people with mental health problems, the homeless, and the community through drop-in centres, worker cooperatives, housing cooperatives, early intervention programs, outreach programs and youth employment programs. He has researched and published extensively in social issues, history, historical ethnography, historical linguistics, and archaeology, and has edited an international journal. The Mental Health Foundation delivers a range of high quality services for people with a mental illness and their carers, engages in mental health promotion and fosters consumer and carer participation.

Comments, Suggestions and Additional Information
Please direct any comments, suggestions or additional information for inclusion in future editions to: **paul.kauffman@gmail.com**

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Preface

Senator Gary Humphries

Senator for the ACT and Deputy Chairman Senate Select Committee for Mental Health

"As deputy chairman of the Senate's Select Committee on Mental Health, it is with great pleasure that I have agreed to write a preface to this important book by Professor Paul Kauffman and Rupert Gerritsen, on mental health rehabilitation.

The first Senate Report, in March 2006, found that there needs to be more money, more effort and more care given to this neglected part of our health care system and that there is not enough emphasis on prevention and early intervention.

The committee was inundated with submissions not only drawing attention to the system's failings, but offering constructive suggestions on how to fix them.

We recommended a substantial overall increase in funding for mental health services over time, to more closely reflect the disease burden and to satisfy the very significant unmet need.

We wish to guarantee the right of people with mental illness to access services in the least restrictive environment, to be actively engaged in determining their treatment and to be assisted in social reintegration and underpin those rights with legislation.

We wish to promote consumer involvement in service provision and promote the recovery model in mental health.

In our Report we proposed:

- A new set of Medicare mental health schedule fees and rebates for combinations of private consulting psychiatrists, GPs and psychologists,
- Reform the National Mental Health Strategy (NMHS) to guarantee the right of people with mental illness to access services in the least restrictive environment, to be actively engaged in determining their treatment and to be assisted in social reintegration and underpin those rights with legislation,
- That Australian Health Ministers promote consumer involvement in service provision and promote the recovery model in mental health.

The importance of Paul Kauffman and Rupert Gerritsen's book is that it builds on this more enlightened approach and provides numerous self-help and practical measures to assist people with an illness gain suitable housing, gain housing support, gain rehabilitation and obtain some part-time employment. Paul and Rupert have made a major contribution to assist people help themselves and help their families provide effective support. I strongly recommend this publication to you."

Senator Gary Humphries

Foreword

Mary Porter AM MLA

Chair of the ACT Government's Legislative Assembly Committee on Education, Training and Young People and Deputy Chair of the Health and Disability Committee

"Mental health is something that all of us strive for, and when we are unfortunate enough to suffer mental ill health, the result is usually devastating for the person affected and for their close friends and family.

There are new medicines available that enable far more people to recover than in earlier times. We do know, however, that in most cases medicines by themselves are not enough.

Community understanding and support, good social programs and meaningful daily activities are vital for everyone, and above all for those affected by a mental illness.

Federal, State and Territory governments are deeply committed to doing more in this area, and to helping as many people as possible recover or achieve their potential. The tragically high rate of suicide among particularly young people, when they are first affected with a mental illness, is something that we all as a community must strive hard to avoid.

Yet the essential truth remains that no government programs, and in most cases no course of medication by itself, will help a person achieve recovery. What is needed is a person's own awareness and insight into their illness, and appropriate support from family and friends. The book is a guide to mental health consumers about what can help them.

I am particularly pleased to commend this small publication to you, as one example of the self-help activities undertaken by carers and the Mental Health Foundation in the ACT.

The book is not a government publication. But it does attempt to help people with these illnesses and their friends and families obtain essential help, concerning accommodation, medical services, rehabilitation and everyday life. It is written from the point of view of sufferers and their families. It focuses on some of the most important facts that you need to know to survive, to recover and to achieve a reasonable life. From time to time the information will change. Hopefully our rehabilitation programs will improve. The authors would welcome your comments so that they can improve future editions. The electronic form of the publication is available free by emailing paul.kauffman@gmail.com

It is by many thousands of such small initiatives that we as a community can make a dramatic improvement in the lives of those suffering from a mental illness. By such small steps we as a community become richer, and we can heal many of those suffering among us."

Mary Porter AM MLA

Introduction - Purpose of this publication

This is a somewhat personal account, and contains information that we have found extremely helpful and effective.

Mental illnesses are complex conditions. It is often unlikely that 'one magic bullet' will solve your problems, such as correct medication, or suitable accommodation, or accommodation support, or rehabilitation activities or part-time employment. All of these can help and this report explains their benefits and how they can be accessed. Three case studies are also included (Appendix B) to provide some guidance and insight into individual circumstances.

All the major mental illnesses are eminently treatable. But everyone needs organisation, structure and support in their lives, and those suffering from a severe mental illness are in particular need of this sort of support. This report explains how one can attempt to achieve that.

There are two major obstacles in obtaining adequate rehabilitation at present in countries like Australia. The first is that there are simply not enough services such as supported shared housing and other forms of rehabilitation for those who need it. This may mean you have to both organise and pay for substitute services yourself. We have found that such essential support for people with a severe illness can cost around $20,000 per person each year for those affected by a mental illness and their extended families. This is above and beyond the cost covered by the Disability Support Pension (DSP). If some policies were changed this financial burden would lessen.

Secondly, even if an appropriate support and/or rehabilitation service is available, carers face difficult decisions in organising the life of their loved one, recognising that such decisions are best made by the person affected in conjunction with their extended family member.

We have also found that there are particularly difficulties for people with a mental illness in a city like Canberra, the centre of federal government in Australia.

We believe that psychiatric illness are more intense forms of various conditions either found in many people, or, say in the case of hallucinations, would be found in everyone if you were subjected to a sufficiently stressful situation, such as being in solitary confinement and deprived of all sensory stimulation. It is therefore important that the mentally ill have enough stimulation and challenges, and not too many stimulations and challenges. Everyone needs order, structure and support in their lives. For those with a mental illness, this is even more true than most.

In much of Australia, the challenges are formidable for both those affected and for their families and friends. Chief among these is the need for recovery and rehabilitation for those who are seriously mentally ill. It is for this reason, that we have called this publication *Odysseus' Labours.* It sometimes seems that the skill and tenacity of the mythical Greek culture hero Odysseus are often required by persons with one of these conditions, and by those who wish to help them get better.

A graphic account, with particular relevance to the ACT, of the struggle faced by someone with a mental illness and their carer can be found in two self-published books by Ruth McFadden. In the eloquent words of the author, there is *No Place for Daniel*, which is the title of her later book and also describes the plight of her son Daniel who has a severe psychiatric illness.

We suggest that special care and support should be provided over a number of weeks after a person is discharged from hospital. There is a need for a follow up team for people released from hospital. This has been a major deficiency in the past, as Mental Health Foundation research has shown that is a period when someone with a mental illness is very likely to commit suicide.

We hope to produce a second publication as part of a series which will discuss recent research into recovery and rehabilitation for people 'suffering' a mental illness. It is anticipated a third report will discuss policy changes that we think are desirable, and provide guidance on how to lobby Ministers and government officials to bring some of these changes about.

Finally, we are aware that this is a constantly changing area, and so we would welcome any comments, suggestions or further information from you, by emailing paul.kauffman@gmail.com, so that we may improve future editions.

Descriptions of illnesses and numbers affected

As a way of providing the advice and guidance we have relied on the accounts of three friends and their relatives in their struggle to overcome mental illnesses. The particular conditions that they were affected by are described in standard reference books in the following way:

Schizophrenia

Schizophrenia is a psychiatric illness characterized by impairments in the perception or expression of reality, which can include hallucinations, delusions, and disorganized thinking.[1] The lifetime prevalence of schizophrenia, that is, the proportion of individuals expected to experience the disease at any time in their lives, is commonly given at about one per cent. It has been recently linked to an inability of the brain to block out 'dream-like' voices and visions, during waking hours.

It is likely that this condition has been around from the earliest times of human history. How we see the condition is significantly affected by the cultural context in which it occurs.

Such individuals are more likely to have trance states, either naturally or as a result of epilepsy or schizophrenia. The neurological components of creativity, spirituality and capacity to develop trance states include religiosity, hypergraphia and enhanced emotional reactions. In traditional hunter gatherer societies such people are called shamans, with a special role to play in that society. They are the forerunner of the artist, prophet and healer, special individuals in our society.
(Dr Robert Kaplan, ABC Occam's Razor, 13 April 2008**)**

The ignorance surrounding the term 'schizophrenia' is so great that in the case of 'M', discussed in this publication (Appendix B), we would generally explain that he is recovering from depression. If pressed by an educated inquisitive friend or flat mate we would further explain that at present he has 'an inability to block out dreams during the day', but that with correct medication and supported housing and employment, there is a high probability of complete recovery over time. We would then refer them to the research and rehabilitation practices which are discussed here, and to E. Fuller Torrey's writings.

'M"s high physical fitness and exercise, intelligence, conscientiousness, and enjoyment of life contrasts with the presentation of many people who suffer from schizophrenia in Australia, where very little realistic social and employment support is provided.

Bipolar Disorder

Bipolar Disorder is a psychiatric condition defined as recurrent episodes of significant disturbance in mood. These disturbances can occur on a spectrum that ranges from debilitating depression to mania. There is often a correlation between creativity and bipolar disorder. The term bipolar disorder is of recent origin and refers to the cycling between high and low episodes. It has replaced the older term 'Manic-Depression'. A 2003 study found that 0.8 percent of the population surveyed had experienced a manic episode at least once (the diagnostic threshold for bipolar I) and 0.5 percent a hypomanic episode (the diagnostic threshold for bipolar II).

An individual's prognosis depends on the right medicines and dosage; on them being well informed; having a good working relationship with a competent medical practitioner; a competent, supportive, and warm therapist; a supportive family or significant other; and a balanced lifestyle including a regulated stress level, regular exercise and regular sleep and wake times.

Obsessive-Compulsive Disorder (**OCD**)

Obsessive-Compulsive Disorder is a psychiatric disorder most commonly characterized by a subject's obsessive, distressing, intrusive thoughts and related compulsions (tasks or 'rituals') which they engage in, in an attempt to neutralize the obsessions.

Community studies have placed the prevalence at between one and three per cent, although the prevalence of clinically recognized OCD is much lower, suggesting that many individuals with the disorder are undiagnosed.[2]

People affected

The Oxford Handbook of Psychiatry broadly confirms the extent to which populations are affected by these illnesses in OECD counties. How many people are affected in a city like Canberra? At 30 June 2006 the population of the ACT was 334,000 people. It is therefore likely that there are about 3,300 people with schizophrenia/integrative disorder. There are an estimated 2,700 people who have experienced an episode of Bipolar I/manic-depression and another estimated 1,600 people with Bipolar II/ hypo-

manic depression. These estimates are broadly in line with ACT Health Department surveys of presentations, and covers people with very severe to less severe conditions.[3]

The number of people who suffer from OCD in the ACT is probably somewhere between 3,300 and 9,900 people, but many do not seek help from psychiatrists or psychologists.

'Benefits' of mental illness

People affected by particular conditions often ask why they have been unfortunate enough to have a serious mental illness. There is also the problem of why feelings, experiences and behaviours that do not seem to be particularly useful occur.

In Darwinian evolutionary terms, it does seem the case that humans and other species are ceaselessly diversifying at the level of the individual organism. If these variations are well-adapted to a particular environment or situation, that individual will reproduce and that variation will become a permanent part of the genome.

However, experiencing voices, visions, and a dream-like state during waking hours is not particularly helpful to the conduct of everyday life and appears to be maladaptive. On the other hand, traditional societies such as Australian and North American Aboriginal peoples place high importance on perhaps similar dreamlike experiences. The religious literature of Hinduism and Buddhism, as well as the Book of Revelations in the Christian tradition, are full of experiences that must be taken as an article of faith, but also could be interpreted as a sign of 'mental illness' in the person experiencing them (See section on India in Appendix F).

From time to time there are behaviours that may be seen as maladaptive, such as living as a hermit on a mountain when the rest of the village are living on the coast. But if a tidal wave came the hermit would survive while the villagers would be swept away. Eccentric behaviour at the level of the individual can therefore be adaptive at the level of the group, when considered from a long-term evolutionary perspective.

The connection of bipolar with high achievement in some but, not all sufferers, suggests that that illness or personality type is well-adapted to intensive application in pursuit of a particular endeavour for short periods of time. It may take a lifetime for a person so afflicted to work out the correct balance of activities and endeavours for themselves.

One person's obsessive-compulsive disorder can be another person's striving and attaining world-best standards in the activity that they have dedicated themselves and their lives to.

Providing care for those labelled 'mentally ill' is a good indicator, we believe, of the general health and robustness of a society, and the compassion, understanding and empathy of individuals within it.

Medication and treatment

In Australia the total cost of prescribed medications for psychiatric illness is paid for by the Federal Government. There is evidence that with good social rehabilitation the level of prescribed medication can be lowered.

For example, the individual discussed in the first case study, and referred to as 'M', for many years was prescribed very high levels of clozaril which is produced by Novartis and costs Federal taxpayers some $8,000 per annum for one person. If one per cent of Australians (210,000 people) were on such dosages, the annual cost to taxpayers would exceed $1.7 billion. Fortunately ACT medical specialists referred his case to Dr Harry Hussig, a visiting Australian expert on medication. Following Dr Hussig's assessment, ‘M’'s medication was reduced to about half of previous levels. This has resulted in a much improved quality of life for 'M'. Reduced medication and a lot of (privately-funded) rehabilitation support has provided a much improved quality of life. It has substantially increased his employment and other skills. It has also resulted in great savings to the Australian taxpayer, through lower levels of medication. Since a privately funded *L'Arche* supported house was established for 'M' early in 2006, and other (privately funded) rehabilitation services put in place, 'M' has also been free of all hospital admissions and presentations.

