



Australian Government
Department of Health and Ageing

PATHWAYS OF RECOVERY

Preventing Further Episodes of Mental Illness (Monograph)

Prepared for the National Mental Health
Promotion and Prevention Working Party

November 2005

Debra Rickwood
University of Canberra



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FOREWORD

This monograph raises the vital issue of the role of relapse prevention in the recovery process for people who have been seriously affected by mental illness. While preventing further episodes of mental illness should be a routine component of treatment and continuing care for people with mental illness, feedback from consumers and carers shows that frequently this is not the case. Too often the experience of consumers, and their families and carers, is of a crisis-focussed mental health system that doesn't respond early enough to avert further episodes, nor prioritise rehabilitation and relapse prevention as essential components of ongoing continuing care to facilitate recovery. Although relapse prevention has traditionally been viewed as an illness-focussed approach, it is reconceptualised here as one of the essential components of a recovery-oriented mental health system.

Evidence from Australia and overseas—most importantly from lived experience, but also from rigorous research—shows that preventing further episodes of mental illness is possible for people who have been affected by mental illness. Where complete prevention is not possible, the duration and negative consequences of a further episode of illness can be substantially reduced. This monograph contributes to our understanding of effective approaches to relapse prevention across the lifespan and for people from diverse backgrounds. It reflects a wide range of views, but deliberately prioritises the lived experiences of consumers and their families and carers, as understanding this issue is vital to their ongoing wellbeing. The paper is a first step in finding ways to ensure that prevention is included as an essential component of continuing care within a recovery focussed mental health system.



Emeritus Professor Beverley Raphael

Chair, National Mental Health Promotion and Prevention Working Party 1998-2005

EXECUTIVE SUMMARY

Relapse prevention has been a major part of the mental health policy agenda since the advent of the *National Mental Health Strategy* in 1992, but it is now time for it to receive specific emphasis. This paper considers the role of relapse prevention within the recovery process for people who have been seriously affected by a mental illness. It has been developed to inform several different audiences for whom this issue is central to continuing care: people of all ages who have experienced mental illness and their families and carers; primary care services, including general practitioners; case managers; providers of non-clinical support services; providers of clinical services; service managers, workforce planners, and policy makers; as well as the whole community.

The methodology used to develop the paper comprised five major components: liaison with Auseinet and the Auseinet Consumer and Carer Consultative Committee; national consultation with consumers and carers; stakeholder consultation; review of the national and international literatures; and a review of current State/Territory initiatives in relapse prevention.

The paper considers definitions of the terms ‘relapse’ and ‘relapse prevention’ and discusses the place of relapse prevention within the spectrum of interventions for mental health. Relapse prevention and the related concept of rehabilitation are placed under the umbrella of recovery, which comprises treatment and continuing care. Specifically, relapse prevention is defined as:

a specific component of the recovery process. It entails maximising wellness for people with mental illness by reducing the likelihood and impact of relapse. It involves empowering people with mental illness to recognise early warning signs of relapse and develop appropriate response plans. It requires identifying risk and protective factors for mental health, and implementing interventions that enhance protective factors and eliminate or reduce the impact of risk factors. Relapse prevention is based on communication and understanding between the person experiencing mental illness, their family and carers, primary health care, the specialist mental health system, and community support services about access to support or treatment if there are early signs of relapse. Relapse prevention is an essential, but not sufficient, component of the recovery process for people with mental illness.

There is growing awareness that the majority of people diagnosed with mental illness will achieve a significant improvement or full recovery. Relapse prevention is not only possible, but desirable on many levels – for individuals, their families and carers, health and community service systems, and the wider community. There is strong support for investing in relapse prevention, rehabilitation and recovery.

A review of the literature shows that relapse prevention involves both illness self-management and illness management with the support of professional-based interventions. It has been categorised as including the following types of approaches: training in recognition of early warning signs; programs that encourage effective use of medication; coping skills training; and broad-based psycho-education programs. The evidence generally supports the effectiveness of these interventions, however, it

is argued that a more comprehensive and holistic approach is required to fully realise relapse prevention within the spectrum of interventions for mental health adopted by Australian mental health policy.

Consultations with people of all ages who have experienced mental illness and their families and carers, other stakeholders, and wider review revealed the following essential elements of relapse prevention:

1. **Awareness** - Awareness is the first component of effective relapse prevention, and is made up of acceptance and recognition. Acceptance means acknowledging and coming to terms with having an ongoing mental health condition. Positive attitudes toward people with mental illness within all sectors of the community facilitate the process of self-acceptance while maintaining a sense of self-worth. Recognition of early warning signs of illness and awareness of personal risk and protective factors are core components of relapse prevention. Acceptance and recognition determine whether people at risk of further episodes of mental illness, and the people and services that they are in contact with, are aware of and able to respond to changing mental health needs.
2. **Anticipation and planning** - Anticipation of potential future episodes of illness and appropriate planning are fundamental to relapse prevention. Planning is what empowers people with mental illness to make the decisions they choose, rather than have decisions made for them. Planning needs to be undertaken on many levels: daily plans, crisis plans and longer-term wellness and relapse prevention plans. Planning is based on the development of trusting relationships and good communication, and places the consumer at the centre of their continuing care. All those involved in the ongoing support of someone with a mental illness need to be involved in planning: the consumer, their family and carers, clinical service providers, and providers of psychosocial and psychiatric rehabilitation services. Relapse prevention plans need to be regularly reviewed and revised and effective plans tailored to each person's unique needs, taking into account their age, personal circumstances, cultural background, and experience of mental illness. Relapse prevention planning needs to become a routine component of continuing care for people who have experienced mental illness: a component that commences at the first point of contact with mental health services, that is ongoing and responsive to changing circumstances, and supported by effective self-management approaches.
3. **Alternatives and opportunities** - Support services need to be available to target all the environmental, physical, social and emotional stressors and supports that comprise the risk and protective factors for mental health. The provision of all these service alternatives needs to be integrated, through planning, partnerships and effective communication strategies, to provide a comprehensive approach to relapse prevention within continuing care. Importantly, there must be a range of supported accommodation options and follow-up services within the community, both clinical and psychosocial. These must be suitable to the age, cultural background and personal circumstances of individual consumers and their families and carers. Provision of community support services must be adequate to meet population needs.

4. **Access and early intervention** - Effective relapse prevention requires early intervention through access to appropriate supports and services. This means, firstly, the development of effective personal coping skills in response to early warning signs. Secondly, it requires a service system that responds to early warning signs, not just acute crises. Step-up and step-down facilities are needed to respond quickly and effectively to changing mental health needs as recognised by consumers and their families and carers.

Acute and specialist mental health services, case management, and primary care (including general practice) are singled out for special mention regarding their role in relapse prevention. It is argued that the more chronic and disabling the experience of mental illness, the more a case management approach to continuing care is required for people with mental illness and their families and carers. For people whose mental illness is less disabling, self-management strategies, along with support from primary care, may be sufficient.

There are several population groups within Australia that are of special significance and have additional needs in relation to relapse prevention. These groups are: *children and adolescents, older adults, Aboriginal peoples and Torres Strait Islanders, people from culturally and linguistically diverse backgrounds, and people living in rural and remote communities*. While the issues covered throughout the paper also apply, the unique features of relapse prevention in terms of awareness, anticipation, alternatives and access for these population groups are highlighted.

It is argued that the actions required to implement relapse prevention have already been identified and are listed as outcomes in the *National Mental Health Plan 2003-2008*. These include: real participation and partnerships with consumers and their families and carers; access to services and service responsiveness; workforce development; and ongoing monitoring, evaluation and research. How these apply specifically in the context of relapse prevention is described.

Relapse prevention must become standard practice within mental health care. This requires specific emphasis on awareness, anticipation and planning, the availability of alternatives and opportunities, and access and early intervention. Underpinning relapse prevention is the need for effective communication that places the person with mental illness at the centre of their continuing care and self-management. The roles of families and carers, primary care, specialist mental health services, rehabilitation services, and allied health need to be negotiated and responsive to the changing needs of consumers. Approaches must be appropriate to people's age, cultural background, personal circumstances, and experience of mental illness, and be supportive of families and carers.

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Secondly, many service providers, from a range of service sectors, contributed their valuable experiences, and these diverse perspectives have also enriched the paper.

Furthermore, a great deal of organisation was required to set up the national consultations, and special acknowledgement goes to the people who spent considerable time and personal effort organising focus groups, interviews and visits in their area.

Finally, there were many people who shared their resources, information and networks. This support was invaluable for covering the wide range of research, literature, practice and views from many different disciplines that contribute to understanding this area.

The efforts of all these people enabled the collation of a necessarily diverse range of experiences and perspectives. It is hoped that this paper captures their views and effectively voices their experiences and concerns.

Note: The original discussion paper and subsequent reports were funded by the Australian Government Department of Health and Ageing and developed for the National Mental Health Promotion and Prevention Working Party, which exists under the auspices of the Australian Health Ministers' Advisory Council National Mental Health Working Group and the National Public Health Partnership.

MEMBERSHIP OF THE NATIONAL MENTAL HEALTH PROMOTION AND PREVENTION WORKING PARTY

The National Mental Health Promotion and Prevention Working Party (PPWP) is auspiced by the Australian Health Ministers' Advisory Council National Mental Health Working Group and the National Public Health Partnership Group. The PPWP is comprised of members or nominees of these auspicing groups as well as representatives of other key stakeholder groups.

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ABBREVIATIONS

ABS	Australian Bureau of Statistics
ADGP	Australian Divisions of General Practice
AICAFMHA	Australian Infant, Child, Adolescent and Family Mental Health Association
AIHW	Australian Institute of Health and Welfare
APA	American Psychiatric Association
CAA	Carers Association of Australia
CAMHS	Child and adolescent mental health services
CAT	Crisis Assessment Team
CBT	Cognitive behavior therapy
GP	General practitioner
HREOC	Human Rights and Equal Opportunity Commission
MHCA	Mental Health Council of Australia
MOU	Memorandum Of Understanding
NGO	Non-government organisation
NHMRC	National Health and Medical Research Council
WHO	World Health Organization

BACKGROUND

Rationale

A significant positive development in the mental health field is growing recognition that a diagnosis of mental illness is not a life sentence to an incurable condition that invariably will have only negative consequences for a person's life course. This was the view that, until recently, was commonly held by many consumers, their families and clinicians. While the onset of mental illness is undoubtedly a serious life event, many people who have experienced mental illness live full and meaningful lives: some remain symptom free after their first episode, while others adapt to the symptoms that they recurrently experience. It is now recognised that it is not inevitable that a first episode will lead to further illness and that even when further episodes do occur, it is not necessary for such illness to put an end to the positive aspects of life.