We suggest that you seek out the best psychiatric support you can obtain. ‘M’ has fortunate in being provided highly professional treatment for many years by a couple of dedicated psychiatrists in the ACT, as well as by a psychiatrist and other specialist staff at the Alfred Hospital in Melbourne. To their credit these practitioners also stressed the importance of a social rehabilitation program so that ‘M’ could achieve a high level of functioning and recovery. This is not always the case, and it is advisable to ask around regarding the reputation of any psychiatrist before you consult with them.

We also found it helpful to obtain a copy of the MIMS handbook of medicines and read the effects of various drugs which have been subscribed in a particular case, and their side effects.

One tendency in Australia is to prescribe valium and related drugs as a supplement to psychiatric medication. Valium produces high dependency and we are advised has no therapeutic benefit. In our experience it often used as a substitute for rehabilitation and support programs and is best avoided.

Bipolar - Treatment

Any website or reference book will list so many geniuses, and men and women of high creativity, who have also endured manic-depression/bipolar disorder. Sadly there are many non-geniuses who also suffer from this debilitating condition. The fact that people are significantly affected by bipolar disorder, schizophrenia, and obsessive compulsive disorder, as well as the occurrence of other major psychiatric illnesses, merely highlights how vastly variable and diverse humanity is.

'Exercise, healthy food and everything in moderation' makes for good physical and mental health for all people. For those unfortunate enough to be afflicted by a major

psychiatric illness, these principles are even more important. Expert medical guidelines are also useful. For example, the Royal Australian and New Zealand College of Psychiatrists' guidelines identify the following behaviours that can lead to depressive or manic recurrence. **The following advice is also very useful for people afflicted with schizophrenia and obsessive-compulsive disorder**:

- Discontinuing or lowering one's dose of medication, without consulting one's physician.
- Being under- or over-medicated. Generally, taking a lower dosage of a mood stabilizer can lead to relapse into mania. Taking a lower dosage of an antidepressant, may cause the patient to relapse into depression, while higher doses can cause destabilization into mixed-states or mania.
- Taking drugs - recreationally or not - such as cocaine, alcohol, amphetamines, or opiates. These can cause the condition to worsen.
- An inconsistent sleep schedule can destabilize the illness. Too much sleep (possibly caused by medication) can lead to depression, while too little sleep can lead to mixed-states or mania.
- Caffeine can cause destabilization of mood, tending toward irritability, dysphoria, and mania. Anecdotal evidence seems to suggest that lower dosages of caffeine can have effects ranging from anti-depressant to mania-inducing.
- Inadequate stress management and poor lifestyle choices. If unmedicated, excessive stress can cause the individual to relapse. Medication raises the stress threshold somewhat, but too much stress still causes relapse.
- Often individuals with bipolar engage in self-medication, with the most common drugs used being alcohol and marijuana. Sometimes they may also turn to hard drugs. Sometimes tobacco smoking can induce a calming effect on people suffering from bipolar disorder.

We have found that bipolar disorder in many cases requires mood-stabilizing medication and therapy as well as a health lifestyle, regular daily exercise, a healthy diet, and support from an extended family or friends. Once these things are put in place a person can return to normal functioning, and with their doctor's permission may be able to go off medication.

The aim for a person trying to manage a mental illness is perhaps similar to that of other people, i.e. to make the most of life, to fulfil one's potential and to realize at least some of one's dreams.

Schizophrenia - Treatment

As with bipolar, there are people recognised as being highly talented, immensely creative, even geniuses, who have had schizophrenia. Nobel Prize winning mathematician John Nash, featured in the movie *A Beautiful Mind*, is an example. Recent developments in medication have seen a range of highly effective medications, known as 'atypical antipsychotics', become available, such as Clozapine (Clozaril), Risperidone (Risperdal), Olanzapine (Zyprexa), Quetiapine (Seroquel), Ziprasidone (Geodon), Aripiprazole (Abilify), Paliperidone (Invega). These have brought about dramatic improvements in the lives of many and with far fewer side-effects.

New medications are being developed all the time. Medication for schizophrenia and bipolar disorder are reportedly the fourth-best selling class of medicines in the United States, with sales of $12 billion in the United States and $18 billion worldwide in 2006. There is therefore a large financial incentive to discover more effective medications.

In the future some of the medications available will probably be even more effective than current medications, at least for some people. For example, in a clinical trial of about 200 patients, an experimental drug reduced schizophrenia symptoms without the serious side effects of current treatments, according to a paper published in September 2007 in the journal *Nature*. The drug is still being evaluated to test for the possibility of undetected side effects, and so will not be released until 2011. This new drug is known as LY2140023. It is based on the observation that PCP, a street drug sometimes called 'angel dust', produced symptoms nearly identical to those of people with schizophrenia. In the 1980s, scientists discovered that PCP blocked brain receptors that are triggered by an amino acid called glutamate. This led some companies and scientists to study ways to stimulate glutamate receptors as a treatment for schizophrenia.

According to Dr. Joseph Coyle, a professor of psychiatry and neuroscience at Harvard Medical School, 'existing drugs are reasonably good at treating the hallucinations and delusions of schizophrenia. But they are far less effective at treating the so-called negative symptoms of the disease — the lack of motivation and emotion that leave many patients unable to work or have normal social relationships'. The side effects of existing medicines, which affect nearly all patients, are also severe, according to Dr Coyle.[4] It is hoped the next generation of medications will overcome these limitations and the side effects.

Obsessive Compulsive Disorder – Treatment and Therapy

Conditions such as Obsessive Compulsive Disorder (OCD) are becoming better known in Australia. A front page report by the *Daily Telegraph* in 2007 discussed the famous and not-so-famous who suffer from the condition. The article referred to the case of Eirene Donovan, aged 39, a corporate writer and editor based in Brisbane, who has a particular preoccupation with patterning. This sufferer of OCD explained:

I would literally spend hours ordering my wardrobe because every item needed to have a friend. Even now, when I am buying carrots at the supermarket, I will choose a pair that look like they want to be together.

It was reported that this desire for symmetry also influenced Eirene's writing, to the point where all her time was consumed balancing the number of punctuation marks, contractions and capital letters in a sentence. It appears that this mastery of detail made her exceptionally good at what she does, now that her OCD is under control. As a proof-reader and editor, she is renowned for being extremely thorough. She was told by her psychiatrist that some degree of obsessionality was necessary to succeed in any field, even in occupations such as neurosurgery and air-traffic control. Typical OCD traits can also lead to success in other areas of life – particularly where persistence, intensity and focus is required.

Famous people afflicted with OCD

One high profile sufferer of OCD, Scott Draper, became a professional golfer after a highly successful tennis career. He revealed his own long-term struggle with OCD in his book *Too Good* (Random House). Draper's OCD manifested as cleaning, checking, tapping and tidying rituals and he describes it as 'the mental equivalent of your car brakes locking on an icy road .. you are careering out of control, silently screaming, and feeling powerless to stop it'.

As more and more high achievers 'come out' about their own experiences with the disorder there is much evidence of people with OCD who are treated for the condition, leading normal lives.

Another famous person afflicted by OCD was Howard Hughes, the entrepreneur who was sympathetically portrayed by Leonardo DiCaprio in the film, *The Aviator*. The world famous soccer player, David Beckham, spoke about his OCD in 2006: 'I have to have everything in a straight line or everything has to be in pairs,' he said. Beckham said that if there are too many soft drink cans in a fridge, for instance, he would throw one out. But the urge that prompts his fridge fiddling, is the same one that compels him onto the pitch to practise and practise, …and work towards perfection in playing soccer.

The *Daily Telegraph* reported in 2007 that one of Australia's greatest cellist, David Pereira, was forced to abandon his career after the medication used to treat his OCD caused his hands to tremble. 'For a long time I struggled with that', he admits. 'Anyone who has experienced OCD ... knows the pain is unbearable'. David has since made a full recovery and is teaching and performing full-time at the School of Music, which is part of the Australian National University. Other reported OCD suffers include the actor Jessica Alba and the scientist Charles Darwin.[5]

Treatment and Therapy for OCD

While some medications may help control symptoms, people with OCD derive greatest benefit from appropriate forms of therapy. Psychologist Michael Fox for example, works on the basis that people suffering from OCD can learn to control and hence enjoy the advantages of this aspect of their personality. Professor Paula Barrett, director of the Brisbane-based Pathways Health and Research Centre, has developed the successful FOCUS (Freedom from Obsessions and Compulsions Using Cognitive-Behavioural Strategies) program to help OCD sufferers. These types of therapy are available through some private psychologists in the ACT. To find such a psychologist in your area you can contact the Australian Psychological Society on 1800 333 497 or through their website www.psychology.org.au.

Depression

Black Dog Institute

Not surprisingly many people with a serious mental illness, and their carers, are also at risk of experiencing depression. In this connection, the Black Dog Institute is an educational, research, clinical and community-oriented facility offering specialist

expertise in mood disorders - a range of disorders that include depression and Bipolar Disorder. The Institute is attached to the Prince of Wales Hospital and affiliated with the University of New South Wales. The Institute was formally launched in February 2002 by the then Premier of New South Wales. The Institute builds on the work of its predecessor, the Mood Disorders Unit, established in 1985 as a clinical research facility. The Institute's mission is to advance the understanding, diagnosis and management of the mood disorders by continuously raising clinical, research, education and training standards. In so doing, the Institute aims to improve the lives of those affected - and in turn - the lives of their families and friends. Access the website to obtain helpful links and information www.blackdoginstitute.org.au

Therapy

Many people who experience depression, whether as a condition associated with OCD, or as a result of their condition or undertaking the role of a carer, can derive benefit from therapy. We would recommend Cognitive Behaviour Therapy, based on the evidence that it appears to be the most effective form of therapy. You can see a private psychologist, get referred to one by your GP, refer yourself to the Psychology Clinics at Australian National University or the University of Canberra, or get online therapy through 'Mood Gym'.

Walking

About a third of people with some form of depression seem to get great benefit from walking. Nobody really knows why, but it does work for some. Even if it doesn't work for you, the exercise is still good for you.

Cultural differences

Cultural differences can make it even more difficult in understanding or assisting a person affected by a mental illness. Fortunately in Australia there is a special organisations which can assist. For example, the New South Wales Transcultural Mental Health Centre (TMHC) provides clinical consultations and assessment, and works in the area of transcultural mental health promotion, prevention and early intervention, publication and resource development, and education and training.

TMHC, based in Sydney, is a statewide service based that promotes access to mental health services for people from diverse cultural and linguistic backgrounds (See www.dhi.nsw.gov.au).

The Centre recognises the significance of cultural and linguistic difference in mental health issues and uses a whole-of-lifespan approach, involving work with children, adolescents, families, adults and older people.

The Centre manages projects using collaborative partnerships with consumers, carers and a range of mental health and health services, general practitioners, non-government organisations, universities, key government agencies, welfare agencies, multicultural and ethno-specific services and culturally diverse communities across NSW. People from the ACT can access this service if necessary. Furthermore, the

numerous publications by TMHC, produced in about ten major community languages, are freely available.

Contact Details:
Transcultural Mental Health Centre
Phone: (61 2) 9840 3800
Email: tmhc@wsahs.nsw.gov.au
Post: Locked Mail Bag 7118 Parramatta BC NSW 2150

Psychiatrists

There are many excellent psychiatrists working in public hospitals and for ACT Mental Health. Usually someone who is admitted to a psychiatric unit will see a psychiatrist with 72 hours. Individuals who are assigned a Clinical Manager will also have access to a psychiatrist.

If you are seeking a psychiatric assessment there are also quite a few private psychiatrists in the ACT. They can be found by looking in the Yellow Pages under 'Medical Practitioners' – there is a section in that listing psychiatrists. Otherwise you can phone the Mental Health Foundation Information and Referral Line on 62826658 and a list will be supplied. A referral from a GP is required for an appointment. It is worth noting that not all psychiatrists in the ACT have a satisfactory level of empathy and skill, and it is advisable to ask around in order to obtain the best possible assistance.

In Australia, public patients have their medical costs paid for by Government. There seems to be a priority based on medical need. We know of several patients who have had great difficulty obtaining psychiatric care on a public or private basis, once they are out of hospital.

Psychologists

Psychologists can assist with Cognitive Behaviour Therapy (CBT) and other therapies, including relaxation techniques and strategies to address such matters as panic attacks. Cognitive behaviour therapy can sometimes involve looking at fundamental assumptions about how life and relationships work. For instance, even an adult child can bitterly resent being abandoned, as they see it, if one of their parents is no longer in contact with them, for whatever reason. Such issues can be partly addressed by talking through their effects, in order to make the best of one's current situation.

For many years we found it impossible to obtain psychological help in the ACT for a person suffering from a severe psychiatric illness, apart from the excellent but severely stretched in-patient facility at the Psychiatric Services Unit at Canberra Hospital. At one point we contacted some 20 psychologists in the Yellow Pages, and stated that we were willing to pay $160 per hour for consultations, but they were all too busy to assist. We are thankful however to Dr John Corcoran, in Civic, for his providing a series of consultations for 'M' in 2006.

In 2006 the Federal Government trialled the 'Better Outcomes for Mental Health Program', administered by State and Federal Governments. In 2007 the Australian

Government extended this psychological assistance to far more people than previously. Under the program, anyone can be referred by their GP to one of the psychologists who are registered under Medicare. You can obtain ten consultations with that psychologist. Health Care card holders may be bulk-billed. Others can now receive Medicare Rebates of $75, which usually means a fee of $35 each visit.