There are three possible scenarios following the initial onset of mental illness:

- no further episodes of mental illness;
- occasional recurrent episodes of mental illness; and
- chronic mental illness with repeated episodes.

For people who have experienced a first episode of mental illness, the risk of future episodes is increased, and efforts to prevent recurrent episodes are essential to reduce the impact of mental illness for consumers, their families and carers, and their communities. Consequently, ways to prevent recurrent episodes and reduce their impact on wellbeing have become a valuable area of investigation. A growing body of evidence attests that such relapse prevention is possible.

Relapse prevention has been recognised as a high priority for some time. The *National Action Plan for Promotion, Prevention and Early Intervention for Mental Health (2000)* [Action Plan 2000] acknowledged the importance of relapse prevention and early intervention for recurrent mental illness and identified these as areas for future action. It was noted in *Action Plan 2000* that many of the issues related to promotion, prevention and early intervention for mental health were also relevant to preventing relapse, but that there were likely to be unique factors for people who had already been diagnosed with a mental illness that warranted separate consideration in another document.

The *Evaluation of the Second National Mental Health Plan (2003)* reported that early intervention, for both first and recurrent episodes of mental illness, was an area where there was still considerable need for improvement in terms of Australia's mental health care system. Continuity of care, in all its forms—across the course of an episode of illness, across the lifespan, and across service sectors—was also an area where greater emphasis and innovative approaches were urgently required.

Most recently, relapse prevention is clearly evident in the *National Mental Health Plan 2003-2008* as an area that requires increased focus. Factors related to relapse prevention are emphasised throughout the *Plan*, particularly in the sections on preventing mental health problems, access to care, continuity of care, support for families and carers, consumer rights and legislation, and consumer and carer participation.

Aims

This paper considers the issue of relapse prevention for people who have been seriously affected by a mental illness. Of primary importance throughout the document are the voices of people affected by mental illness and their families and carers, whose experiences are highlighted. The paper investigates the role of relapse prevention within the recovery process, through the following:

- definitions of relapse prevention and a discussion of its place within the recovery process;
- a review of the literature in terms of what is currently understood about the effectiveness of relapse prevention and the types of processes that are involved;
- a description of the elements of relapse prevention;
- a consideration of the unique needs regarding relapse prevention for significant population groups in Australia; and
- a summary of the main actions that need to be undertaken to implement relapse prevention as part of continuing care.

Exploration of the multiple views regarding a definition of relapse prevention is first undertaken. The paper then considers the place of relapse prevention within the spectrum of interventions for mental health and its role within a recovery framework. The current level of evidence related to the factors that may impact on relapse is presented: these are the factors that need to be understood to develop interventions to enable people with mental illness to stay well by reducing the likelihood and impact of relapse. The basic elements of relapse prevention are then described, followed by consideration of how these elements need to be considered for population groups with special needs and that are of particular significance within Australia. Finally, the actions that need to be prioritised under the current directions of the *National Mental Health Plan 2003-2008*, in order to maximise wellbeing for people with mental illness through relapse prevention, are considered.

The overall aim is to present the issues related to relapse prevention as currently understood in an Australian context. It is hoped that collating this information will provide a resource that enables people affected by mental illness, their families and carers, as well as policy makers, service planners and providers of clinical and non-clinical support services, to implement relapse prevention as an essential component of continuing care for people who have been seriously affected by mental illness.

Audiences

The monograph has been developed to inform several different audiences, recognising that understanding relapse prevention needs to be progressed from multiple perspectives. These diverse audiences are:

- **People of all ages who have experienced mental illness** — It is hoped that this monograph will provide information to enable people who have experienced mental illness to understand the factors that may affect their risk of relapse so that they can more effectively self-manage their condition to maximise their wellbeing. These people also need information to enable them to negotiate the mental health care system to access all the services they require to prevent relapse. For some, it is also important to have information to enable them to advise and advocate for consumers, in general, and to be able to participate in ensuring the safety and quality of services by advising service providers, service planners and policy makers.

- **Families and carers** — Families and carers also need information to understand relapse prevention and how they can provide effective support for consumers. They need to be aware of their role in self-management and also to be able to negotiate the mental health care system to obtain the services they and their family member require to prevent relapse and support recovery. Some family members and carers also need to be informed so as to be able to advise and advocate for carers, in general, and participate in ensuring the safety and quality of services by advising service providers, service planners and policy makers.
- **Primary care services, particularly general practitioners** — Primary care providers, including general practitioners, have an essential role in relapse prevention. They need to be informed and supported in this role to ensure that effective relapse prevention is implemented for their clients/patients.
- **Case managers** — Case managers also have a vital role in relapse prevention for many people who have been seriously affected by mental illness. Case managers need to be recognised and supported in this role and be able to ensure that relapse prevention plans are in place for their clients and that their clients receive all the services they require to maximise their recovery.
- **Providers of non-clinical support services** — Providers of non-clinical support services need to have their essential role in relapse prevention recognised and supported. Psychosocial and psychiatric rehabilitation services need to be integrated within continuing care pathways, and be appropriately resourced to meet the level of population need.
- **Providers of clinical services** — Providers of clinical services, both acute and non-acute, must begin to routinely implement relapse prevention planning for their clients/patients. This means ensuring that the care pathways, support services, communication systems and partnerships are in place to support continuing care through support for self-management, rehabilitation and recovery.
- **Service managers, workforce planners, policy makers** — The management, planning and policy-making systems that are necessary to support implementation of relapse prevention need to ensure that the procedures, workforce skills, infrastructure, policy and funding frameworks are put in place to enable relapse prevention to be routinely and effectively incorporated within continuity of care.
- **Whole community** — Community education is required so that all members of the community understand the impact of everyday actions, particularly stigma, on the wellbeing of people who have experience mental illness and their families.

Scope

There is no simple or universally agreed definition of mental illness, and a wide range of conditions and disorders can be included under this term. In the *National Mental Health Plan 2003-2008*, mental illness is defined as “a clinically diagnosable disorder that significantly interferes with an individual’s cognitive, emotional or social abilities. A diagnosis of mental illness is generally made according to the classification systems of the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-IVR) (APA 1994) or the International Classification of Diseases, Tenth Edition (ICD-10) (WHO 1992). These classification systems apply to a wide range of mental disorders (for the DSM-IV) and mental and physical disorders (for the ICD-10).” (p5).

In the context of this paper, a more narrow view of mental illness is adopted, with mental illness comprising psychotic and major mood disorders: primarily psychosis, schizophrenia, bipolar affective disorder, major depression, anxiety disorders and eating disorders. Imposing

these boundaries around the definition of mental illness was necessary to contain the scope to be more manageable. These particular disorders were selected as the primary focus because they are of major concern to consumers and their families and carers as they seriously impact on current and future wellbeing. They also tend to be the mental illnesses that have received the most attention in the literature and are the core business of many specialist mental health services. Nevertheless, it is expected that the issues covered in the paper will be relevant more generally to other mental illness and mental health problems, as well as other long-term health conditions.

Methodology

It was imperative that this paper be based on and guided by the experiences of people with mental illness and their families and carers. It was also important that the views of service providers, who have the responsibility of providing clinical and non-clinical support to people with mental illness, be incorporated. Consequently, the methodology used to develop the paper was based on ensuring that the views of all these people were presented.

There were five main components to the methodology, as shown in Figure 1. These components were undertaken in late 2003 and comprised:

- *Liaison with Auseinet and Auseinet Consumer and Carer Consultative Committee* — The Australian Network for Promotion, Prevention and Early Intervention for Mental Health and Suicide Prevention (Auseinet) was an important resource, providing networks and information. Of particular note, Auseinet's Consumer and Carer Consultative Committee provided essential guidance. This Committee comprised consumer and carer representatives invited from all States and Territories, with New South Wales, Victoria, South Australia, Western Australia, Tasmania and the Northern Territory represented at the time of developing this paper. These people helped to access consumer and carer networks within each of the jurisdictions. Their personal experiences were also an invaluable resource, and a focus group was undertaken with the members of the Consultative Committee prior to the other consultations to develop a discussion framework.
- *National consultation with consumers and carers* — Focus groups and interviews were conducted across Australia with male and female consumers of all ages and representing a cross-section of the community in terms of social, economic and cultural backgrounds, as well as their families and carers. Focus groups and interviews were generally taped and transcribed (after which the original tapes were erased) and direct quotes from these conversations are anonymously presented throughout the document. Focus groups and interviews were undertaken according to the principles outlined in the *National Statement on Ethical Conduct in Research Involving Humans* (NHMRC 1999). Furthermore, specific ethical issues related to undertaking research with mental health consumers were also taken into consideration (see Peterson 1999).
- *National consultation with service providers and stakeholders* — The views of service providers, from both clinical and community support services, and representatives from peak mental health organisations were also obtained through focus groups and interviews conducted across Australia. Direct quotes from these conversations also are anonymously presented throughout the document.
- *Review of the national and international literatures* — A review of the national and international literatures related to relapse prevention was undertaken. This involved a search of relevant computerised databases, as well as resources provided by Auseinet and some of the stakeholders contacted during the national consultations. The literature

review was not intended to be exhaustive, but rather was used to provide a summary of the main issues that have been researched relevant to relapse prevention for mental illness.

- *Review of current State/Territory initiatives in relapse prevention* — Each State and Territory nominated a representative from the government mental health sector to provide information on current State/Territory initiatives related to relapse prevention. These representatives were personally contacted by phone and email to elicit information around current initiatives in each of the jurisdictions. This process aimed to develop an understanding of some of the major initiatives being undertaken that related to relapse prevention in each of the States and Territories, to provide a current Australian context to the discussion paper.

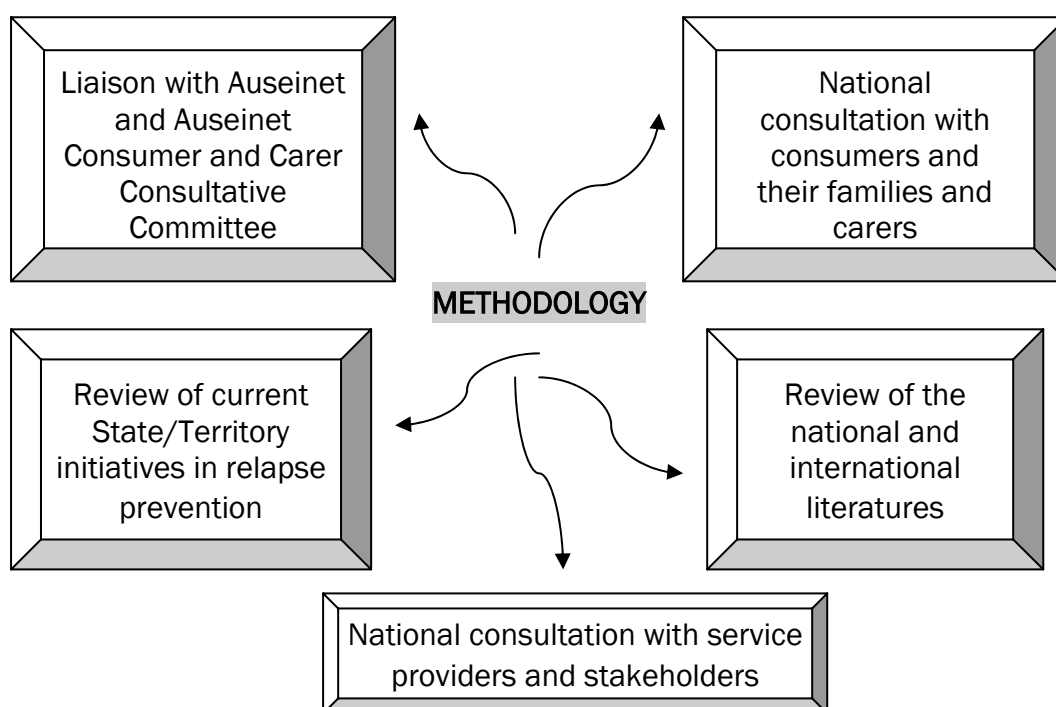


Figure 1. Methodology used to develop the paper

Please note that this monograph is an up-dated version of the discussion paper developed through this methodology. The original discussion paper was entitled, *Pathways of Recovery: Preventing Relapse. A discussion paper on the role of relapse prevention in the recovery process for people who have been seriously affected by mental illness*. This discussion paper formed the basis of a further national consultation around the issue of relapse prevention, undertaken in late 2004. Consultations were held in all States and Territories and submissions were invited from over 50 relevant organisations. The methodology and major findings of this national consultation are documented in a separate report, and an implementation Framework was developed as an outcome of the further consultation. These supporting documents are:

- *Pathways of Recovery: 4As Framework for Preventing Further Episodes of Mental Illness*
- *Pathways of Recovery: Report of the National Consultation on Preventing Further Episodes of Mental Illness*

Policy background

Relapse prevention has been a major part of the policy agenda since the advent of the *National Mental Health Strategy* in 1992. It was fundamental to many of the priority areas for reform and especially pertinent in the move from institutional to community-based mental health care. In the *First Plan*, which applied from 1992-1998, relapse prevention was evident in the prioritising of community care options following deinstitutionalisation. In the *Second Plan*, which covered the period from 1998-2003, relapse prevention was made more explicit with greater emphasis placed on promotion and prevention at that time.

In response to the higher priority afforded promotion and prevention in the *Second Plan*, a *National Action Plan for Promotion, Prevention and Early Intervention for Mental Health [Action Plan 2000]* was developed and published in 2000 by the National Mental Health Promotion and Prevention Working Party, which is auspiced by the Australian Health Ministers' Advisory Council National Mental Health Working Group and the National Public Health Partnership Group. This document, and its accompanying *Monograph 2000*, presented a rationale and framework for intervening earlier in the developmental trajectory of mental health problems and mental illnesses, based on a growing body of evidence demonstrating that more could be done to reduce the impact of mental illness by widening the spectrum of interventions beyond a treatment approach. Interventions to promote mental health for all Australians regardless of their current mental health status, to prevent the development of mental health problems and mental illnesses for those at risk, and to intervene early for those people showing signs of mental illness, were advocated in order to invest in the longer-term to improve the mental health and wellbeing of Australians.

Action Plan 2000 and *Monograph 2000* describe a spectrum of interventions for mental health, arguing that a balance of interventions across the entire spectrum is required to effectively meet challenges in mental health care (see Figure 2). These documents concentrated on the first half of the spectrum and did not consider issues of promotion, prevention and early intervention in terms of continuing care for people with mental illness. It was acknowledged, however, that many of the issues relevant to promotion, prevention and early intervention for mental health were also likely to be pertinent to relapse prevention, but that there were sufficient distinctions to warrant the separate consideration of relapse prevention within another document.

In *Action Plan 2000*, relapse prevention was included in the spectrum of interventions under the sections termed 'Continuing Care', which was defined as:

Continuing care comprises interventions for individuals whose disorders continue or recur. The aim is to provide optimal clinical treatment and the necessary rehabilitation and support services in order to prevent relapse or the recurrence of symptoms, and to maintain optimal functioning to promote recovery. Rehabilitation may focus on vocational, educational, social, and cognitive functioning. Ongoing mental health promotion and the reduction of risk factors and enhancement of protective factors are still relevant at this end of the spectrum to facilitate and support recovery and ongoing wellbeing. (Monograph 2000 p33)

Monograph 2000 defined relapse prevention as:

Relapse prevention refers to interventions in response to the early signs of recurring mental disorder for people who have already experienced a mental disorder. Relapse prevention is a critical issue for this group of people, their families, mental health services and the wider community. Recognition of the early signs of recurrent disorder and the appropriate treatment responses comprise a unique area of investigation. (p33)

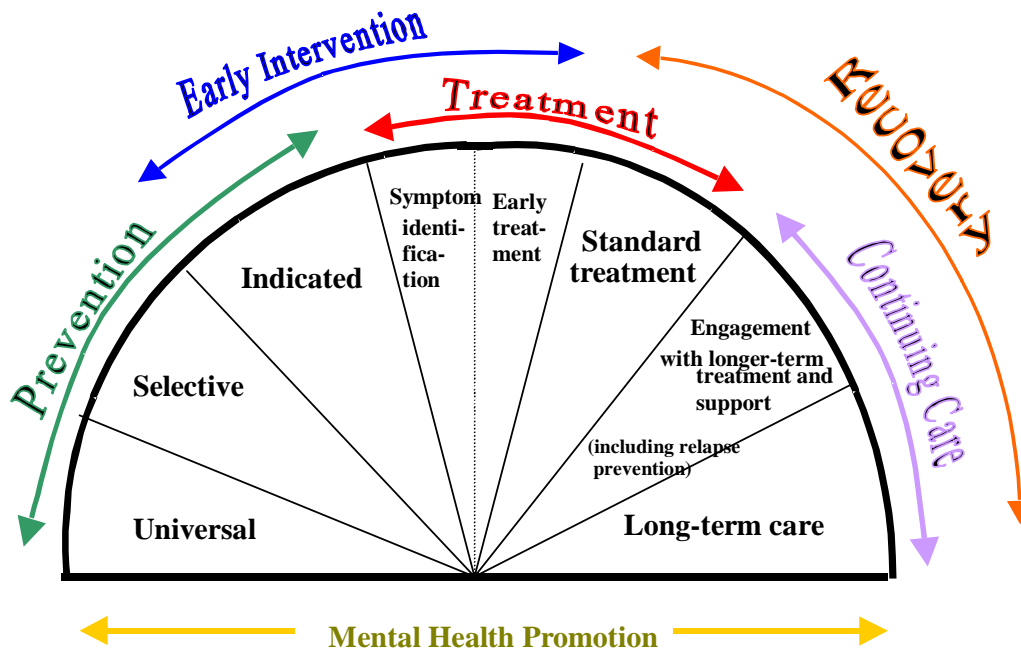


Figure 2. Spectrum of interventions for mental health

Source: Adapted from Action Plan 2000 and Mrazek & Haggerty 1994.

Note: This Figure shows the spectrum as amended to include recovery as in the *National Mental Health Plan 2003-2008*.

Since publication of *Action Plan 2000* and *Monograph 2000* there has been increased emphasis on continuing care pathways for people who have experience mental illness. The *Evaluation of the Second National Mental Health Plan (2003)* reported that continuity of care “remains an elusive goal for the complex systems that deliver mental health care. In particular, follow-up care into the community after hospitalisation for an acute episode is often lacking and puts consumers at risk.” (p2). Relapse prevention and early intervention, for first and recurrent episodes of mental illness, were identified as areas where there remains considerable need for improvement in terms of Australia’s mental health care system. Continuity of care, in all its forms—across the course of an episode of illness, across the lifespan, and across service sectors—urgently required action and innovation.

The importance of applying a recovery orientation within mental health services was also identified in the *Evaluation of the Second National Mental Health Plan*. The concept of recovery has emerged as a central issue and is strongly advocated by many people who have been affected by mental illness. As a consequence, providing services to people with mental illness within a recovery orientation is a fundamental principle of the *National Mental Health Plan 2003-2008*, in which recovery is defined as:

a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful and contributing life. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of psychiatric disability. (adapted from Anthony 2000 p11)

A growing body of clinical evidence reveals that the long-term prognoses of people with mental illness are more hopeful than previously realised (Anthony 2000). Outdated beliefs of the inevitable adverse impact of mental illness should no longer be perpetuated, and instead, an atmosphere of hope and a belief in human potential must pervade mental health service delivery. Implementing a recovery orientation requires an attitude shift for many service

providers in order to support consumer rights and provide the types of services that maximise wellbeing for people with mental illness. Specific approaches and plans aimed at reducing the likelihood and impact of relapse are an important component of this approach to continuing care.