The Australian Psychological Society (1800 333 497) www.psychology.org.au lists specialisation of each clinical psychologist. You can contact them requesting a psychologist with the desired specialty and they will provide you with the names of the three nearest to where you live.

Around Australia it appears that some 400,000 people had already taken up this form of psychological assistance in the first eight months of 2006/2007. It is not clear at this point how many of this number includes those with a serious mentally illness.[6]

We remain gravely concerned about the ability of the 720,000 Disability Support Pensioners to access this billion dollar program, which was originally designed to provide essential therapeutic assistance to those with serious mental health issues, and not to provide free psychological assistance to the 'worried well'.[7]

Books and films about mental illnesses and rehabilitation

There are many fine publications and excellent movies about mental illnesses, people's struggles to overcome these limitations, and how to achieve recovery and rehabilitation. We would particularly recommend some of the high quality, accessible and readable books such as E. Fuller Torrey's book *Surviving Schizophrenia: A Manual for Families, Consumers and Providers*, and E. Fuller Torrey and Michael B. Knable's *Surviving Manic Depression: A Manual on Bipolar Disorder for Patients, Families, and Providers*. Both books are in public libraries or can be purchased new or second-hand on www.amazon.com.

Books

It is desirable if those afflicted, or more particularly their families and friends, read as much evidence based research material as possible, so that they are aware, and take advantage, of new methods of treatment, recovery and rehabilitation.

Many books on serious mental illness have also been written by people with a diagnosed condition, as well as by their carers. We would encourage you to write your own story as the act of writing about one's experiences can be quite therapeutic. Such books can be written by a health professional, who has seen many patients, often over many years, but often it is in a specific role and without the gut-wrenching identification of having a child with a serious mental illness over many years.

One of the most eloquent books written by a person who was severely affected by schizophrenia and who then recovered is Carol North's *Welcome, Silence: My Triumph Over Schizophrenia* (Simon and Schuster, 1987). Carol North was an articulate medical student who developed a very severe form of schizophrenia in her second year of medical school. She writes lucidly about the experience, and in particular the torment of her troubling voices. Carol North is also trained in observing

and recording illness. The book is therefore an insightful description of what having schizophrenia is like for someone who has it. Carol North is now a professor of psychiatry at Washington University School of Medicine in St Louis.

One of the most practical and helpful books for those afflicted with schizophrenia and their families is Roberta Temes' 2002 book, *Getting your Life Back Together When You Have Schizophrenia.* As the dust-cover says, this book is an 'excellent, easy-to-read guide for persons with schizophrenia. I highly recommend it to consumers who want to learn to manage their illness and get on with their lives'.

The book discusses cognitive behaviour therapy, and also coping skills. These include reality testing, social skills, coping with high sensitivity and the importance of routine, which includes:

- Taking your medicine at the same time every day
- Waking up at the same time every morning
- Going to sleep at the same time every night
- Getting some physical exercise daily
- Checking in with one's 'support team' members every week.

Termes describes a support team that most people in Australia can only dream of. They include the patient, the family, a psychiatrist, a pharmacist, a social worker, the team leader, a psychopharmacologist, a psychotherapist who apparently meets weekly with their patient, a friend and a peer. Of course very few individuals in Australia would have so many professionals available to assist. For anyone in Australia with a serious mental health problem you can at least complement and compensate for limited professional input by making sure that the family, extended family and friends at least touch base every week with their affected relative/friend. This is very important for the person's wellbeing and so they don't become isolated.

We have also found it important that the person affected obtain and secure some sort of ongoing employment, even if it is only part-time work, e.g. three to six hours per week. For many people we have encountered over many years we have found that even this limited regular paid employment is highly beneficial in providing a social role, an identity, a useful occupation, structure to their lives, as well as being and extremely helpful in supplementing the income to those who are seriously unwell.

Sarah Edelman's 2006 book, *Change Your Thinking*, explains cognitive behaviour therapy and techniques to use it to help manage a serious mental illness. The techniques described include confronting situations that one fears, using assertive communication, practising deep relaxation techniques, problem solving, goal setting, utilising social support, and activity scheduling. It is not only people with OCD and other anxiety/depression based conditions who find significant improvement, just about anyone with a serious mental illness can benefit from these techniques.

Many other books are listed on http://www.schizophrenia.com/media/. These books and articles are of varying quality but the challenge is to be informed and find material that can really help you.

Films

There are over twenty Hollywood films featuring people with schizophrenia. Perhaps the most famous is *A Beautiful Mind*. In this film Russell Crowe plays the Nobel prize winning mathematician John Nash, who was afflicted with schizophrenia, and realized that the young girl and the CIA men who regularly visited him during the course of many years were not real, because unlike his wife and colleagues, they never aged. Because of Nash's intelligent approach to his illness, and the support of family and friends the film has a happy ending. There are websites that evaluate many of the films which cover major mental illnesses, such as www.chovil.com, www.schizophrenia.com/media/video, and http://ap.psychiatryonline.org.

Rehabilitation and recovery

Even those with a potentially severe mental illness, such as schizophrenia, about 75 per cent show significant improvement after ten years, **provided that they engage in a rehabilitation program,** according to extensive research by Dr Fuller Torrey and others. However, it seems likely that this percentage is not achieved in Canberra, simply because of the lack of programs here, compared to say Melbourne, or European best-practice models as described in the Senate Select Report's on Mental Health in 2006.

In 1995, the head of Mental Health ACT confirmed the common sense approach that it is dangerous for people with a serious medical illness to live alone. Yet this remains the major option for many with a serious illness in the ACT. The effects of such policies on just one individual, Daniel McFadden, have been well documented in the two highly readable and tragic books written by his mother Ruth McFadden. The books lead one to deeply question the current lack of adequate rehabilitation and social support for most people with a serious mental illness.

Clearly there is a need to increase funding for rehabilitation and lack of supported accommodation? Would the plight of the seriously mentally ill be helped if the long term disabled had their rental assistance doubled, from $52 per week to twice that amount? The weight of research evidence establishes that this is the case. Should the seriously mentally ill be given priority for psychological counselling? We think so. If the federal or ACT government allocated 0.1% of all staff positions to people who had been on Disability Support Pension for two years or more, and each position was shared by 10 disabled people during the course of a week, that would create hundreds of paid part-time positions in cities such as Canberra. It would create a place in the work-force for people like Daniel McFadden and some thousands of others like him. Sadly, such measures were in place twenty years ago but were discontinued.

Despite the best efforts of the many dedicated and skilled professionals working in Canberra, there is a particular problem. There are simply not enough professionals and resources to go around. This is not surprising when one consider there are an estimated 7,600 people in the ACT just with schizophrenia or bipolar, with at least another 3,300 people with OCD. Consequently most people with a mental illness, particularly those who are severely affected by their condition, are not receiving, and may never receive, adequate rehabilitation and social support through publicly funded

programs. Nevertheless, there are strong prospects of full recovery if the person affected, their carers and their friends take the initiative, read the medical literature, obtain the best medical help, and embark on a program of rehabilitation through their own determined efforts. In other words, Odysseus-like labours, skills and application are called for, but there are substantial rewards. Some guidance in how to do this are included in the following pages.

Housing

Dr Stephen Rosenmann, who was a practising psychiatrist and formerly head of ACT Mental Health, stressed as far back as 1994 the importance and benefits of living with other people if you have a mental illness. This is a principle underlying advocacy of the 'Trieste' model, as discussed in Senator Lyn Allison's 2006 Senate Report on Mental Health.[8] Research from Australia and overseas clearly indicates that for people with a mental illness, quality accommodation, particularly supported shared housing, is a key ingredient in their recovery, and in the prevention of hospital readmissions.[9]

In this context it is worth noting that there do not seem to be good outcomes when adults in our society live long-term with their parents. We are aware of some people with a mental illness who have lived with their parents for many years. They are now concerned because their parents are approaching old age, and may themselves have to move into a nursing home. Ideally their adult son or daughter would have been better prepared for this major change if they had begun to practise skills for independent living many years beforehand. But neither is living by oneself in a bed-sitter or one-bedroom flat, particularly if one is unemployed, conducive to good outcomes and quality of life.

We are aware of at least 230 places in hospitals, institutions and government houses in the ACT where more than two people with a mental illness share accommodation with each other. These sorts of situations require extra planning, support and resources. Unfortunately such arrangements are the exception rather than the rule in the ACT,[10] and in most instances other options need to be considered.

As one response to the need to provide adequate housing for people with a mental illness the Catholic Church in France established *L'Arche* households, where one or two people with no illness or disability share a house with one or two people who are disabled or who do have a mental illness. There are at least two such houses in the ACT for people with physical disabilities, but no government supported houses for people with a mental illness that follows this model. There are in Western Australia, and they work very well. Rupert Gerritsen lived in such households in Western Australia, part of a service called the Household Network, prior to coming to the ACT. In the case of one of the authors, it took many years of frustrations with inadequate government housing or no housing at all, to prompt him to set up a privately funded *L'Arche* house.

Privately funded *L'Arche* houses[11]

The international non-profit organisation *'L'Arche*' provides accommodation to people with an intellectual disability, in housing that is shared with mainstream people. The organisation has about 2,700 members with a disability. There is no obstacle to you

setting up your own *L'Arche* house for a relative or friend diagnosed with a mental illness, if you have enough determination and resources. It is a viable option, perhaps the best, as it allow independence whilst having support on hand if needed.

Publicly funded *L'Arche* houses

It would be possible for the government or a community organisation to set up a *L'Arche* housing scheme. But this would require a funding commitment not only to meet the rental shortfall of at least $120 per week ($6,240 per annum) for each tenant being supported, as well as the administrative cost of running the scheme. Issues such how to decide who will live with whom, and how to deal with any emergencies that arise, would need to be addressed. Nevertheless, this may be a more cost-effective and supportive way to provide stable accommodation for those with a mental illness than current options such as ACT Housing.

Private renting

One option is for a parent or relative to take out a lease on suitable accommodation for two years or longer, and advertise on a site such as www.allhomes.com.au for suitable persons to share a room. The best strategy in this instance is to provide quality housing with about a 10 per cent discount on market rents, and interview prospective boarders to ensure that they are sensitive and compatible people. In most cases where this has succeeded in Canberra, these have turned out to be public servants in full-time employment.

Because most people on a Disability Support Pension cannot afford to run a car, it is best to live near a town centre, where it is possible to commute by bicycle, so it is not necessary rely too much on our limited public transport system.

The most cost-effective housing in most capital cities is a two or three bedroom house or flat. Single bedroom accommodation is the most expensive form of housing. Unfortunately, figures show that rental levels even for the most cost-effective option are still well above what can be afforded on a $52 per week maximum rent subsidy (25%) together with a maximum single disability pension of $250 per week:

Average rents in Australia in 2007[12]

CITY	**3 BED HOUSE ($/WEEK)**	**2 BED FLAT ($/WEEK)**
Sydney	280	330
Melbourne	250	260
Brisbane	290	280
Adelaide	250	200
Perth	300	280
Hobart	270	210
Darwin	395	300
Canberra	350	330

The cost of renting a 3 bedroom home of reasonable quality in the ACT near one of the four town centres usually exceeds $400 per week. The cost of each room therefore ranges from $120 to $160 per week. If a couple of compassionate people could be found to rent two rooms they would contribute $130 per week each, a total of $260. However a disabled pensioner's rental allowance is only about $52 per week, leaving about a $90-100 per week shortfall. Either the person on the pension must somehow make that up out of their meagre pension, or a parent or other relative helps out. Potentially they could be up for $5,000 per annum. Of course this gap could be significantly more if rooms cannot be filled or the person on the pension is living in a one-bedroom flat.

Private borrowing

Another housing alternative is for a parent or relative to buy a house, and vest title in their own name, or in the name of a trust, for the family member with a disability. In 2006 the Federal Government changed legislation so that a disability pensioner could own a house or benefit from a housing trust established for them by a family member or friend, up to the value of $500,000, and not be penalized in their disability payment. Centrelink also provides an example of a trust deed that you can use when establishing such a trust.

For the majority of people who do not have a spare half a million dollars available, and who are unlikely to be left such an amount in a will, it is still possible to borrow enough to provide adequate supported housing.

If purchasing near a town centre in the ACT you will probably need at least $450,000 to buy a 3 or 4 bedroom house, plus stamp duty and legal fees on the purchase. If you have a deposit of about $150,000 you can borrow about $300,000. The key requirements for such a loan is that you must be employed and have sufficient borrowing capacity.

The cost of repaying a loan of $300,000 over twenty-five years is about $26,000 per annum, or $500 per week. If two other residents can be found and they pay almost commercial rents, thus sharing the cost of the mortgage payment, and one person on a disability pension also lives in the house, there is a shortfall of about $200 per week for the parent or friend to make up (about $10,400 per annum), plus rates and maintenance. On the other hand this ‘loss’ should be tax deductible each year, together with the cost of rates, repairs, maintenance and depreciation, thus minimising the level of subsidisation needed.

This is a viable option. One of the authors of this guide, for example, was given a substantial redundancy payment from their employer of many years, and managed to obtain another position in another industry shortly after. Consequently he was able to apply the redundancy to a deposit on a house, and to obtain a loan secured by their new salary.

It should also be noted that market rents rise over time, so it will be possible to change the other tenants more, thus reducing the gap between rental income and mortgage repayments.

If you wish to seek free advice on how to structure a loan, and provide such housing for a relative or friend on a private basis, please email paul.kauffman@gmail.com.