WHAT IS RELAPSE PREVENTION?

In the *National Mental Health Plan 2003-2008*, relapse prevention is defined as “reducing recurrence of illness and strengthening functional capacity” (p37). This minimal definition does not, however, adequately account for the diversity of views regarding relapse prevention nor its conceptual richness, and it is timely to more fully develop this definition.

Defining relapse

‘Relapse’ is a word that is used in many different ways in a variety of contexts. It is defined in the Macquarie Dictionary as “to fall or slip back into a former state, practice, etc”. In the Australian Concise Oxford Dictionary, it is defined as “deterioration in a patient’s condition after a partial recovery”.

It is used most commonly within a medical context, where it is a word that is clearly understood by health practitioners to mean returning to a diagnosable state of mental illness: a mental state that has previously been diagnosed and the symptoms of which have returned to the point where the threshold has again been reached for diagnosis. Relapse is evident by recontact with services in the form of another acute episode of illness that requires service intervention, often hospitalisation. Most acute service providers within the mental health care system use the word relapse and believe that it is a useful and commonly understood term.

We all understand, clinicians that is, what we mean by relapse in a mental health context. It’s another acute episode that requires intervention, often hospitalisation. —Clinician

Relapse is a term that is less well accepted and less clearly applied within the more personal context of the experience of people with mental illness. It is seen as a “clinical term”, “not the usual language” and “not used in everyday language”. In general, most people who have experienced mental illness do not use the term relapse at all and are more likely to talk in terms of being “well” or “unwell”. For many people who have experienced mental illness, relapse has an underlying negative sentiment; it implies “going backwards”, “failing” and “back to square one”.

Relapse is a sense of failure. Relapse means this kind of concept of falling right back into it, back where you were. When what’s really happening is that I’m moving on all the time; sometimes it’s two steps forward one step back, but I’m always learning and moving on. Relapse means going right back to the start and nobody can stand to think like that. —Consumer

The negative connotations of the term ‘relapse’ are evident in that it is a term used primarily in the context of mental illness and substance use disorders; it is not generally applied to other illness conditions. As one consumer noted:

If you have had a heart attack and have another heart attack, no-one says you have relapsed; they say you had another heart attack. —Consumer

Furthermore, some consumers seriously affected by mental illness argue that the notion of relapse is irrelevant to them because they “have not really been well since the first time”. The chronic nature of their illness has meant that while they have periods of being more or less well, they do not think that they have been well enough to have been able to ‘relapse’.

I've never been to hospital myself and my episode has lasted 17 years. I've never had a relapse because I've been there ever since. I mean I go up and down but I don't think I've ever been well. —Consumer

There are also degrees of relapse, and what one person defines as a relapse, another may not. In contrast, the medical diagnosis of relapse depends on meeting specific thresholds that dichotomise experiences into either illness or health.

I sometimes think about it in terms of if someone's got a problem with their knee and they limp, some days they'll be better than others and they might still limp all the time but they'll still be able to do the things that they want to do. So, in terms of having a mental limp is a way of looking at the extent of mental illness: some days it might be crutches, some days it might be the wheelchair, some days you might be fine. —Consumer

It depends whether relapse means a complete hospital experience — whether you come back to the very, very lowest of low or just not being as well as you want. —Consumer

Most people with mental illness do not think of their life course in terms of relapses. Generally, the reality of experiencing mental illness is a process of change and development: the same process experienced by all people as they age and mature. Few people think in terms of going backwards to a previous state as implied by the term 'relapse'.

The negative associations of the word 'relapse' are not congruent with a recovery orientation to mental illness. Consequently, some consumers argue that relapse is a "non-word" and that "it doesn't exist". When consumers were asked during the consultations what would be a better word, they had difficulty coming up with a preferred term, but generally agreed that they tended to use the term 'episode' rather than 'relapse'. The experience of recurrent symptoms of mental illness is perceived as a continuous move forward through the life course. This is consistent with a recovery orientation, where people with mental illness are acknowledged to change and mature, as all people do.

I see episodes - it's just a pattern of life – this is part of my life. Relapse is a sense of failure. Episodes is a more neutral term. It's just the reality of certain people in our community. To relapse means a sense of it's our fault when the reality often is that we have done an amazing job to stay calm and healthy for such a long time. —Consumer

Families and carers are also aware that "illnesses fluctuate". They can become aware of "something happening", "all's not well", "a feeling" and the "need to do something". They agree that the term 'relapse' is generally applied within the context of medical intervention; it is when an acute episode of illness occurs that requires medical intervention. However, it is also applied by family members to acknowledge the change from when the person is "coping" to when they are "not coping and need help". Relapse implies upheaval and disruption for families and carers and for some it implies a constant process of monitoring and source of distress.

I'm always watching for the signs. I'm horribly fearful of a really bad patch starting all over again. —Family member

Differences of opinion sometimes occur between the person with a mental illness and their family members regarding whether a relapse may be occurring, but there is also frequently agreement.

I can always tell when another episode is on the way, it's so clear to me, but he can sometimes get really angry and accuse me of being smothering and hypervigilant. —Carer

It might take my mum to say you really don't seem to be feeling very well and then I'll realise and it will all click into place. It does creep up sometimes. —Consumer

The concept of relapse is also less clear for providers of psychiatric disability support and rehabilitation services compared with acute and clinical services. While a “full-blown relapse that requires hospital admission” is clearly understood as a relapse, providers of support services are also aware of periods of more or less “wellness” as experienced by their clients. Periods of being “unwell” can affect clients’ ability to cope with their lives, and it is this level of complexity that is evident to non-clinical and non-acute service providers who argue that they are in a position to recognise variations in wellness.

We see them when they're well, sometimes when they're really unwell, and everywhere in between. —Rehabilitation services provider

Finally, it is important to note that there does not need to be an agreed definition of the term ‘relapse’ in order to consider ways to prevent relapse. There are no generally accepted criteria for relapse; it is a relative term and must take into account: the person’s condition before the original onset of illness; his/her level of functioning before the present episode; and the severity of the relapse in terms of symptom severity, duration and interference with personal functioning. Relapse needs to be evaluated at the symptomatic, phenomenological and behavioural levels (Lader 1995). It impacts on interpersonal, social and occupational activities and has wider implications for the family in general, the provision of medical and social services, and for health economics.

Regardless of lack of total agreement on what comprises relapse, maximising wellness by reducing the recurrence or exacerbation of symptoms was universally acknowledged in the consultations as an important goal for people who have experienced mental illness, their families and carers, and mental health and community support services.

Defining relapse prevention

The term ‘relapse prevention’ also prompted considerable debate and elicited a wide range of views during the consultations. Again, negative connotations and a strong perceived association with medical terminology were commonly reported.

Relapse prevention implies a medical perspective and a definition that is one of control and one-sided. —Carer

Within the medical literature, relapse prevention generally refers to illness management through compliance with medication regimes. It is widely accepted that people who have been seriously affected by mental illness are at risk of relapse if they do not take their medication as prescribed. Consequently, much of the relevant literature focuses on encouraging compliance with medication regimes through psycho-education and cognitive behavioural techniques (see Mueser et al 2002).

Relapse prevention is also generally acknowledged to involve recognising early warning signs of relapse and responding quickly and effectively. Awareness of early warning signs and planning around how to respond to these were seen as key tools for preventing relapse.

I've had eight relapses and I recognise that if I start hearing voices or hallucinations or visualisations and if that increases a couple of days in a row, and I start isolating myself and not eating properly – that's a clear sign that I'm getting unwell again. Then I'll do less work or study and activities for awhile and when I get over it I'll build them up again. If it goes on for awhile I might have to change my medication or increase it. —Consumer

I notice him start to isolate himself. He stays in his room, won't come out for meals. The best thing to do to start with is get one of his friends in touch. Getting him up and out and about can stop it progressing. —Family member

He [flatmate] knows if I'm staying in bed too long he'll knock on my door and say "Get up! Come on mate, get up, get out of bed" He'll be a bit like a parent, but you need that every now and again. —Consumer

Beyond awareness of early warning signs and complying with medication there was, however, no clear view regarding what else relapse prevention might entail. Many people in the consultations initially had a negative reaction to the term 'relapse prevention', which they thought comprised only medication compliance. However, when they began to think of what they actually did to reduce the recurrence of symptoms, they realised that they did undertake many actions that would be defined as relapse prevention, and that these were important and empowering for them.

Most people recognised that relapse prevention means putting in place supports to stay as well as possible and to reduce the likelihood and strength of future illness symptoms. This was seen as a process of "illness management" in the context of a chronic illness rather than 'relapse prevention' per se. It was understood to be a learning process that takes time and is constantly evolving. It is a process that "is a continuum" and "occurs in a context".

Many people reported that they did not have much insight into preventing relapse after their first episode, but learned with repeat episodes what their triggers and wellness needs were. Relapse prevention is seen as part of the process of self-discovery. It involves developing "personal strategies" to cope with symptoms and stressors and to maintain wellness.

Families and carers similarly regard relapse prevention as a learning process of coming to understand "how and if to act". Relapse prevention was highlighted as "happening on an interpersonal level" and "being part of the education process".

Providers of non-clinical and non-acute services also emphasised evolving learning about the individual at risk and their environment and the importance of developing trusting relationships to facilitate this learning.

Planning was viewed as fundamental to relapse prevention. Many people who had experienced mental illness and their families and carers had, either explicitly or implicitly, a plan to attempt to reduce the likelihood of relapse when the early warning signs commenced. Many services also had relapse or recovery plans for clients.

I used to have a list of things to check that I put on my fridge with basic things like to ring someone and ask, 'How do you think I'm sounding?' or 'When was the last time you saw your psychiatrist?' and 'Have you taken your medication?', 'How many coffees have you had today?'. If you get to the end of the list maybe there are some other things you need to do because you're going to need some help. —Consumer

It's all about planning and knowing what to do and making sure you've checked everything. You have to get together and agree on it all and then have it all there in front of you ready to go through. —Carer

Lists are important in terms of what do I have to do today. Do I have to go and have a coffee with someone or do I have to go and exercise. Just like everybody else does, it's just that the consequences of what can happen if you don't maintain your mental health can be a lot more severe. —Consumer

Identifying stressors and ways to deal with them was another common element. Repeatedly, people who had experienced mental illness and their families and carers emphasised the importance of minimising stress and reducing stressful activities when early warning signs began to emerge.

Just not stressing myself out. Not do too much. —Consumer

One clear one was cutting down stress levels. —Carer

Finally, fundamental to attempts to prevent relapse was an emphasis on building relationships, communication and trust. Recognition of early warning signs and developing effective responses to them was invariably based on having trusting relationships and good communication with other people, preferably with a whole range of people involved in the ongoing support of a person with mental illness.

My case manager can tell when I'm listening to voices – she's really good. That's someone I've been with for three years. I've had three or four doctors in that time, but she's good. You need to build the trust with someone. You need to build a stable relationship with someone – it doesn't matter if it's a doctor or a mate – someone who recognises what's going on, will get you out of bed, motivate you, know you can look after yourself and they can look after you. That's a big part of stopping relapses getting extremely dramatic. —Consumer

The consultations revealed that relapse prevention is not a concept that is explicitly well understood, but it became evident after prompting that people were, in fact, implementing elements of relapse prevention. While in the research literature relapse prevention has a narrow definition and is usually applied in the context of medication compliance and recognition of early warning signs, there is clearly much more to preventing relapse that has not been explored. It is a construct that needs to be more fully understood and its role and functions, within a recovery orientation, clarified.

Relapse prevention, recovery and rehabilitation

Relapse prevention, recovery and rehabilitation are distinct, although related, concepts. Nevertheless, it was difficult for many people in the consultations to differentiate these concepts and they were often used interchangeably. In general, however, relapse prevention was perceived as having a more negative and symptom-related focus than recovery, which was more strongly related to identifying potential for wellbeing in people's lives. Mueser et al (2002) maintain that relapse prevention is a form of illness management, with an emphasis on minimising symptoms, whereas recovery aims to help people develop and pursue their personal goals in life.

Interestingly, negative connotations were not restricted to relapse prevention and the notion of recovery was reported by some people in the consultations to be threatening and negative. This was especially true for older people who had long histories of mental illness and contact with mental health services. Some of these people found the notion of recovery confronting, partly because they felt they had not managed to 'recover' and felt that this implied a serious failure on their part.

There are a whole lot of platitudes that are bandied around like this and it can be very hard for people who have been battered around by the system. —Consumer

For people with very severe or multiple issues, so called complex clients, recovery is an abstract concept that they can't quite wrap their heads around. Maintenance or some sort of

level of functioning that they can accept is more palatable perhaps because it is something that they can aspire to. —Rehabilitation services provider

I think that really needs to be remembered from working with the aged, that language is really important, that compared to a 30-year-old an 80-year-old would not talk about recovery, it brings up very different things for an 80-year-old. —Aged care services provider

Preliminary definitions

It is important to realise that the rhetoric surrounding these issues is contentious, potentially confronting and certainly not universally agreed. Nevertheless, it is necessary to attempt to develop definitions for these ambiguous terms in order to provide a common language for discussion and a platform for progress. Consequently, the following preliminary definitions are offered for relapse, relapse prevention, recovery and rehabilitation:

- **Relapse** is a subsequent episode of mental illness. It is a recurrence of symptoms of mental illness similar to those that have previously been experienced. The threshold of symptoms required to identify a relapse varies according to the differing perspectives of the person experiencing the symptoms, their family and carers, and service providers. Relapse is generally agreed to have occurred when the person experiencing the symptoms is not able to cope using their usual supports and requires a greater intensity of intervention. The word ‘relapse’ is viewed by many as a negative and medicalised term, and the words ‘episode’ or ‘being unwell’ may be preferred.
- **Relapse prevention** is a specific component of the recovery process. It entails maximising wellness for people with mental illness by reducing the likelihood and impact of relapse. It involves empowering people with mental illness to recognise early warning signs of relapse and develop appropriate response plans. It requires identifying risk and protective factors for mental health, and implementing interventions that enhance protective factors and eliminate or reduce the impact of risk factors. Relapse prevention is based on communication and understanding between the person experiencing mental illness, their family and carers, primary health care, the specialist mental health system, and community support services about access to support or treatment if there are early signs of relapse. Relapse prevention is an essential, but not sufficient, component of the recovery process for people with mental illness.
- **Recovery**¹ is “the development of new meaning and purpose in one’s life as one grows beyond the ... effects of mental illness” (Anthony 1993). It means maximising wellbeing, within the constraints that might be imposed by symptoms of mental illness.
- **Rehabilitation** is also known as ‘psychiatric rehabilitation’ and is a set of targeted interventions that are intended to prevent further, or reduce the disability that is associated with, mental health problems. It is a process of assisting people to acquire and to use the strengths and skills, supports, and resources necessary for successful and satisfying living, learning, and working in the environments of their choice (NSW Health 2002a p5).

Within the spectrum of interventions for mental health, relapse prevention and rehabilitation are placed under the arc of recovery, which comprises treatment and continuing care. Relapse prevention and rehabilitation are elements that form part of and facilitate the recovery process. From this viewpoint, Deegan notes, “Rehabilitation refers to the services and

¹ The concept of recovery is more fully explored in the document, *Sharing Responsibility for Recovery*, Queensland Health, 2005.

technologies that are made available to disabled persons so that they might learn to adapt to their world. Recovery refers to the lived or real experience of persons as they accept and overcome the challenge of disability.” (1988 p11). Relapse prevention is part of continuing care where there is a deliberate focus on ongoing illness management aimed at reducing the likelihood and impact of future episodes of illness.

The spectrum of interventions can, therefore, be modified to incorporate growing understanding of this section (see Figure 3). Best practice treatment incorporates provision for continuing care, comprising plans for relapse prevention and rehabilitation, which must be provided within a recovery orientation that prioritises the lived experience of the person with mental illness and works to maximise their wellness and wellbeing, along with that of their family and carers.

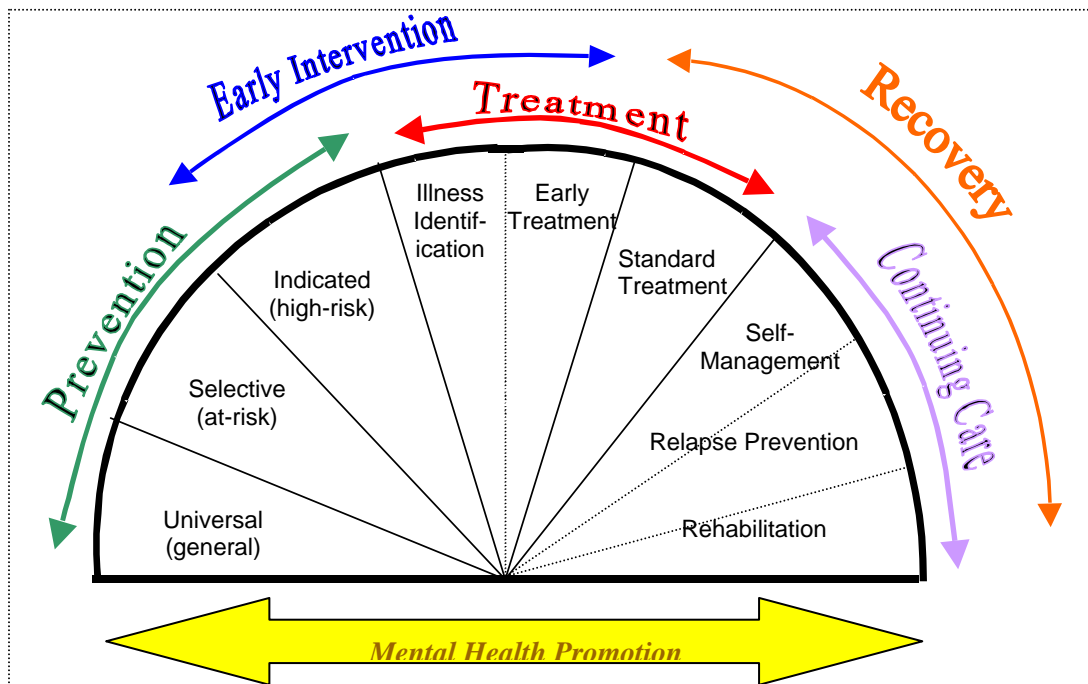


Figure 3. Modified spectrum of interventions for mental health

WHAT IS OUR CURRENT STATE OF KNOWLEDGE?

To review the current state of knowledge regarding relapse prevention requires considering both the research evidence showing whether relapse prevention is possible in the context of mental illness, and the lived experiences of people with mental illness and their families and carers.

Likelihood of preventing relapse

It is only recently that the possibility of preventing mental illness has gained credibility (*Monograph 2000*). As already noted, there are three possible scenarios following the initial onset of mental illness: no further episodes of mental illness; occasional recurrent episodes of mental illness; and chronic mental illness with repeated episodes.

Prior to the 1990s, which has been termed the ‘decade of recovery’, the third scenario was commonly held to be the inevitable outcome of a diagnosis of mental illness. This view was assumed by most clinicians and presented to people who experienced an episode of mental illness and their families as a fact that needed to be accepted. In the 1990s, two bodies of knowledge converged to change this view (Anthony 2000). The first was the writings of people seriously affected by mental illness. These compelling personal accounts provided anecdotal evidence of the many and varied individual pathways of recovery (eg, Anonymous 1989, Deegan 1988, Leete 1989).²

The second was examination of outcome studies of people with mental illness. Harding and colleagues reviewed long-term studies of outcome, which showed that people with severe mental illnesses were, in fact, recovering (Harding et al 1987, Harding & Zahniser 1994). It was clear that the prognosis for people diagnosed with mental illness was much more favourable than previously thought (Anthony 2000).

Outcome data usually come from investigations of the duration and restitution of mental illness in small samples of referred patients (Pevalin & Goldberg 2003), and are, therefore, subject to many methodological problems. Nevertheless, the evidence is convincing enough to argue that the majority of people diagnosed with a mental illness can be expected to improve significantly or fully recover.