Government provided housing (Housing ACT)

A significant proportion of people with a mental illness are either homeless, unable to afford private accommodation, or are not eligible for, or able to access, supported accommodation. While their carers may be very concerned, they may not be able to accommodate them either, for a variety of reasons. In such cases publicly funded housing is the only other option. At the present time even the supply of this form of accommodation is not meeting the demand, the need. People who are homeless are of course given top priority in accessing Housing ACT, but it may still take 3 months for accommodation to become available. Those who live in inadequate accommodation but are not homeless, or are already in Housing ACT but wish to relocate, have to wait for significantly longer periods.

To apply for accommodation with Housing ACT an application needs to be made. This can be done at the Housing ACT Applicant Services Centre, which is located at Nature Conservation House, corner of Emu Bank and Benjamin Way, Belconnen.

Alternatively go to www.dhcs.act.gov.au/hcs/public_housing_/how_to_apply to download or print off the relevant form. **Applications must be submitted in person.**

It is advisable to get a support statement from a GP, psychiatrist AND a mental health professional. This can be as part of the application form or as separate letters. Such support statements/letters spell out the need and establish eligibility, as well as greatly assist where relocation is requested.

Tenants of Housing ACT pay either a maximum of 25% of their income in rent, or the market rent, whichever is lower.

Contacting Housing ACT

Clients may contact Housing ACT by phoning 13 DHCS (133 427). A free Housing ACT courtesy telephone is installed at the Tuggeranong Canberra Connect Shopfront and within the City and Phillip Health Centres.

For those who are already tenants of Housing ACT and need something fixed they should call 6207 1500 (24 hours, 7 days a week). For all other Housing ACT enquiries please call 133 427. Tenants are usually assigned a Housing Manager or Client Service Officer. If you do not know their direct numbers, you can receive assistance by telephoning 133 427.

Housing Advocacy

If issues arise, such as a rejection of an application for housing, or a tenancy issue, in which you think there has been unfair or inequitable treatment it may be advisable to lodge an appeal, and/or get the assistance of an advocate. This can be a carer, a

support worker or a dedicated advocacy service such as ADACAS (6242 5060) or the Welfare Rights and Legal Centre (6247 2177).

If you are caring for someone who has a mental health disability and you are still having difficulty gaining adequate housing, particularly government provided housing, you should write or contact your local member of ACT Legislative Assembly or federal parliament and ask them to write to the Minister for Housing, to seek advice about how a person who may have a significant disability can obtain housing.

One of the authors has found that 'going to the top', i.e. writing to the responsible Minister, then if necessary telephoning the Minister's office and requesting to speak with a member of their staff, is an effective means of securing assistance.

Domestic assistance

Services such as Home Help (6287 3777) and Tandem Respite (6288 0955) can provide heavily subsidised domestic assistance, personal care, episodic major cleaning, and home and garden maintenance to people with a mental health disability, and their carers. Bringing in a Home Help person for a couple of hours a week can be of great benefit in helping those who struggle with domestic routines to keep on top of things and maintain their independence.

Employment

Classical psychiatric textbooks written in the 1960s by experts such as Slater and Roth noted the high degree of difficulty that people with acute mental illnesses experienced in gaining and keeping employment, and they concluded that the best prospects of success was for a person suffering from such an illness to gain a job requiring highly ritualized, repetitive activity. We do not necessarily agree that this is the case, and many people underestimate the capacities of people with a mental illness. Nevertheless it is important that those with a mental illness be given the opportunity and assistance to obtain employment. There is extensive medical and other research which shows the benefits of work for mental and physical health.

Certainly many people with a mental health disorder experience some difficulty in obtaining employment. Stigma can be one barrier. But the unpredictable nature of mental health conditions also can present problems in obtaining or keeping employment. For instance 'G' (Case Study Three) in Victoria, who was diagnosed with Bipolar Disorder, completed her university degree but it took seven years. She either handed in an assignment and gained a high distinction, or could not manage to hand in an assignment at all.

Similarly, another student at the Australian National University, who had extremely high marks in Year 12, would either gain a high distinction for every examination that he sat for, or he withdrew from the subject. He too eventually gained a pass degree from the university, then spent a lifetime unemployed, on a disability pension.

For better or worse all Australian public services nowadays are performance driven. Consequently there is a trend which appears to require that all staff be self-directing,

and have high resilience and adaptability. There is also high turnover and mobility in the public service, with more frequent re-structuring, compared to a generation ago. Such demanding environments are not conducive for people with a mental illness, even those who are high-functioning, and so making it difficult for them to gain or maintain employment with the public service. In the past, some public services have had a quota requiring them to employ a small percentage of people with disabilities, including mental health disabilities. Such requirements appear to have completely disappeared in the last decade, as noted in recent ACT Human Rights Commission Reports. Given this, and the current high performance requirements, it is now much more difficult for people with a mental health condition to obtain government employment, be it in Canberra or elsewhere. Therefore it is advisable that strong consideration be given to seeking employment in the private and voluntary sector.

From 1996 to 2007 the focus of the Government's effort, through its social obligation approach, was to get people on Disability Support Pensions who are able to work for five hours each day and for four or more days each week, into the workforce. Even a cursory reading of basic psychiatric reference works shows that such an approach is unrealistic for many people with a mental illness, particularly a severe mental illness, unless specialised assistance is provided. Over 90 per cent of all Disability Support Pensioners in Australia have no employment at all. But many could be employed to some extent if a more appropriate approach is taken. For example, if some provision were made for regular part-time work requiring a commitment of no more than eight hours each week.

Despite intensive lobbying no Commonwealth or ACT Government department has made provision for dedicated positions for people who are on Disability Support Pensions. Should they decide to do so, such a scheme would need to take into account the individual capacities of people with a serious mental illness. Many are not able to work for more than a limited numbers of hours per week, whereas most of the workforce remains structured for full-time or near to full-time employment. There are few jobs where one can work regularly for two to eight hours each week. But this could be overcome by creating job-sharing positions for example. Roger Beale, who has a physical disability, was originally hired under such an arrangement and rose to become head of the Industries Assistance Commission. He has said that if he were starting now, he would spend a lifetime unemployed on a disability pension.

While it may be a little less efficient to provide such a job-sharing scheme in the public service, there is a substantial body of research indicating that such limited employment has significant therapeutic benefits. There would also be off-sets in terms of savings to Centrelink and reduced hospitalisation rates.

Even a small amount of regular part-time work is of great benefit financially for those who are otherwise forced to subsist on the bare minimum. Employment, or even voluntary work, also helps to structure the week, and allows interaction with the rest of society, with all the benefits that flow from that. Those who are not socially engaged through employment or some other form of participation are effectively 'left out' of society.

'M', who is discussed in the case studies in Appendix B, secured part-time employment by approaching a friend whose husband was a large employer. And he

has managed to retain his position for several years. It is an important part of structuring his week, connecting to mainstream employment and increasing his skills.

In European towns such as Trieste in northern Italy, it is the norm for those with a mental illness, even serious mental illnesses, to be engaged in some part-time work. In many other European countries a common pattern is for people with a serious mental illness to have some part-time work.

Australia-wide there are over 720,000 people on Disability Support Pensions. About 26 per cent of people on Disability Support Pensions have a mental illness, and a further 11 per cent have a severe mental incapacity. Less than 10 per cent of the people in these categories undertake any part-time work.[13] In the ACT in 2005 there were 1,900 people on Disability Support Pensions as a result of having a psychiatric illness.[14] Our impression is that in Canberra the percentage of people who are seriously affected by mental illness, and who obtain any part-time work during the course of a year, may be as low as 2 per cent. But no formal study or survey has been undertaken regarding part-time employment for people on Disability Support Pensions in the ACT, so this is only an estimate.

It can be helpful to have a client's psychiatrist notify Centrelink if a person is not well enough to work for longer than five hours per week in total, and for longer than a three hour period in any given shift. This reduces Centrelink reporting requirements.

In practical terms the support of family and friends can be critical in gaining any sort of employment. Increasingly, gaining and keeping a job also depends on learning new skills. Having some basic computer skills, an understanding of the internet and abilitiy to use email is extremely important nowadays. Some options in terms of gaining the required skills and capacities are discussed in the section on ‘Telephones, mobile phones, computers and the internet’.

There are agencies that assist with employment. NorthSouth Contractors, for example, provide the equivalent of four full-time positions. These four positions are shared by some 20 or more people, each person working half a day per week. While this does not bring a great deal of income to the participants it is a good stepping-stone to ongoing part-time employment in the mainstream labour market. Unfortunately there is usually a waiting list to gain employment with NorthSouth Contractors.

NorthSouth Contracts is a community business run by the Mental Illness Fellowship in the ACT. Their office is located at 41B David Street O'Connor. To register, contact them on 6205 1349 or by email northsouth@mifact.org.au.

NorthSouth Contractors provides:

- Garden and Home Maintenance
- Lawn mowing
- Gardening
- Tree trimming
- Rubbish removal
- Yard maintenance
- Small furniture removal

We would encourage you to use NorthSouth Contracts wherever possible as a way of supporting those with a mental illness.

The Mental Illness Fellowship operates another community business, **Café Pazzini,** which is a rehabilitation and training scheme for people recovering from mental illness. About three people are employed there at any one time, receiving hospitality training as part of their placement.

Again, if you're looking for a place to have lunch or a coffee, we would encourage you to give Cafe Pazzini your patronage. It is located on the Ground Floor of the ACT Health Building on the corner of Moore and Alinga Streets, Canberra City. (Ph. 6205 1209)

Workways is a specialist employment placement agency which provides 2 programs as well as a Disability Open Employment for people with a mental illness. They conduct employer education to minimise discrimination and stigma. They can be contacted by phone on 6247 3611 or by email at admin@work-ways.com.au.

There are probably over 6,000 people with schizophrenia and bipolar disorder alone in the ACT, and over 2,000 of them are on long-term disability Clearly NorthSouth Contractors, Café Pazzini and Workways can only provide or arrange employment for a few of these people. But, in terms of the recovery and rehabilitation process, they provide important opportunities to gain initial employment.

Getting a job in the open market

There are numerous opportunities for positions that are relatively easy to get, although they may not be very high paying. You might want to try the nurseries and other businesses such as supermarkets (for checkout positions or stacking shelves) in your local area. Letterbox distribution is also easy to get into, and although the effective pay rate is low, it gets better as you get more efficient, and the walking is good for your health and wellbeing.

If you are looking for a more mainstream job keep in mind that more jobs are advertised on specialist websites, such as SEEK, than in the employment section of newspapers.

We would suggest you use personal connections as much as possible, research indicates that 60% of people looking for work obtain it through personal connections rather than by impersonal formal applications.

Volunteering can be an effective way to assist in getting employment. It helps you to make personal connections, you may get your ‘foot in the door’ with a potential employer, the potential employer can see you performing in a work environment, it gives you at least some experience you can point to when applying for jobs and it demonstrates that you are motivated. If things work out as a volunteer the employer may even write you a reference or agree to be your referee. This can be very helpful if you don’t have an extensive work history.

As an example there is a reference for 'G" included in Appendix B. This was written to help her obtain a part-time job.

Keeping a job

There are many people who have mild or temporary conditions who participate in the mainstream of the workforce, and who manage perfectly well. But sometimes they have an ‘episode’, or their condition worsens. Having a sympathetic and understanding employer who follows good management practices that value the employee and assists them through difficult times is of course very helpful. In most cases the employee is not obliged to disclose their condition to their employer. However, depending on circumstances, it may be advantageous to do so. If the employer is aware of the situation, arrangements can be put in place that take into account the periods where an employee’s mental state deteriorates. This can included extended periods of sick leave, reduced workloads, reduced hours and extra workplace support. We are aware of situations where this has worked very successfully.

Nevertheless, there are instances where people who have temporary conditions or periods of unwellness have considerable difficulty retaining their 'permanent' employment. One of the case studies discussed below documents what David Pereira and his friends had to do in order to secure his re-instatement at the Australian National University's School of Music in 2006 and 2007. In situations such as these the support of family and friends, and the mobilisation of industrial and mental health advocates, is critical to achieving an appropriate outcome.

If you do get some sort of employment, keep in mind, from the employer's point of view, the main thing they require is absolute reliability. So, if you work 9 til 12 noon every Friday, you would have to always be there. If for whatever reason you are unable to make it, it is preferable that you arrange for another staff member to cover for you if at all possible. Otherwise, give the employer as much notice as you possibly can.

It is advisable to assess your capacity to work, what a prospective job entails and what remuneration you will receive. Jobs with low effective rates of pay ($6-10) may not be helpful if you take into account the costs of being employed (clothing, transport to job etc.). Some jobs, while superficially attractive, may take too much out of you, such as heavy industrial cleaning. Seek the advice of people who know you and your capabilities, and people who have done that sort of job, before committing yourself.

Centrelink and Employment

If you are in receipt of some form of benefits through Centrelink and you obtain part time employment you must inform Centrelink of your earnings. If you only earn a small amount it will not affect payments. As earning increase Centrelink will begin to reduce benefit payments, depending on the scale, but usually by about $1 for every $2 earned, until a point is reached where Centrelink payments are longer required.

If your doctor completes a form which states that you cannot work for more than eight hours each week, it is not necessary to complete fortnightly forms for Centrelink about hours worked. But it is worthwhile photocopying the form that your doctor has signed and you have provided to Centrelink. You can then give Centrelink a copy of the form, if they again request fortnightly reports of your hours worked.

If you were on a Disability Support Pension prior to 1 July 2006 and are capable of working 30 hours each week, or on DSP after that date and deemed to be capable of working 15 hours per week, you are required to compulsorily return-to-work. Centrelink may make contact in that regard, but keep in mind your appeal rights if you disagree with the assessment.

Social engagement, rehabilitation and recovery

We strongly advocate that people with a mental health condition ensure they are socially engaged, that they have friends and social contact. A lot of people in such situations become isolated and lonely and this is not conducive to healthy mind. We there encourage people to work on maintaining their social engagement and their social networks. If someone has become isolated, working on a plan to become socially re-engaged is imperative. Social engagement promotes resilience, through shared experiences, validation, reality checking and the opportunity to offload to someone if need be.

Places such as Rainbow provided an excellent opportunity to connect with others. Various leisure programs, art programs and day-to-day living programs also offer valuable opportunities in this regard.

Clubhouse activities - Rainbow

The research literature emphasizes that club-house activities and mutual self-help support are invaluable and a great help in rehabilitation.

For example, we cannot speak highly enough of the dedicated group who operate the Rainbow Clubhouse at Canberra Technology Centre, the former Watson High School, in Phillip Avenue in North Canberra. This is one of the key resources in the ACT for rehabilitation, recovery and social engagement.

The Rainbow Clubhouse was established in the year 2001. It is a community-based consumer facility for psychosocial rehabilitation for people with a mental illness.

The Rainbow has now operated for a number of years and is currently open for four days a week (Monday - Thursday, 9.00 am to 5.00 pm). It is run by dedicated skilled staff and some volunteers. Rainbow clients, its members, have a say in how the place is run.

There is a large open area with lounges, a games room (pool, table tennis, air hockey), an activities room (musical instruments and exercise equipment), a meeting room, an art room, a vegetable garden, an outdoor barbeque area and an office area. There are some 15 computer terminals for the use of members. There are planned activities and groups each day, such as music classes, art classes, women's group, exercise sessions, cooking classes etc. These change from month to month and the members have input into what groups will be running each month. Every day there is a communal lunch at nominal cost. There are music classes, art classes, cooking classes and walking groups, often led by members. Just about every week members who want to go on excursions to visit some of Canberra's many attractions, or to the movies, picnics and so on. From time to time members also go on trips away.

The thoughtful interior design, user-friendly layout, individual attention and nurturing environment of Rainbow all help to provide a calm and supportive setting for the participants.

For further details contact or visit **The Rainbow**:

H Block, Canberra Technology Park,
Phillip Avenue, Watson,
(head for the very rear of the complex to find Rainbow)
Ph: 6242 6575
Email: rainbow@mhf.org.au
Opening hours: 9am-5pm, Monday to Thursday (except for Public Holidays.)

We have had the pleasure of getting to know many of the Rainbow members over time. A surprising number are from the families of eminent Canberrans. Many are highly talented and pass on their skills and knowledge to other members.

Any donation to the Mental Health Foundation for the Rainbow is always most welcome, as the Rainbow Clubhouse provides a most valuable service to many people.

Other Recreational and Leisure Activities

As mentioned earlier, there are a range of leisure programs, art programs and day-to-day living programs available in the ACT that offer opportunities to engage in positive activities, and which offer the possibility of meeting people and making new friends. The types of activities such programs offer normally include such things as:

- Scrabble
- Soccer
- Walking
- Creative Writing
- Gardening
- Jazzercise
- Cooking
- Tennis
- Movies
- Bowling
- Singing
- Sculpturing
- Pottery
- Drawing
- Chess
- Meditation
- Woodworking
- Badminton
- Backgammon
- Swimming
- Nutrition
- Photography
- and so on ....

The organisations offering these types of activities are:

Belconnen Leisure Program 6264 0202
Tuggeranong Leisure Program 6293 3951
Open Art Program 6264 0249
Day to Day Living Program – Kambah and Tuggeranong 6293 3951
Day to Day Living Program – Canberra City (Ainslie Village) 6257 0512

Please contact them if you wish to find out more and what activities are currently offered.

Of course there are many different opportunities for mainstream recreation and leisure activities. Canberra is extremely well-endowed with iconic national institutions which offer exhibitions, tours and other resources. A very helpful booklet in this regard, *The Fantastic Activities Book*, which lists a wide range of social/recreational/activities options based on cost categories, is available for free from the Mental Health Foundation (6282 6658)

Music and art

Just like many others in the community, people with a mental illness have a passion for music or art. In fact, some of the world's greatest musicians and artists have been afflicted with a mental illness. For them, art may be a necessity, a means of regaining their sanity. But you, as a consumer, do not need to possess unique artistic talents to have your life enriched by music or art.

If you have a desire to develop your creative talents you can easily obtain a reasonably priced second-hand musical instrument through websites like www.allhomes.com.au, other websites, or simply by looking at ANU's School of Music notice boards. It is even possible to arrange a suitable teacher who may come to your house each week for a $30 half-hour lesson. In addition, art and music classes are often provided by community centres, such as the Belconnen Community Centre in the ACT. As mentioned earlier, the Open Art Program, the Tuggeranong and Belconnen Leisure Programs and Rainbow have music, art and many other creative activities included in their programs.

Exercise

For humans, exercise is an essential part of life. Our ancestors, from the first hunter-gatherers onward, have had to engage in physical activity. If they didn't they died, exercise was an integral part of obtaining food. As a consequence we have evolved to exercise. The Latin saying, a 'healthy mind in a healthy body', is really an ancient Greek expression which identified the importance of exercise for good physical and good mental health. Even Shakespeare alluded to this in *Hamlet*:

I have of late..lost all my mirth, foregone all custom of exercise[15]

He perceptively linked lack of exercise and depression.

Nowadays we recognise the importance of regular exercise, so we see the likes of Presidents Bill Clinton and George Bush, and former Prime Minister John Howard, all engaging in some form of running or walking on a daily basis.

Exercise is even more important for those with a serious mental illness, as often the medication that is prescribed is extremely constipating, and also tends to make a person obese. Of course you can overcome the first problem by eating prunes for example, but exercise is virtually essential. And there is no lack of opportunities. You can swim, walk, jog, cycle, go to a gym and so on, in order to obtain what is essential for your good health.

You may find joining some form of organised activities, such as offered by Rainbow or the Leisure Programs, walking clubs, Pedal Power and so forth may be more suitable in terms of motivation and enjoyment. Whatever the case, keep in mind that exercising for 30 minutes or more on at least three occasion each week is the minimum level recommended by doctors.

Financial management

In our experience even the most skilled financial management will not be sufficient to cover basic needs of someone with a serious mental illness who relies on the Disability Support Pension. Securing part-time employment and employment skills, paying rent in a shared housing, music therapy, caring for a calm friendly dog, transport around town, an annual holiday, buying healthy food, going to see a movie or going out for coffee, even if at a concessional rate, all cost significant amounts of money for those on a DSP. Yet extensive research shows that these are just some of the essential ingredients for successful rehabilitation and recovery.

If financial resources are insufficient the chances are that an individual with a mental health disorder will find it difficult to achieve effective rehabilitation and recovery. That means the chances of relapse are significantly increased, with the likely outcome being a period of hospitalisation. There is a significant cost to taxpayers when someone is confined to a psychiatric ward or a public hospital, perhaps $500 per day. The cost of ‘intensive care’, where someone may be confined to the High Dependency Unit. may be as high as $1,000 per day.[16]

In reality in Australia the shortfall in essential living expenses is often made up by family and friends. Our case studies show that the annual additional personal costs, which normally extend over several years, amount to some $10,000 to $20,000 per annum per person, depending upon the circumstances, particularly if the individual concerned has difficulty in obtaining or keeping full-time employment in the mainstream.

There are difficulties with any government, however compassionate, enlightened and generous, making up this shortfall. The 2006 initiative of the federal government in allowing long-term disability pensioners to have a trust fund of $500,000 from their own resources, for their housing, without it impacting on their pension, is a step in the right direction. It is not clear how many people of the 750,000 people on disability pensions, have been able taken advantage of this policy change. Currently 35 per cent of Disability Support Pension recipients are home owners, with 80% of the home owners being aged 50 years or over.[17]

Depending upon the circumstances, the assistance relatives or friends in regard to some aspects of financial management is often required. After a relative in Victoria was left a modest amount of money by her deceased father's estate, my wife and I were asked by the relative to manage that estate on a *pro bono* (without charge) basis. We were able to do this relatively easily by consulting with our relative, paying annual costs of essential services one year in advance, (in order to avoid essential services being cut off, as they had nearly been in the past), and arranging an automatic monthly bank transfer for a modest amount for incidental expense.

With the help of the internet one can manage even complex affairs at a distance. The following is an example of the type of letter we would send every six months, providing a clear summary of the individual's financial position, projected expenditures, existing arrangements and entitlements they may be eligible for.

> Dear .....
>
> You asked for a financial statement of your assets. I sent one to you on 26 March 2007. The position at 21 August 2007 is as follows:

Account	**Balance ($)**	**Date**
CBA Key card Account No.		21 August 2007
CBA 8 month Account No. Fixed term maturing on 8 January 2008		21 August 2007
CBA 8 month Account No. Fixed term maturing on 8 January 2008		21 August 2007
CBA Retirement Savings Account		21 August 2007

Expenditure items ($)	**Item**	**Date**
	Estimate of 12 month's expenditure for electricity	7 January 2007
	Estimate of 12 month's expenditure for gas	7 January 2007
	Estimate of 12 month's expenditure for Telstra	7 January 2007
	Estimate of 12 month's expenditure for medical insurance	7 January 2007
	Estimate of 12 month's expenditure for pharmaceutical	7 January 2007
	Estimate of 12 month's expenditure for doctor's fees	7 January 2007
	Estimate of 12 month's expenditure for dentist's fees	7 January 2007
330	Monthly automatic bank transfer	January – December 07
600	Emergency payment to Origin Energy Gas	3 August 2007
120	Emergency payment to Dr	3 August 2007
260	Emergency payment to Telstra	6 August 07

In summary I believe that you are doing a very good job of managing your finances. You are spending about $10,000 per annum from your deceased estate Trust, and the income on bank interest is about $6,500 per annum after all costs and charges. You also have the maximum flexibility with this arrangement.

If you obtain Superannuation Co-Contribution each year it will amount to an additional $1,500 or more. To qualify you need to earn about $24 per week or $1,250 per annum or more, and lodge a tax return and supplementary tax return, and record that $1,000 has been deposited into your Retirement Savings Account, at a bank such as the Commonwealth Bank of Australia. In 2005 a co-contribution of $3,000 was paid by the Federal Government. In other years it has been $1,500. At 150% or 300% government guaranteed annual return it is the best investment going.

On 8 January 2008 your term deposits will earn interest for the previous eight month period, but you will have to pay one year in advance, (for administrative simplicity), for electricity, gas, and private health insurance, dental, pharmaceutical and possibly some other medical expenses. There is also the need to ensure that you have a small monthly amount automatically transferred into your bank account for incidental expenses.

Please let me know what you want to do about Telstra. I recommend that you get a free land line for incoming calls, and buy a basic mobile from Optus and purchase $30 credit as and when you need it. You are currently spending a high amount on your Telstra land line.

Yours sincerely

Holidays

The major obstacle preventing many people with a mental illness going on holidays, particularly if they have a more severe condition, is lack of finance and lack of support. Yet travel and vacation and having a trip to look forward is important for almost all people's mental health, including those who are suffering or unwell. There is much anecdotal evidence that a holiday can have therapeutic effects. A difficulty for many of the disabled, apart from lack of financial resources, is the difficulty of finding someone to holiday with. In this instance the support of family and friends is really important. But there are other options however.

Youth Hostels Association enables access to hundreds of hostels around Australia and the world, which are clean, safe and enjoyable, and for a modest cost (see www.yha.org.au) Accommodation starts from $26 per night, and single rooms and twin rooms are available at an additional cost. Annual membership is $37 per annum, and life time membership is available. You can access 4,000 hostels in 60 countries, including hundreds around Australia. Membership also entitles you to discounts on bus travel, car hire with some companies and travel insurance. Unlike most ‘backpacker’ hostels, YHA is a not-for-profit organisation that has a history of service, a more diverse clientele and an organisational infrastructure. This generally makes YHA more accepting, supportive and flexible in its operations.

Clubhouses, such as the Rainbow in the ACT, and some supported accommodation services, also organise occasional trips away, such as visits to the coast, the bush or the snow.

Pets

It seems likely that pets (dogs and cats) can provide therapy for people with major psychiatric illnesses such as bipolar disorder and schizophrenia. What researchers call 'Animal-assisted Therapy' has been shown to encourage mobility, interpersonal contact, and communication while reinforcing activities of daily living, including personal hygiene and independent self-care.

A calm and friendly dog, rather than a puppy that requires a lot of attention, can also provide good companionship for people who have depression, anxiety, or schizophrenia and do not socialize much.[18]

It now seems to be the case that some service dogs, at least in the United States and in some states in Australia, are being trained by professional organizations that specialize in service dog training. Since Psychiatric Services Dogs (PSDs) are a relatively new phenomenon, there has not been much time for organizations in the ACT to develop PSD training. However we anticipate this service will be available here shortly. In the meantime, we suggest you consider the option of training one's own PSD. This is, in and of itself, a therapeutic and beneficial activity. Don't be deterred by the thought of training your own service dog; it isn't as hard one might think.