Some of the most compelling evidence comes from the studies by Harding and colleagues. For example, Harding and Zahniser compared the results of five long-term outcome studies of people diagnosed with schizophrenia (see Table 1). They concluded that:

² For an anthology of Australian recovery stories, see Inner East Mental Health Services Association Inc – Terra Firma (2003) *Recovery Paths. An Anthology of Personal Journeys of Hope*. Terra Firma, Box Hill, Victoria.

“These studies have consistently found that half to two thirds of patients significantly improved or recovered, including cohorts of very chronic cases. The universal criteria for recovery have been defined as no signs or symptoms of any mental illness, no current medications, working, relating well to family and friends, integrated into the community, and behaving in such a way as to not be able to detect having ever been hospitalized for any kind of psychiatric problem.” (Harding & Zahniser 1994 p140)

Table 1. Outcomes from long-term follow-up studies of persons diagnosed with schizophrenia

Study	Sample Size	Average length (years)	Percent recovered or significantly improved
Bleuler (1972a,b) Burghölzli, Zurich	208	23	53–68%
Huber et al (1979) Bonn Studies	502	22	57%
Ciampi & Müller (1976) Lausanne	289	37	53%
Tsuang et al (1979) Iowa 500	186	35	46%
Harding et al (1987a,b) Vermont	118	32	62–68%

Source: Harding, Zubin & Strauss 1992 p29

The evidence is even more positive for people diagnosed with major depression. Data from the NIMH Collaborative Depression Study, a prospective long-term naturalistic study of mood disorders in 550 people seeking treatment at five different medical centres in the United States, reveal that the recovery rate after two years was about 80%, and increased to 94% after 15 years (Keller & Boland 1998). Nevertheless, relapse was common: after two years of prospective follow-up, 25–40% of people experienced a second episode of depression, and after 15 years, 87% had experienced a relapse. After a severe episode of depression, persistent sub-syndromal levels of depression are common, and these tend to fluctuate with full episodes of depression (Kennedy, Abbott & Paykel 2004).

Growing awareness that the majority of people diagnosed with mental illness will achieve a significant improvement or full recovery greatly enhances hope for people diagnosed with mental illness, and provides strong support for investing in relapse prevention.

Importance of relapse prevention

Relapse prevention is not only possible, but desirable on many levels. It is fundamental to providing effective continuing care for people with mental illness. Relapse prevention is essential to developing individual care pathways for people with mental illness that incorporate the multiple areas needed to effectively support treatment and recovery. It is part of a longer-term investment in the wellbeing of Australians—aiming to reduce the prevalence and duration of mental illness and thereby its impact on individuals, families, communities, and health and community services.

Relapse prevention is desirable for several pragmatic reasons. Firstly, it reduces the negative impact of mental illness on individuals and their families and carers, as well as their communities. Prolonged and repeated periods experiencing the symptoms of mental illness severely disrupt a person’s life and erode their confidence and wellbeing (Ralph 2000). The more relapses, the more disabled a person is likely to become; there is evidence that each

relapse increases both residual symptoms (Shepherd et al 1989) and social disabilities (Hogarty et al 1991).

As a result, people who experience repeated episodes of mental illness are more dependent on their families and carers. This greatly increases the burden on families and carers, contributing to their distress and reducing their quality of life. It has been estimated that individual carers contribute, on average, 104 hours per week caring for a person with mental illness (MHCA & CAA 2000). Repeated relapses impact in multiple ways on families and carers, including severely limiting the employment and social opportunities for those with a major role in caring for someone with mental illness (CAA 1998, 1997).

Preventing relapse vastly improves the quality of life of people with mental illness and enables them to more fully participate in work, leisure and relationships. Effective relapse prevention enables people to gain mastery over their symptoms, which increases their sense of control over their lives (Mueser et al 2002). A greater sense of control and efficacy can reduce the feeling of being 'entrapped' by the illness, a feeling that is commonly reported by people with mental illness and that may lead to depression (Birchwood et al 1993).

Being able to participate in meaningful activities is also important to the productivity of communities. The lack of participation of community members with mental illness is a considerable cultural and economic loss to communities. Mental disorders were the leading cause of years of 'healthy' life lost due to disability in 1996, accounting for nearly 30% of the total years of healthy life lost (AIHW 2002 p109).

Secondly, preventing relapse reduces the cost of mental illness to the Australian community. People who experience recurrent episodes are more dependent on health and community services, and every relapse that requires medical intervention imposes a cost on the health care system. In a recent randomised controlled trial in the UK, costs for the patients who relapsed were over four times higher than those for the non-relapse group (Almond et al 2004).

Expenditure for mental disorders has increased from \$2,247 million to \$3,741 million in the period 1993–94 to 2000–01 (AIHW 2005). This represents a change from 7.4% of total allocated health expenditure in 1993–94 to 7.5% in 2000–01. In the same period, expenditure on community mental health has increased from \$340 million to \$842 million. The increase in expenditure on community mental health shows the change of focus in mental health from hospital care to community care.

For Australia, in 2000-01, \$3.7 billion was spent for people with mental disorders. This accounted for 7.5% of health system costs (AIHW 2005). This expenditure includes expenditure for depression, anxiety, psychotic disorders and substance use disorders, but does not include expenditure for dementia, which is categorised as part of nervous system disorders in the AIHW disease expenditure classification.

Expenditure on mental disorders compares with \$5.5 billion for cardiovascular diseases, \$4.9 billion for nervous system disorders, and \$4.6 billion for musculoskeletal diseases (AIHW 2005). Mental disorders were identified as the third leading cause of overall health burden (14%) after cardiovascular diseases (20%) and cancers (19%) in 1996 (AIHW 2002 p109).

Health care expenditure for mental disorders for 2000-2001 can be broken down as follows (AIHW 2005):

- Hospital and aged care homes \$1,561M;
- Medical and other health professionals \$633M;

- Pharmaceuticals \$616M;
- Research \$109M; and
- Community and public health \$821M.

Mental illness also imposes costs to the welfare, aged care, police and justice systems, although these costs are difficult to accurately quantify because data collections in these systems do not accurately or routinely record psychiatric health status.

Direct evidence to support the cost-benefit of relapse prevention is not currently available. This is because few programs are clearly defined as relapse prevention, as separate from interventions that provide treatment, rehabilitation or recovery services; so, it is not possible to isolate the effects of programs specifically aimed at relapse prevention. Furthermore, effective relapse prevention spans many different sectors of service delivery, and it is difficult to clearly specify, quantify and cost such multifaceted and multisectoral interventions. For example, despite their extensive data collections for health and welfare, the AIHW is not able to extract the costs for people with mental illness from most of the databases related to the multiple health and welfare sectors from which people with mental illness might receive services.

One of the few interventions clearly identified as relapse prevention is teaching people to recognise the early warning signs of their mental illness. Novacek and Raskin (1998) report evidence from a large uncontrolled study of 370 people with severe mental illness, showing that teaching recognition of early warning signs was associated with better outcomes, which included fewer relapses and hospitalisations and reduced treatment costs.

Indirect evidence of the effectiveness of relapse prevention is available, however, from several sources. Randomised controlled clinical trials show that effective treatments that can prevent or reduce the severity of relapse have positive effects by reducing hospitalisations, decreasing length of stay if a hospitalisation is required, increasing the number of days in the community, reducing the level of symptomatology, and increasing the likelihood of obtaining employment (Mueser, Bond & Drake 2001). The European EPSILON study revealed that higher needs, greater symptom severity and longer psychiatric history are associated with higher health care costs (Knapp et al 2002). Furthermore, a study examining the cost of mental health care in the United States from 1993 to 1995 by analysing insurance records for mental health claims, reported that greater use of outpatient care (which is more likely to be focused on relapse prevention) decreased the costs of care by reducing the level of more expensive inpatient care (Outcomes and Accountability Alert 1999).

Current major approaches to relapse prevention and evidence of their effectiveness

Approaches to the longer-term management of mental illness can be divided into two separate processes: illness management and illness self-management. Illness management is defined as “professional-based interventions designed to help people collaborate with services in the treatment of their mental illness, reduce their susceptibility to relapses, and cope more effectively with their symptoms”, whereas illness self-management has been used to refer “to peer-facilitated services aimed at helping people cope more effectively with their mental illness and facilitating people’s ability to take care of themselves” (Mueser et al 2002 p1273).

In the medical and academic literatures, relapse prevention interventions have been categorised as including the following types of approaches: training in recognition of early warning signs; programs that encourage compliance with medication; coping skills training; and broad-based psycho-education programs. Both service-based and self-help programs are, therefore, clearly relevant to relapse prevention, although self-help and peer-based approaches have been researched less frequently and rigorously in terms of outcomes.

Mueser et al (2002) have reported a comprehensive review of the literature related to the effectiveness of these different types of programs. Randomised controlled trials provide the 'gold standard' of evidence to evaluate health interventions. Evidence-based practice is essential in order to provide effective and safe interventions for people with mental illness. Compelling evidence for the impact and effectiveness of mental health interventions, particularly when considered with a recovery framework, is, however, provided by a broader range of methodologies than randomised controlled trials. Anthony, Rogers and Farkas (2003) provide a list of points to consider to build the evidence base for practice within a recovery-oriented framework.

Awareness of early warning signs

Intervention approaches tagged specifically in the literature as relapse prevention are programs that focus on teaching people how to recognise their early warning signs and the environmental triggers of their symptoms. Such programs generally involve training in identification of early warning signs and stress management. In their review, Mueser et al (2002) report that randomised controlled trials of five such programs all reported decreases in relapse and rehospitalisation. Results from a large uncontrolled study of the use of early warning signs (Novacek & Raskin 1998), as well as a study of family members being trained in recognising early warning signs (Pitschel-Walz et al 2001) also reported positive outcomes in terms of reducing relapse and rehospitalisation, as well as decreasing treatment costs.