With Psychiatric Service Dogs (PSDs), dogs are individually trained to work or perform tasks for individuals living with mental illnesses. To date there has been only limited research into the effectiveness of PSDs for people with mental illness. But Dr Aaron Katcher, M.D., Emeritus Professor of Psychiatry at the University of Pennsylvania, who has examined the interaction between animals and people, found there is 'much evidence that social support is a critical variable in the recovery from many serious biological disorders including psychiatric illnesses.' Some of the tasks that PSDs can be trained to perform include:

- Remind handler to take medication on time
- Warm handler's body during a panic attack
- Interrupt repetitive behaviours
- Attend to handler during emotional distress
- Accompany handler outside of the home
- Provide discernment against hallucination
- Mitigate paranoia with reality testing

The website suggests that researching Psychiatric Service Dogs on the Internet and joining a Service Dog email discussion listserv are two things you can do that cost nothing. It also suggests communicating with as many PSD owners as possible in order to evaluate whether this life choice is for you. You may wish to visit The Psychiatric Service Dog Society web site http://www.psychdog.org/, particularly if you already own a dog, or are considering getting one.

The Psychiatric Service Dog Society provides information for persons living with severe mental illness who wish to train a service dog to help manage symptoms. Some of the services that a trained dog help you with are as follows:

Disorder	Symptoms	Trainable Tasks
Major Depression	Apathy	Tactile Stimulation
	Hypersomnia	Wake-up handler
	Feelings of isolation	Cuddle and Kiss
		Hug
	Sadness	Lick Tears
	Tearfulness	Bring Tissues
		Initiate Play
	Insomnia	Stay with and focus on handler
	Suicidal ideation	
	Psychomotor retardation	Walk on a leash
	Memory loss	Remind to take medication
		Help to find keys or telephone
	Disorganization	Assist with daily routines in the home
	Thoughts racing	
Bipolar (Manic phase)	Distractibility	Tactile Stimulation
	Hyper focus	
	Irritability	Alert to incipient manic episode
	Hyper locomotion	
	Olfactory cue?	
	Aggressive driving	Alert to aggressive driving
	Insomnia	Alert to insomnia
	Memory loss	Remind to take medication
		Help to find keys or telephone
	Disorganization	Assist with daily routines in the home
	Derealization	
Panic	Depersonalization	Tactile Stimulation
	Olfactory cue?	Alert to incipient anxiety or panic attack
	Fear	Lead handler to a safe place
	Fight or Flight response	
	Pounding heart	
	Trembling	Staying with and focusing on handler
	Nausea	
	Sweating	
	Dizziness	Brace or lean against the handler
	Chills	Lay across handler's body
	Memory loss	Remind to take medication
		Help to find keys or telephone
Obsessive Compulsive	Intrusive thoughts or images	Tactile Stimulation
	Anxiety	
	Repetitive or compulsive behaviour	Interrupt
	Memory loss	Remind to take medication
		Help to find keys or telephone
Schizophrenia	Flat affect	Tactile Stimulation
	Hallucinations	Hallucination Discernment
	Catatonic behaviour	
	Disorganized speech or behaviour	Staying with and focusing on handler
	Psychosis	
	Delusions	
	Forgotten personal identity	Carry handler identification documents
	Confusion or disorientation	Take handler home
	Social withdrawal	Facilitate social interactions
	Feeling overwhelmed	Buffer handler in crowded situations
	Memory loss	Remind to take medication
		Help to find keys or telephone

In Australia, the organisation www.awaredogs.org.au attempts to provide a similar service, and can be contacted by emailing: admin@awaredogs.org.au or telephoning Che Forest on 07 4093 8152.

Other Useful Information

Retirement Savings Account

An additional incentive for working for those earning small amounts of money is the Retirement Savings Account scheme and Australian Government's Superannuation Co-Contribution. For several years the Australian Government has operated a superannuation co-contribution scheme, whereby they will pay $1,500 to $3,000 each year into your bank account if you contribute $1,000 a year, (which is only $20 per week), into your Retirement Savings Bank Account. It is a most welcome government initiative, because it rewards self-help and the great challenge of finding part-time work if you have a mental health disability.

You can open a Retirement Savings Account at the Commonwealth Bank for free. You must be earning less than $58,000 per annum to receive a Federal Government Superannuation co-contribution, and less than $28,000 a year to receive the full benefit (which is the case for many people with a serious mental illness). You have to earn 10 per cent or more of your income each year. In other words, if you are on a disability pension of about $14,000 a year, you have to earn $1,400 a year or more. **You also have to complete a taxation return each year.** The Australian Taxation Office then pays your superannuation co-contribution into that account some months later.

If you are married to a person who is also on a pension, you need to earn about $24 per week or $1,250 per annum or more to qualify for a Federal Government Superannuation co-contribution. You also need to lodge a tax return each year, and ensure that $1,000 is paid into your Retirement Savings Account at the Commonwealth or another major bank. Government Co-contributions have been between $1,500 and $3,000 per annum in the past. At 150% to 300%, the government guaranteed annual return it is the best investment going.

It means that if you work for say $12 per hour for say three hours every week, you not only receive $36 a week for your labour, but you also receive between an additional $30 or $60 per week for that work. You are really earning $66 to $96 for three hours work each week, because of the Superannuation Co-Contribution.

Superannuation can be accessed at age 55, or earlier in extraordinary circumstances. Over thirty years, $1,000 deposited each year should amount to over $150,000, which will be of great assistance when you turn 55, because of the Superannuation co-contribution, plus interest payments.

Telephones, mobile phones, workstations, the internet and email.

If you ring 1800 676 766 you can obtain a free contact service whereby you can receive telephone calls made to your home, but you cannot ring out on that phone.

You need to have or purchase your own handset, and you cannot also have a Telstra mobile service with this free service. It means other people can ring you, but you cannot ring out from your land-line. Because of the high cost of telephone calls and telephone rental, this may be a reasonable option for many people on a disability pension.

We found it useful to purchase a basic mobile phone and buy $10 worth of calls as needed.

It is strongly advisable not to ring Sensis, which has very high charges. If you have to telephone for directory assistance, you should either ring 12 455 or 1223.

Some Disability Support Pensioners have been paying $250 each year to obtain help from directory assistance, because their White Pages telephone directory book has been lost or never delivered. It is possible to obtain a replacement White Pages by telephoning 1800 810211.

If you are unable to pay a telephone bill, and seek an extension of time to pay it, you can write to Telstra at 36 Gurwood Street WAGGA WAGGA NSW 2650.

Rainbow and some Community Services in Canberra now have workstations with internet and email connection. You can also purchase a new computer from a company such as Dell for about $900, and the cost of internet connection over a 24 month contract usually amounts to $15 to $30 per month. Paying for a computer and connections is beyond the financial reach of most people receiving a Disability Support Pension, without extended family support. However, Centrelink does provide a $10 per month service rebate on internet connections.

There is also a need to undertake training courses in basic computing and internet and email skills. Often these are available for local educational providers such as Canberra Institute of Technology or Rainbow.

Respite care and assistance at home

Respite care can provide quality one-on-one assistance to the frail aged, people with disabilities, including people with mental health problems, and their carers. There are a number of services which provide respite directly or indirectly for carers.

As mentioned earlier under ‘Domestic assistance’, Home Help and Tandem Respite can arrange regular help with cooking/ cleaning/shopping if appropriate.

We cannot speak highly enough of the wonderful services provided by Respite Care (now known as Tandem Respite) for example. Since early 2007 they have provided four visits of one hour per week, at the highly subsidized cost of $5 per hour, to assist 'M' with cooking, cleaning and shopping. We have found this a highly beneficial service which makes a major contribution to rehabilitation (and support for carers).

The background to obtaining this service was ‘M’'s admission to the Alfred Hospital in Melbourne, and being told by doctors there that extensive rehabilitation and support services were essential for his rehabilitation. They emphasized the importance of

having an organized predictable routine, which helps to reduce the effects of the voices and visions and dream-like experiences that accompany conditions such as schizophrenia.

Respite services in the ACT and region

There are 5 organisations that provide respite in the ACT where a mental illness is the primary diagnosis. Respite may be provided as "in-home" or "time-out" services. There are emergency, short-term and regular options depending on the service, assessment of need, available staffing and places, and negotiation with the provider. These are:

Carers ACT – Commonwealth Carer Respite Centre
Phone: 1800 059 059 **Fax:** 02 6290 2977
1 Torrens Place, Torrens ACT 2607
Email: carers@carersact.asn.au
Web: www.carersact.asn.au
Service Description: Provides short term and emergency in home respite to carers. Access to residential respite is available to carers and self carers.
Hours: Mon-Fri 9am-5pm
Contact: 24 hours 02 6296 9900
Area Served: ACT Region

Commonwealth Carer Link and Respite Centre - Queanbeyan
Phone: 02 6298 0140 **Fax:** 02 6298 0197
13 Cassidy Arc, 72 - 74 Monaro St, Queanbeyan NSW 2620
Mail to: PO Box 90, Queanbeyan NSW 2620
Email: Ros.Watson@qcc.nsw.gov.au
Service Description: Offers emergency and short-term respite for carers. Provides information on and referral to community services.
Hours: Mon-Fri 9am-5pm
Area Served: ACT Region,

Mental Health Foundation Respite Care Program
Northside (Warren I'Anson House)
Phone: 02 6247 1936 **Fax:** 02 6247 1936
13 Jarrah St, O'Connor ACT 2602
Service Description: Short term respite program for people 18 years or over, with confirmed psychiatric disability. Individuals who are self managing in household, personal care, treatment and regimes and able to cooperate with others and live unsupervised.
Email: respite@mhf.org.au
Web: www.mhf.org.au
Hours: Mon-Fri 9am-5pm
Fees: Service fees apply, concessions available
Area Served: ACT Region
Southside (Mark's Place)
Phone: 61624980 **Fax:** 02 61624980
1 Looranah St Narrabundah ACT 2602
Service Description: Mark's Place aims to provide carers of people living with a mental illness with the opportunity to have a short break, in order to enhance their own health and wellbeing. Carers have the option to stay at Mark's Place with or without their care recipient.

Email: marksplace@mhf.org.au
Web: www.mhf.org.au
Hours: Mon-Fri 9am-5pm
Fees: Service fees apply, concessions available
Area Served: ACT Region

Tandem Respite Inc.
Phone: 02 6288 0955 **Fax:** 02 6288 0996
25 Stapylton St, Holder ACT 2611
Mail to: PO Box 3534, Weston ACT 2611
Email: admin@tandem.org.au
Web: www.tandem.org.au
Service Description: In-home long-term support for frail aged people, adults with disabilities and adults with mental health issues. Service available daily 24 hours.
Hours: Mon-Fri 9am-5pm
Fees: Fees are means tested
Eligibility: As per ACT Health (HACC and Mental Health) and Disability ACT contracts. Details available on request. From 18 years.
Area Served: ACT Region

Tandem Children and Young Persons Program
Phone: 02 6287 2870 **Fax:** 02 6287 2680
27 Mulley St, Holder ACT 2611 display map
Mail: PO Box 3301, Weston ACT 2611
Email: admin@tandem.org.au
Web: www.tandem.org.au
Description: Provides support services at home and in the community for children and young people who are affected by disability and/or mental health conditions, and their families and carers.
Hours: Mon-Fri 9am-5pm
Eligibility: Up to 20 years. Children and young people with a moderate to severe disability, complex medical needs, behavioural conditions
Fees: Fees Apply
Contact: 0413 459 813 (Emergency Contact)
Disability Access: Yes (Parking, Toilets)
Area Served: ACT Region

Communities@Work – Respite Options ACT
Phone: 02 6288 4744
Parkinson St, Weston Creek ACT 2611
Mail to: PO Box 1066, Tuggeranong ACT 2901
Email: RespiteOptionsACT@commsatwork.org
Web: www.commsatwork.org
Service Description: One to one respite and support service for carers of people who are experiencing severe mental illness and physiological/intellectual disabilities. Provides time to recover, social contact, greater independence, empowerment, referrals, domestic support, family support, activities and information.
Hours:
Fees:
Eligibility:
Area Served: ACT Region

There are a range of other organisations that offer respite where the primary presentation is focussed on a neurological condition or condition other than a mental illness. However, where there is a co-morbidity (e.g. depression and dementia; schizophrenia and age; bipolar and physical illness), the carer and cared for may qualify. The other service organisations are:

ACT Nursing Service: 6290 2499 (frail aged, disabled)
ACT Respite Links: 6255 0722 (dementia)
Barnardos: 6241 5466 (children and family)
Dementia Respite Program: Queanbeyan 6298 0194 (dementia – Queanbeyan)
Home from Home Respite: 6285 2082 (dementia and changed behaviour)
Kincare Community Services: 1300 733 510 (some in-home respite for "people with disability"
The Lodge: 6248 6840 (dual diagnosis – 4 bed respite program)

Crisis management, counselling, support and advocacy for carers

Given the demands of being a carer places on carers, the complications that arise in being responsible for the welfare of another person, and the need for carers to deal with their own issues to ensure they can sustain themselves in their role, it is helpful to have someone to talk to and provide support from time to time. There are a number of intervention, counselling and support options available to help meet this need.

Crisis Management

From time to time the person being cared for will shows signs of an emergence of acute symptoms of their condition. This may be temporary or it may be a sign they are relapsing.

If it appears to be a temporary crisis, perhaps driven by a stressful situation, it is advisable and helpful to:

- Act calm
- Distract the person by involving them in something interesting
- Offer them something to look at, e.g. a newspaper article, a DVD
- Engage them in pleasant conversation that focuses on something other than what they are experiencing and is 'future focussed'
- Get them to talk with another person whom they know well, who they like and who has a calming influence

If it appears the person is relapsing you can contact their Clinical Manager if they have one. Otherwise, contact the Crisis and Assessment and Treatment Team (CAT Team) on 1800 629 354.

The CAT Team will not normally intervene unless the individual poses a danger to themselves or others. However, contacting them prior to this may be helpful as they are then made aware of an emerging situation.

If you ring the CAT Team when there is a crisis situation, be aware that they may not be able to respond immediately as there may be other people in crisis at that time as well, and

they will need to prioritise their responses. Furthermore, they may be constrained in their response by the availability of beds in the local psychiatric care facilities

Counselling

Carers ACT (6296 9900) provide a dedicated counselling service for carers.

You can talk to someone on the phone as well through the Carers Advice Line on 1800 242 636.

Carer Peer Support is also provided by Carers ACT. Carers are available at particular times to talk to other carers and provide advice. Contact Carers ACT for specifics on times and places.

The Mental Health Foundation has an extensive list of low-cost/no cost counselling and therapy services in the ACT, including services that provide relationship, financial and drug and alcohol counselling. This list can be obtained online by visiting the 'Counselling, Therapy and other Treatments' button on the MHF website (www.mhf.org.au), or by phoning the Information and Referral Line (6282 6658) and asking for it to be sent out.

Skills for Carers

CIT run 'Skills for Carers' course, aimed at improving the level of skills and training of carers who are caring for someone with a mental health problem. Contact them on 6207 3628 or CarerSkills@cit.act.edu.au for course details.

Carer Support Groups

There are a number of carer support groups in the ACT which provide support in different ways and for carers from a variety of backgrounds. The main carer support groups are:

The **Mental Health Carers Network** which meets on the 2nd Tuesday of each month, from 7.00 – 9.00 pm at Carers ACT, Churches Centre, Benjamin Way, Belconnen,

and

Mental Illness Fellowship, which has an informal get together over a meal on the 2nd Wednesday of each month, alternating between the Harmonie German Club in Narrabundah and West Rugby League Club in Kippax. Contact 6205 1349 for details

There are other specialist groups, such as a Spanish-speaking Women's Group. Contact the MHF Information and Referral Line for details of this and other groups.

Stress Management

It is important for carers to look after their own mental health by the adoption of good stress reduction strategies. These can also bring considerable benefit to people with a mental illness and help to minimise primary symptoms, thus reducing the

chance of relapse. It may also assist in dealing secondary symptoms associated with negotiating daily life e.g. anxiety, depression, etc. Some simple ways to reduce stress are:

- walking
- relaxation, meditation
- talking with a friend
- listening to music
- recreational and leisure activities

Carer Advocacy

There are numerous services that will advocate for people with a mental illness and their carers. There are several advocacy services that are particularly relevant to carers and the person being cared for. These include:

- The ACT Disability Aged and Carer Advocacy Service (ADACAS - 6242 5060), which provides individual advocacy for people with disabilities, the elderly and their carers. They take up issues such as housing and service entitlements, and discrimination in employment.

- The Welfare Rights and Legal Centre (6247 2177) is another valuable advocacy service, particularly in dealing with tenancy issues (both public and private) and Centrelink benefits.

- The Tenants Advice Service (6247 2011) deals with tenancy issues, in regard to both public and private tenancy.

If you as a carer see problems in the mental health system, or have ideas for change, the Carers Alliance is the body which takes up systemic issues and represents the interests of carers. Contact the Mental Health Community Coalition (6249 7756) for details of meetings and other forums where carers issues may be relevant.

APPENDIX A

"14 Principles for Carers" (www.mentalhealth.asn.au)

1. Realise that mental illness is not rare.
2. Learn as much as possible, as soon as possible, about mental illness, its cause, its course and its outcome.
3. Never become a moth around the flame of self-blame, it can destroy your chances of coping forever. It can destroy you. Free yourself with modern knowledge that mental illness is not caused by relatives.
4. Seek professional helpers that are EFFECTIVE. Identify them by their compassionate natures, informative styles, eagerness to have you as their ALLY, and ability to ensure that you receive comprehensive education in understanding and coping with mental illness.
5. Contact a self-help group for families with mental illness.
6. Accept that with complex mental illnesses, the prompting of our natural instincts are often an unreliable guide to coping and caring. We, the relatives, do need training.
7. Get to know the origins of the ever-increasing pressures that we, the relatives, are subject to.
8. Pay great attention to the needs of the other members of the family.
9. Take heed that unlimited unconditional self-sacrifice on behalf of someone with a mental illness is fatal to effective caring and coping.
10. Be aware that spending massive amounts of time with someone with a mental illness can make matters worse.
11. Maintain and establish friendships, activities and hobbies, particularly those that take you outside the home.
12. Set your sights on appropriate independence for your relative and yourself.
13. Don't be surprised to discover that it is the ability to change and adapt our thinking that distinguishes relatives that can cope from those that can't.
14. Take very great care of yourself.

APPENDIX B: Case studies

Case Study 1: 'M' in Canberra

M tended to be shy, sensitive and dreamy at school. He successfully completed Year 12 in Canberra, became ill at 18 and was later diagnosed with schizophrenia.

He has been on medication for many years. He did benefit from residence in a Richmond Fellowship House for his first year. The Richmond Fellowship manages some 28 beds at Havelock House in Canberra City, some two houses in Lyneham and four other units for intensive living support. They provided excellent support for 'M' during his first year after diagnosis. Subsequently, for many years following that, he shared a government-provided group town-house with two people who were much more ill than himself, and he was able to help and support them in some ways. The difficulty was that the small three-bedroom government townhouse lacked home-making or rehabilitation support. He shared it with a female and male of similar age, described here as 'D' and M2'.

'D' had been the daughter of diplomats and had grown up in embassies in Europe, before becoming ill. She had urinated throughout the government-owned house and surrounds. She took her two fellow-residents' food from the shared fridge to eat, which was not a major problem, but then also took her housemates food and threw it out, which was a problem. She would spend the day sleeping in the lounge room.

Although we telephoned and wrote letters regularly to ACT Health, we were told for many years by ACT Health that it was impossible for them to hire a cleaner for three hours per week, or for them to allow us to hire a cleaner for three hours per week. The stench of urine made the house difficult to live in.

The other male resident, 'M2' was intellectually challenged, and also had a mental illness. He would greet you by saying 'How's it going,' repeatedly, but had limited conversation beyond that.

His only relative in Canberra was an uncle who was deputy chief executive officer of a major Canberra department. 'Uncle Peter' spent five hours every Sunday cleaning M2's room, helping him wash his clothes, helping him shop, apportioning his disability pension into seven equal amounts each week, to try and prevent M2 spending it in one day. As far as we know M2 always visited the Rainbow Club for several days per week, but had no other rehabilitation available to him. Uncle Peter also unsuccessfully wrote and lobbied government departments, and asked them to assist him with the five hours of home making support that he provided to his nephew each week and to provide rehabilitation activities. After several years, we were told that M2 was put into a 24-hour care institution. What he wanted was some supported accommodation. We have heard that recently M2 has moved into a flat with one other male who has a mental illness, and they have some regular homemaking support in their flat, organised by Respite Care.

M spent many years living with D and M2 and for several years worked one half-day each week at NorthSouth Contractors, until they changed their policy to offer six months employment then rotate to new employees.

Since 2006 his living conditions, quality of life and life skills have improved substantially. We believe that chief among the reasons for improvement are:

Living

- The creation of a privately-funded *L'Arche* house, with compatible mainstream house companions, who are in full-time employment in February 2006. His companions in 2007 are a couple, both government lawyers, who share the house with him.

Employment

- Regular mainstream employment every Friday with a sympathetic (private sector) employer. He also worked part-time for about six weeks as a receptionist for a large research agency. These duties amounted to less than eight hours each week, but were tremendously helpful in building skills and self-esteem.

Skills

- A home workstation and internet connection and mobile phone, to communicate with family and friends in Canberra, Melbourne and overseas,
- Training programs such as a seven week computer course of three hours a week,

Rehabilitation

- Participation in Rainbow Club activities every Wednesday,
- Under medical supervision, halving his medication together with a program of rehabilitation,
- Respite Care visiting for one hour, four times per week, to assist with shopping, cooking food and supervising house cleaning,

Exercise

- Regular saxophone lessons at home every Monday,
- Cycling some 20 kms most Saturday mornings with the group Pedal Power
- A regular program of physical activity including swimming twice per week,

Leisure

- Having a large fish tank of gold fish to look after and a thriving vegetable garden, and researching a dog which is to be acquired shortly,
- Visiting films and galleries with extended family members at weekends
- Having about two short holidays a year to look forward to with friends in Melbourne or Queensland.

In short, his quality of life has improved with substantial family and other support. This requires some planning and extensive financial and other support, mainly from an extended family. His last hospital admission was in March 2006. We are optimistic about his long term prognosis.

Case Study 2: David Pereira

David Pereira has starred in the Australia Ensemble, as Principal Cello, Australian Chamber and Sydney Symphony Orchestras and taught at the Sydney Conservatorium and the School of Music at the Australian National University. His experience of Obsessive Compulsive Disorder has received extensive media coverage because of his high profile. He has now recovered from his ordeal. Hence the decision, with his permission, to refer to David by name in this publication.

His recordings on the Tall Poppies Records label include Peter Sculthorpe's works for cello, solo and with piano and J. S. Bach's 6 solo suites. His book '*Violoncello! One With Your Sound*' - a 200,000-word exploration of cello technique and artistry is a serious study and a practising cellist's companion. It can be found at violoncello.biz on the Web and can be downloaded for no charge.

The Australian National University (ANU) in Canberra was fortunate enough to permanently employ David in 1990. He did, however, have a period of some six weeks illness in 2005.

In July 2006 he became ill again, and was a patient at Calvary Hospital in Belconnen in North Canberra, being diagnosed as suffering from Obsessive Compulsive Disorder by his excellent treating psychiatrist Dr Anna Burger.

At that time he had sick leave credit of about 34 weeks on full pay, less eight weeks sick leave taken out in 2005, and a further eight weeks sick leave taken out in 2006, leaving him with a sick leave credit of about 18 weeks.

As background here one must note that all Australian universities are under funding pressure, and funds to them are allocated on number of students enrolled, number of doctoral students supervised, amount of Australian Research Council research grants awarded and amount of consultancies funded by government departments or business. In all of these respects, the School of Music does not sit well with the government funding formula.

The ANU's response to David's illness, we believe, was disgraceful. Firstly a duty statement was prepared, then an ANU official presented this to him at Calvary Hospital on 10 July 2006. The list of some 15 duties headed 'fundamental requirements of the position of Senior Lecturer' included 'Ability to perform at an international level and to take a leading role in performances at the School of Music and with outside national musical organisations.'

We were told by other senior academic staff at the School of Music that they do not have duty statements or written statements of 'fundamental requirements' for their positions.

David had in fact had in previous years presented international performances, but as far as we are aware, this is not a normal requirement for senior lecturers at the ANU.

Dr X is a Senior Lecturer in Geriatric Psychiatry at the Australian National University Medical School. His letterhead states that he is senior lecturer in the Psychiatry of Old

Age at the ANU, and he met twice with David Pereira, after he became ill in 2006, at the request of the ANU.

On 16 September 2006 the *Canberra Times* arts journalist, Helen Musa, wrote a two page feature article on David Pereira, headed 'Pereira enjoys new dawn' and featuring a sexy photograph of David playing cello.

On 21 September 2006, on David's 53rd birthday the ANU sent him the following letter:

> 'Dear David
> I am writing to formally advise you the University will be ceasing your employment, as we have been advised by Dr X that it is unlikely that you will be able to perform your duties at the University within twelve months'.

You would think it would take any fair-minded person in a position of authority about one day to make some inquiries and then reverse this outrageous injustice.

In fact it took four months of sustained action by David and his friends and supporters.

The key factors which resulted in a successful outcome were probably the following:

- Written advice by David's treating psychiatrist, Dr Anna Burger supporting his re-instatement at the ANU,
- Lobbying by members of the ACT Parliament,
- The *Sunday Program* contacting the ANU Vice Chancellor, and
- David's many friends, who include senior ANU professors, making it clear that they would do whatever it took to get him his job back.

David's treating psychiatrist, Dr Anna Burger, provided consistent written advice over many months that David should be re-instated and return to work.

Ms Mary Porter AM, MLA, head of relevant parliamentary committees in the ACT, telephoned the ANU Vice-Chancellor on at least two occasions arguing that he should be re-instated.

Ms Porter is Chair of the ACT Parliament's Education, Training and Young People Committee and Deputy Chair of Health and Disability.

In Australia universities are funded by the federal government but special arrangements apply to the School of Music at ANU. As reported by the *Canberra Times* in 1996, the School of Music was threatened with closure in 1996. David lobbied the then Chief Minister of the ACT, the Hon Kate Carnell MLA and also taught her cello for six months so that she could better understand the work of the School of Music. Subsequently the ACT Government provided substantial annual grants to the School of Music, which have continued since 1996.

David's friends, which included members of academic staff at the School of Music and senior professors at the ANU, were initially told by ANU administration that

this was a private matter and no communication could be entered into. Nor would ANU reply to letters from ANU professors requesting David's re-instatement.

David's friends assisted him in writing polite, firm letters to the ANU on a regular basis, of about every two weeks, summarising relevant points in the case and pointing out the ANU's lack of action and lack of appropriate response. Copies of all letters written or signed by David were delivered to the office of the Vice-Chancellor, the Dean of the Faculty of Arts. Copies of the letters were also given to ANU professors and senior staff and the National Tertiary Education Union, who all supported David. The ACT Government is an interested party because it provides special funding to the ANU's School of Music. Because they fund the ANU, copies were also sent to Ms Mary Porter AM, MLA, who had discussed David's case with him.

The *Sunday Program*, Australia's major current affair television weekly, at the request of David's friends, telephoned the Vice-Chancellor and advised him that they were producing a television program on the treatment of the mentally ill in Australia. They asked why David had been treated in this way, and supported his re-employment.

David's friends, including ANU professors, heads of government departments and senior lawyers, wrote letters to the Vice-Chancellor stating that they had read all relevant correspondence and supported his re-instatement.