Considerable research has been undertaken into understanding early warning signs, particularly for psychosis and schizophrenia. These disorders are known to have a prodrome, or period when there are subtle, but identifiable, changes in thought, affect and behaviour that signal the onset of an episode of illness. However, it should be noted that the term 'prodrome' derives from the medical literature and "implies a disease progression that cannot be disrupted" (Birchwood, Spencer & McGovern 2000 p93); therefore, referring to these symptoms as early warning signs is a more accurate conceptualisation and allows for the possibility of preventive efforts to intervene to arrest the development of a full-blown episode.

There are common early warning signs for psychosis that are frequently reported and relatively predictable (see Birchwood, Spencer & McGovern 2000 p98). For depressive and anxiety disorders, the early warning signs have not been as thoroughly researched and are less well understood, although the indicators of the presence of depression and anxiety are well documented (see www.beyondblue.org.au). Sub-syndromal levels of these disorders are highly predictive of relapse to a full episode (Cuijpers & Smit 2004).

Early warning signs vary between individuals, and a personal set of early warning signs is referred to as a 'relapse signature'. There is ample evidence that people with psychosis are often aware of these signs, which generally prompt them to undertake personal coping strategies to actively intervene (eg, McCandless-Glimcher et al 1986).

Some people are not able to recognise their early warning signs, however. There are those who actively deny their symptoms and have no insight into their mental illness. Others have 'past insight', or retrospective insight, into their relapse signature, but lose 'present insight'

early in the relapse process. For these people, family members and significant others may be involved in monitoring early warning signs. Effective training programs have been developed to help families and carers do this. There are also standardised measures of early warning signs that can be applied (Birchwood et al 1989).

When early warning signs are noticed, people need to know how to respond effectively and what their role in the response is. This requires having a relapse prevention plan. An example of such a plan is presented in Table 2. This particular plan contains a ‘relapse drill’, which is a three-stage action plan with responses corresponding to the type of warning signs. It recognises that the earliest signs are usually non-specific and, therefore, early interventions for these early symptoms are based around relaxation and stress reduction. Interventions with greater risk attached (such as increasing medication) are reserved for when the relapse signature is clearly indicating the onset of a psychotic episode.

Table 2. Relapse prevention sheet in response to different types of early warning signs

Relapse signature	Relapse drill
Increased feelings of inadequacy	Step 1: Stay calm – yoga or meditation
Preoccupied about self-improvement, including constantly monitoring yourself for faults	Contact keyworker/services to go out and discuss feelings
Increased feelings of anxiety and restlessness	Make time for yourself, use partner and mum for support Coping with thought/problems
Racing thoughts/intrusive thoughts	Step 2: Distraction techniques
Feelings of elation/spirituality	Take ___mg _____ from emergency supply
Do not need to sleep (one night or more)	Daily contact with services, if necessary (discuss feelings, reality-testing)
Suspicious of people close to you	Contact doctor regarding recommencing or increasing medication
Not wanting to eat	
Horrific thoughts and paranoia	Step 3: Admission to hospital or respite care
Beliefs of being punished by God or possessed by the devil	
Severe paranoia	
Tactile hallucinations	
Keyworker :	Hours of contact :
Co-worker :	Mon-Fri (9.00-5.00)
Present medication :	Tel :
Carer contacts :	Sat-Sun (10.00-5.00)
Triggers :	Tel :
	Out-of-hours contact :

Source: Birchwood, Spencer & McGovern 2000 p96

Research pertaining to the effectiveness of different types of relapse plans has not been undertaken. Such plans need to be individually tailored and regularly reviewed as an individual’s relapse prevention needs will change over time. However, there are likely to be common elements that should be considered for all people at all points in time. Identifying

these common elements would significantly progress our understanding of relapse prevention. Routinely implementing such planning within continuing care pathways for people seriously affected by mental illness would reduce relapses and increase the scope for recovery.

Compliance with medication

Medication non-compliance is a major risk factor for relapse. This is the case for psychotic illnesses (eg, Marder 1998) as well as depression (eg, Geddes et al 2003). There is clear evidence that maintenance medication and taking medication as prescribed significantly reduces the risk of relapse.

Despite this, many people do not take their medication as prescribed. For example, it is estimated that fewer than 10% of people with unipolar major depression take the appropriate therapeutic dose of medication, and more than 20% fail to even fill their first prescription (Keller & Boland 1998). Furthermore, people often discontinue their medication long before it is advised by their medical practitioner. Adherence to taking antipsychotic medication is particularly problematic, and a wide range of factors, including unpleasant side effects and poor communication with doctors, have been shown to contribute to this reluctance (see Marland & Cash 2001).

The majority of interventions aimed at preventing relapse, focus on compliance with medication. Mueser et al (2002) differentiate between programs that use psycho-education to encourage taking medications as prescribed and cognitive-behavioural programs that use techniques such as behavioural tailoring, simplifying the medication regime, motivational interviewing, and social skills training (to improve interactions with prescribing practitioners so as, for example, to be better able to discuss the side effects of medications).

From a review of eight randomised controlled trials of psycho-education, Mueser et al conclude that the psycho-education approach alone improves knowledge, but does not affect the behavioural outcome of taking medication. In contrast, randomised controlled trials of 14 cognitive-behavioural programs concluded that the majority of these programs were effective at improving the behaviour of taking medication, and that the strongest evidence was for behavioural tailoring (Mueser et al 2002). Behavioural tailoring is a particularly effective and relatively simple technique that comprises simplifying the medication routine and teaching people ways to ensure that taking medication becomes a habit by being incorporated alongside everyday activities, such as teeth brushing (see Cramer & Rosenheck 1999).

Coping skills training and cognitive behavioural approaches

Coping skills programs aim to help people manage stress or deal with persistent symptoms. Randomised controlled trials were reviewed for four coping skills programs by Mueser et al (2002). All these programs were quite different in their approach, ranging from an interactive approach centred around cognitive appraisal of perceived threat, to enhancing a sense of empowerment, but all had in common the use of cognitive-behavioural techniques. All four programs reviewed were shown to be effective in terms of reducing symptom severity.

Cognitive-behavioural approaches generally focus on modifying dysfunctional beliefs as well as improving coping skills, such as distraction. Mueser et al (2002) report on the outcomes of eight randomised controlled trials of cognitive-behavioural therapy (CBT) programs. A consistent outcome of all the studies was that CBT was more effective than supportive counselling or standard care in reducing the severity of psychotic symptoms.

Broad-based psycho-education programs

It is a commonly held belief that greater knowledge empowers people to make better decisions regarding many behavioural choices, including those affecting their health. Broad-based psycho-education programs provide people with information about their mental illness, generally focusing on symptoms, stress-vulnerability, and treatment options. In a review of the outcomes of four randomised controlled trials of broad-based psycho-education programs, Mueser et al (2002) reported that while these increase people's knowledge about mental illness, they do not impact on other outcomes. This is a finding that is consistent with other health applications of psycho-education programs: improving knowledge does not automatically lead to changes in behaviour (see Whitehead & Russell 2004).

Self-help programs

Consumer self-help groups developed partly out of dissatisfaction with the mental health care system and the need for consumers to combat the stigma of mental illness (Emerick 1990). These groups have expanded to include a wide variety of programs and to also comprise family and carer support groups. Wissman (2003) outlines the following different types of support groups: education groups; skill-development; self-help and support groups; recreation groups; social and social skills development groups; issue or interest-based groups; and advocacy and community education groups.

There are few methodologically sound research studies available regarding the efficacy of self-help programs. Peer-based and self-help approaches are not amenable to randomised controlled trials because they grow out of the shared needs and experiences of people with mental illness and are not provided as specific and randomly assignable interventions. The complexity of group processes makes their elements and dynamics difficult to capture and quantify within a rigorous research design (McDermott 2003). One available study, Arns (1992, cited in Accordino & Herbert 2000), reported that length of attendance at a Clubhouse program was associated with more positive outcomes in terms of better employment status, better physical functioning, improved personal care and better social relationships.

Despite the lack of methodologically rigorous evaluations of self-help programs, descriptive and anecdotal evidence abounds regarding the importance and effectiveness of these groups for both consumers and carers (eg, Chamberlin, Rogers & Ellison 1996). Yalom cites 11 factors that he argues are the keys to group effectiveness. These are: instillation of hope; universality; imparting of information; altruism; corrective recapitulation of primary family group; development of socialising techniques; imitative behaviour; interpersonal learning; group cohesiveness; catharsis; and existential factors (1975 see McDermott 2003 for a summary).

Most importantly, self-help groups provide social contact and fellowship. Many people with mental illness are socially isolated, as a result of the symptoms of their illness or the disruption to their lives that the illness has caused (Goldberg, Rollins & Lehman 2003). There is a growing evidence base of the positive impact of self-help groups on the social networks of people with mental illness (eg, Hardiman & Segal 2003). While the social support provided specifically by self-help groups has not been systematically studied, the positive effects of social support in general on health and wellbeing are firmly established in the literature (eg, House, Liandis & Umberson 1988).

Risk and protective factors

The approaches considered so far generally take a singular emphasis for intervention: for example, interventions to improve compliance with medication prioritise a medical approach;

a cognitive view is adopted in the case of CBT interventions; and social and educational viewpoints are emphasised for self-help programs. It is argued, however, that a single model of intervention is not sufficient, and that there are major advantages to more comprehensive and holistic approaches that respond to multiple areas of intervention need (eg, Kramer et al 2003).

A more holistic approach to prevention focuses on identifying the multiple risk and protective factors for mental health. Risk factors are those that contribute to a person's vulnerability to relapse, whereas protective factors mitigate against relapse by enhancing wellbeing; "risk factors increase the likelihood that a disorder will develop and can exacerbate the burden of existing disorder, while protective factors give people resilience in the face of adversity and moderate the impact of stress and transient symptoms on social and emotional wellbeing, thereby reducing the likelihood of disorders." (*Monograph 2000* p13).

Evidence related to the risk and protective factors for relapse of mental illness is an area of much needed research activity. Stress is commonly implicated in exacerbating mental illness (eg, Ventura et al 1989). In particular, longer-term stressors in a person's social and physical environment and lack of opportunities for 'fresh starts' are factors that are likely to increase the likelihood of relapse and impede recovery (Brown et al 1988, Paykel et al 2001). "Risk and protective factors occur through income and social status, physical environments, education and educational settings, working conditions, social environments, families, biology and genetics, personal health practices and coping skills, sport and recreation, the availability of opportunities, as well as through access to health services." (*Action Plan 2000* p9).