They sent the Vice-Chancellor and his staff the relevant pages of the *Oxford Handbook of Psychiatry*, pointing out that Obsessive Compulsive Disorder is not a geriatric condition, and that most people do recover with adequate care and rehabilitation, including employment.

Luncheons in the gardens of ANU's University House were organized, to which David's friends and the Dean of Arts were invited, and offering superb cello recitals.

David, his treating doctor, Dr Anna Burger, and his friend had been requesting his re-instatement and his return to work since October 2006. In February 2008 David was finally permitted to return to work by the ANU.

One wonders about the effects of such treatment - a duty statement requiring ‘international performances’ to a hospital patient followed by a letter advising of dismissal - upon a person less resolved and without informed friends.

Since his return to work, David has flourished and is enjoying teaching and ably supported by his partner Gillian and their four children. He no longer has to take any medication. As well as his teaching duties, he is practising three hours each day and once again giving much enjoyed concerts in the national capital.

What can one conclude about this case? Even institutions that one would think were enlightened and had a good knowledge of major mental illnesses, can behave in a bizarre and outrageous fashion to people with a mental illness, unless their employees have support.

Case Study 3: 'G' in Victoria

'G' lives in a provincial town in Victoria, is highly intelligent, gained a university degree and worked for some years on a part-time basis as a librarian assistant.

She has been ill for many years since being diagnosed at age 18 with bipolar disorder while at university. She lived mainly with her parents for many years, until they moved to another city.

She now rents a flat on the private rental market and relies on a disability pension and rental assistance of some $52 per week to survive.

Through an interest in a small deceased estate left to her by her father some years ago, my wife and I are trustees for its administration. We took legal advice but found that the cost of administering the money left to her was prohibitively expensive.

From that trust, we pay twelve months in advance gas, electricity, pharmaceutical bills, private health insurance, dentist, telephone bills, and $20 per week Retirement Savings Account.

The deceased estate trust also has an automatic transfer which supplements her $250 per week Disability Support Pension. It allows her to plan and save for an annual holiday.

Over the past two years ‘G’ has re-commenced employment, gaining three hours paid ironing work per week. With the Australian Government's superannuation (of $1,500 per annum) her paid work becomes a useful source of income and occupation.

'G' is an active member of a local church and a local cycling club, and it was there that she met her husband and married him last year, at the age of 53. 'G' has also brought great happiness and optimism to many young women in Canberra, and their mothers. When I mentioned to work-colleagues and friends that I was travelling to Victoria in the near future to attend a wedding of woman who was to be married for the first time at 53 years of age, all the women I met, would think or say something along the lines of 'That is tremendous news Paul. Just wait. I will ring my mother straight away. I am 32 years of age, and my mother has given up hope (of my getting married).'

APPENDIX C

Sample reference for obtaining a part-time job

To whom it may concern

I have known G since she was eighteen years of age.

She is highly intelligent and keen to obtain part-time employment.

She has a university degree and has worked in libraries, as a telemarketer, in call centres and in landscaping and domestic cleaning. She is keen to obtain regular part-time work, in any capacity, but preferably on a regular weekly basis.

G was a champion swimmer as a teenager and is an active member of the Uniting Church and has lived in Y for many years. She has made a major contribution to her family and to the Geelong community. Recently she married X, also of Y. They are both keen cyclists. They live at Unit Z/V Road Y and their phone number is . They also own a car.

G is presently on a disability support pension, like some 800 000 other Australians. Unfortunately less than 10 per cent of such pensioners obtain any part-time work, even though it is well known from medical and other research that regular part-time work is extremely beneficial mentally and physically.

It is possible for G to earn $60 per week without it affecting her pension, and she would be most grateful for three to five hours work each week.

I hope that it will be possible for you to provide some trial work for G. If I can assist with any other information at any time, please do not hesitate to contact me.

Dr Paul Kauffman

APPENDIX D

Sample letter requesting connection to Telstra's free phone service

Chief Executive Officer
Telstra
Locked Bag 5039
MELBOURNE VIC 3000

cc Telstra Help Service
36 Gurwood Street
WAGGA WAGGA NSW 2650.

Dear Sir

I refer to your bill requesting payment of $75 by 22 September 2007 for the telephone account of xxxxx. A copy of the bill is attached.

G and her husband are both on Disability Support Pensions of about $220 a week each, and are unable to pay this account until 8 January 2008.

I am a financial adviser to G and have strongly urged them to take advantage of Telstra's generous phone service for incoming calls. I have asked them to ring 1800676766 so that they can register their current number with this service. I understand that this only allows them to receive incoming calls, and that they can call 000 in life threatening emergency, and that they have to pay for or provide their own handset. G's phone number is and her postal address is .

On 22 September 2007 I telephoned Telstra on 1800 810211 and asked that a Telstra White Pages for the City of .... be mailed to G, which I understand will occur over the next few days.

Because she did not have a White Pages, G has consistently recorded a high usage of Sensis services during the past year, and paid high charges for this. During recent months she also had to make many calls to medical specialists in the capital city to arrange for medical operations, which have also imposed financial burden.

She was also unaware of cheaper Directory Assistance 12 455 and 1223 options, and the cheaper options for registering for lower service charges. In these circumstances we would therefore be most grateful if G could be credited with $75 towards her outstanding telephone account.

Yours sincerely

Dr Paul Kauffman

APPENDIX E

Letter requesting dog to be registered as a service dog with ACTION buses

Email Liz.Clarke@act.gov.au or Tel 131710 or Tel 6207 8095 and ask for Karl Pillig. ACTION buses in perhaps a first for Australia, will provide you with a special pass to allow your dog to accompany you on any bus trip in the ACT, if you advise them that your dog is a service dog, and needed for your well-being, as outlined in www.psychodog.org in the USA.

Ms Liz Clark
ACTION
Disability Officer
PO Box 158
CANBERRA ACT 2601

Dear Ms Clark

Following discussions with Mr Ivan Bulley of your office, we seek your advice and assistance so that _____ can register his dog called "_____" as a service dog, so that he can travel with the dog on Canberra Buses.

Marcus suffers from a severe psychiatric illness and has been in the care of the psychiatrist Dr _____ of ACT Mental Health for many years.

There is now extensive research literature, which I can send you if required, on how such dogs perform invaluable work as service dogs for people with severe psychiatric illnesses (see www.psychdog.org). _____'s dog is small, especially trained and extremely quiet and unobtrusive.

Can you please advise if there currently exists a provision either explicitly or implicitly in current ACT or Commonwealth legislation, to allow _____ to travel with his dog. Alternatively, can you advise if current ACT and Commonwealth disability legislation, after taking into account the facts of this case, does in fact make it illegal for a bus-driver to refuse entry to _____ with his dog on a Canberra bus.

_____ regularly needs to travel to the city for work and to the Rainbow clubhouse in north Watson, for rehabilitation programs, and he lives at _____. At present his only way of returning from there is to walk. He also needs to travel to other locations in Canberra for rehabilitation, and it presents an unreasonable burden if he is unable to travel on Canberra buses with his small well-behaved dog, which has been specially trained at RSPCA dog-training classes.

It would be greatly appreciated if you could provide a letter or a pass to _____, in order for him to travel with his dog. _____'s date of birth is _____. You are also authorised to make any inquiries you desire at ACT Mental Health in order to verify the need for this service.

Yours sincerely

Dr Paul Kauffman

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Quill Harper Collins , New York

Torrey E. Fuller and Michael B Knable 2005
Surviving Manic Depression: A manual on bipolar disorder for Patients, Families, and Providers. Basic Books, New York

Useful websites

Beyond Blue
www.beyondblue.org.au

Bipolar Disorder
www.bipolarexpedition.org
Provides basic information and organises fund-raising activities such as expeditions to the Antarctica.

Mental Health Community Coalition of the ACT
www.mhcccact.org.au

Mental Health Council of Australia
www.mhca.com.au

Mental Health Services Website (Vic)
www.health.vic.gov.au/mentalhealth

Mental Illness Fellowship of Australia
www.mifellowshipaustralia.org.au

Mental Illness Fellowship Victoria
www.mifellowship.org

National Alliance of the Mentally Ill
(NAMI) (USA)
www.nami.org

SANE Australia
www.sane.org

http://www.schizophrenia.com/media/
Started in 1995, Schizophrenia.com is a non-profit web resource based in the United States.

APPENDIX F

Recent research and publications on rehabilitation

(i) GOVERNMENT ON-LINE REPORTS

1.1 ACT Legislative Assembly Report A*ppropriate Housing for People with a Mental Illness.* ACT Legislative Assembly. Canberra 2007.
http://www.parliament.act.gov.au/committees/index1.asp

1.2 Department of Employment and Workplace Relations. 'Characteristics of Disability Support Pensioner recipients. Australian Government, Canberra, 2007.
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1.3 Senate Select Committee Reports "A national approach to mental health: from crisis to community" First Report March 2006, Second Report August 2006. Parliament of Australia, Canberra. http://www.aph.gov.au/Senate/committee/formercommittees/mentalhealthcommittee/report

1.4 Senator Lyn Allison's Report of mental health services observed in Trieste, Italy, January 2006 *(Chair, Senate Select Committee on Mental Health)*

1.5 Non Government on-line directories:
Directory of Mental Health Services. January 2007. 63 pages. Mental Health Foundation, Canberra.
http://www.mifact.org.au

1.6 ABC Radio Science Programs on mental illnesses
RECENT RESEARCH ON REHABILITATION FROM MAJOR PSYCHIATRIC ILLNESSES
(i) BIPOLAR DISORDER
Lewis, Tania et al [Ten women writers]
***Mosaics: sharing stories of faith, hope and courage*. Geelong Mood Support Group, 139 Yarra Street, Geelong, Victoria 3220 ISBN 978-0-9804091-0-9**

Torrey E. Fuller and Michael B Knable 2005
***Surviving Manic Depression: A manual on bipolar disorder for Patients, Families, and Providers*. Basic Books, New York**

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***The Invisible Plague: The Rise of Mental Illness from 1750 to the Present*, New York**

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Anxiety Disorders Association of America (ADAA) www.adaa.org
Mental Health America (formerly NMHA) www.mentalhealthamerica.net)

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(iv) SCHIZOPHRENIA/ INTEGRATIVE DISORDER IN INDIA

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[1] In Japan in 2004 the term 'schizophrenia' was changed to 'integration disorder'.
[2] www.Wikipedia.com. See also works by Fuller Torrey and *Oxford Handbook of Psychiatry*, under relevant headings.
[3] There were 707,000 people on Disability Support Pensions at 30 June 2005. Psychological/ psychiatric conditions accounted for 26.2 per cent. The ACT had 70,312 people on a Disability Support Pension (DSP). It is therefore likely that about 1,840 people in the ACT were on DSP and disabled due to a psychiatric condition in 2005. Other people with major psychiatric illnesses are studying, working part-time, on the old-age pension or not otherwise registered for income support. http://www.workplace.gov.au/workplace/Publications/LabourMarketAnalysis/CharacteristicsofDisability Support Pensioner recipients/30 June 2005. 'I am grateful to Ray Jeffery of FAHCSIA for this data. He advised on 27 August 2008 that there are now some 730,000 Australians on Disability Support Pensions, and only nine per cent of them work for one hour or more per week. The annual reports for 2006 and 2007 should be published and be available on-line by December 2008. It is likely that in 2008 the ACT has some 7,300 people on disability support pensions, and that 6,600 of them do not work for even one hour or more per week. It is possible that many of these people are unable to work for one hour per week. From our involvement with organisations assisting the disadvantaged, we do know that many do desperately wish to work. For the past eleven years government efforts have been focused on those able and willing to work for eight hours per week or more, with the aim of shifting those pensioners into the full-time workforce. Kauffman and Gerritsen believe that this policy has failed some 660,000 people, and it is now time to introduce pilot projects to assist disabled pensioners with work opportunities of up to eight hours per week.' [PK]
[4] 'New schizophrenia drug shows promise in trials' by Alex Berenson *The New York Times*. September 3, 2007. If a 2009 trial is successful, a Phase III trial that could cover 2,000 patients will be commenced. See http://www.iht.com/articles/2007/09/03/business/03drug.php
[5] *Daily Telegraph*, "Obsessive Compulsive Disorder" page 1, by Denise Cullen, August 19, 2007
[6] '*Mentally Ill diverted to cheaper care' The Age* Annabel Stafford, 14 August pages 1 & 2.
[7] Total disability recipients by State in Australia in October 2007 were NSW 229,853, Victoria 172,640, Queensland 137,026, Western Australia 58,826, South Australia 69,133, Tasmania 25,142, ACT 6,971 and Northern Territory 14,147, a total of 720,188. (DEWR data sources as at 27 November 2007).
[8] www.aph.gov.au/Senate Reports/Senate Select Report on Mental Health 2006.
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[10] About two thirds of DSP recipients are not partnered, although females are more likely to have a partner than males. Some 35% of DSP recipients own their own home, mainly among the older recipients. http://www.workplace.gov.au/workplace/Publications/LabourMarketAnalysis/CharacteristicsofDisability Support Pensioner recipients. [30
[11] See www.larche.org
[12] Source: Real Estate Institute of Australia, AFR, 8 September 2007.
[13] About 10 per cent of DSP recipients declared an income from employment in 2005. In 2005, it was possible for a single DSP recipient to earn up to $61 per week and a couple to earn $108 per week, before their DSP income was reduced.
[14] See footnote 2.
[15] Hamlet Act 2, Scene 2.
[16] McFadden 2007.
[17] See footnote 5.
[18] Barak *et al*. 2001.