Lists of potential risk and protective factors are provided in *Monograph 2000* (pp15-16), which cautions, however, that it is important to note that while the available evidence shows that these factors are *associated* with mental health outcomes, the strength of association and level of evidence for 'causation' varies. Consequently, no *causal* relationship can be assumed for these factors; for some individuals there will be no impact of any particular factor or combination of factors, while for other people a particular factor or combination of factors may have a major impact on their ongoing mental health.

Importantly, *Monograph 2000* (p34) points out that it is possible that quite different factors influence the relapse and recurrence of disorder compared with those that influence its onset (Zubrick et al 2000a). For example, a determinant of the onset of conduct disorder in children may be poor fetal growth (Zubrick et al 2000b, Breslau 1995) while determinants of the persistence of this disorder at the time a clinician sees the child may be poor parental monitoring and a deviant peer group (National Crime Prevention 1999). These latter determinants form part of the prognosis for treatment and need to be considered as targets for relapse prevention, while the former determinant, now no longer amenable to treatment, is an early risk factor and target for indicated prevention.

Clearly, all the domains of life—environmental, physical, social and emotional—can be a source of both strength and stress. Varying levels of evidence suggest that risk and protective factors are likely to be evident in the areas of accommodation, employment, forms of meaningful activity, harmful alcohol and other drug use, physical health, social relationships, violence, and factors that shape personal resilience.

A word of caution is required regarding the implementation of relapse prevention in terms of applying a risk-based approach. *Monograph 2000* presents the following potential problems of such an approach.

Firstly, risk factors have limitations as predictive tools. The extent to which any particular risk factor contributes to an episode of mental illness is not certain, as risk is based on probability. Not everyone who is exposed to a risk factor will have an adverse outcome. Knowledge related to the risks for relapse is not yet well developed and it is important to realise the limitations of our understanding in this area.

Furthermore, the nature of risk varies in terms of the element of choice or voluntariness of the risk factors identified, which affects the extent to which the risk is amenable to intervention. The Canadian Association of Gerontology (see Health Canada 1997 p8) identifies personal risks on a continuum of voluntary choice as follows:

<i>risk pursued as opportunity</i>	<i>freely accepted risk</i>	<i>reluctantly assumed risk</i>	<i>risk with little or no choice</i>
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Thirdly, *Monograph 2000* states that the process of identifying risk can be biased. Risk is not a neutral concept; decisions regarding what are acceptable or unacceptable levels of risk are subjective.

“The generalized use of the ‘at risk’ label is highly problematic and implicitly racist, classist, sexist and a 1990s version of the cultural deficit model which located problems or ‘pathologies’ in individuals, families, and communities rather than in institutions and structures that create and maintain inequality” (Swadener & Lubeck 1995 p3).

The process of ascribing risk can be disempowering for consumers, as the assessment of risk factors is often carried out by services. Asking people themselves what is important for their wellbeing can generate factors very different to those determined by a service provider. Interventions can be paternalistic and at odds with the concepts of consumer empowerment and participation.

You can put too much emphasis on relapse prevention and there’s the risk of trying to be too overprotective; you can highlight vulnerability to the extent that it kind of restricts people’s sense of wellbeing. —Clinician

Risk factors interact, and multiple and persistent risk factors predict more strongly than any individual risk factor (Mrazek & Haggerty 1994, Fraser 1997). Addressing a single risk factor or having a short-term orientation to prevention is likely to be ineffective. These types of simplistic approaches are all too common and derive from and underlie the fragmented, sector-specific nature of many services. Structural barriers can hinder intersectoral approaches and impede more multi-focused, holistic and intersectoral prevention interventions.

If risks are improperly identified, interventions can be targeted at the wrong factors. At best such interventions may be ineffective and a waste of scarce resources; at worst they may exacerbate other risk factors. An example of an intervention that may increase risk is the premature removal of children from their families in response to perceived risk and placing them in foster care or institutions. The stolen generation of Aboriginal children resulted from a biased, misguided, paternalistic and racist decision to remove part-Aboriginal children from the ‘risks’ associated with growing up within Aboriginal communities and, instead, provide them with the ‘benefits’ of being assimilated into the ‘dominant’ culture. The disastrous and multi-generational outcomes of this intervention are now evident.

The overzealous application of a risk approach is all too well understood by parents who have mental illness. These people risk the removal of their children when they become acutely unwell and then may have difficulty getting them back once they are well again.

DOCS doesn't consider mental illness, it's outside of their Act, if they get involved the children just disappear. —Consumer

You learn to make sure they [the children] don't get noticed. —Consumer

Finally, a risk approach focuses on the negative. A risk focus concentrates on weaknesses rather than strengths, and can encourage an approach akin to 'rescuing' those in need. Alternatively, there is a danger that enforced intervention will be seen as desirable or even necessary.

While it is important to reduce risk factors where possible, and enable people to better cope with the risk factors that they cannot modify, a concomitant focus on improving protective factors greatly enhances the effectiveness of interventions and is essential in order to place relapse prevention within a recovery orientation.

WHAT ARE THE BASIC ELEMENTS OF RELAPSE PREVENTION?

Currently, there is no comprehensive framework agreed for relapse prevention within the context of mental illness. There are frameworks available for recovery and for psychiatric rehabilitation, but the focus of these is quite different, although highly relevant to relapse prevention. Review of the national and international literatures shows that most relapse prevention initiatives are single-issue medically-based responses that prioritise maintenance medication and recognition of early warning signs. The chronic illness management and rehabilitation literatures provide useful guidance, but have not been applied in the context of mental illness. It is possible, however, to identify the core components of relapse prevention for mental illness and show how these contribute to providing effective continuing care within a recovery orientation.

Fundamentally, relapse prevention requires awareness, planning, and the provision of timely and appropriate intervention responses. Laurie Curtis operationalises relapse prevention as the 4As of crisis prevention: awareness, anticipation, alternatives and access (Curtis 1997). To implement such an approach, actions need to be undertaken by all those involved in the continuing care and recovery of people with mental illness: by people who have experienced mental illness, their families and carers, clinical service providers and planners, non-clinical service providers and planners, policy makers, and communities.

Awareness — acceptance, attitude and recognition

Awareness is the first component of effective relapse prevention, and is made up of the essential elements of acceptance and recognition. These factors determine whether people at risk of recurrent mental illness, and the people and services that they are in contact with, are able to accept and recognise changing mental health needs so as to be able to respond appropriately.

Acceptance

Acceptance that one has a mental illness and is at increased risk of relapse is an important first step for relapse prevention. Acceptance is acknowledged to be an important step in developing effective illness management strategies and working effectively with mental health services and complying with medications and treatments (Van Meijel et al 2002a,b). This can be a difficult process, however, and takes time (Nemec & Taylor 1990). Acceptance is unlikely to occur immediately after the first episode; at this time, most people want to return to their previous self and previous life and are very reluctant to accept that they may have ongoing problems with their mental health.

Looking at your life and how it's changed, the what ifs, how am I going to go back to my life, the grief is overwhelming. —Consumer

The process of acceptance is somewhat of a paradox: it requires acknowledging the illness as part of the self, but not seeing oneself as a sick person and defining the self solely within the boundaries of the illness (Deegan 1988). The process of acceptance is particularly complex for younger people as it may not be clear what a first episode of apparent mental illness

means in terms of future mental health and child and adolescent services do not prioritise diagnostic labelling. Pathologising the self is not conducive to wellbeing at any stage of the lifespan, but particularly for young people. Self-help and peer group programs can be uniquely effective in helping people to come to terms with having a mental illness.

It's like, "Welcome to the club! You may not have chosen to be here, but this is where you are!". —Consumer

Acceptance of mental illness is not, therefore, a clear-cut issue. What is important is that people come to have a developmentally appropriate realisation that they may be at increased risk of future mental health problems so that they are able to put appropriate supports in place. However, there are additional barriers to acceptance of mental illness in the form of substantial stigma and its impact on self-worth. In the context of mental illness, acceptance needs to evolve over time and be appropriate to the current life-stage of the person concerned.

It means coming out of denial, accepting it in yourself and not hating yourself for it. Once you stop hating yourself you become more open to doing the things that will help. —Consumer

Often, it is only after further episodes or a particularly traumatic episode that many people acknowledge and are prepared to accept that they have mental illness. This can be a period of intense loss and grief—of self and of one's previous life—and it is important that other people involved recognise this process. The process of grieving differs for the person involved compared with their family and significant others. When the family accepts a diagnosis of mental illness, but the person concerned does not, this can create significant conflict and frustration between the consumer and their family. People need to have the support to go through the process of acceptance in their own way and in their own time. Some adults continue to deny the label of mental illness, despite repeated episodes, and it is possible that techniques like motivational interviewing (Miller & Rollnick 1991) may be useful in helping people to accept that they have a condition that needs particular management strategies.

There is a displacement between when the carer starts grieving and when the consumer starts grieving. When someone first gets ill the carer starts grieving but the consumer is still going through a period of illness, so they don't start grieving until further down the track and then there's displacement between the grief of the consumer and the carer and that can cause problems and conflict because people want to move on at different paces. —Carer

Coming to terms with having a mental illness is a time when people need easy access to information that is developmentally and culturally appropriate. Self-help groups are a significant resource in terms of providing information and advice and fill in the many information gaps that remain after contact with mental health services. There are, however, some cautions regarding relying on peers as a source of help and advice, if they are not ready to be in a support role by being untrained or misinformed.

If you talk to some inpatients you might get the wrong idea because they might say the medication does something but it doesn't do that so you don't take that medication for that reason ... You need people who are well. —Consumer

Importantly, self-help groups can provide role models of people living well with mental illness. This is essential to give hope to people who have recently been diagnosed with mental illness and their families. Many people still fear that such a diagnosis means the end of a "real life", but contact with other consumers who are "living proof" of the prospect of building a new and meaningful life is an essential part of the recovery process and important to building

confidence to prevent relapse, which can be triggered by isolation, hopelessness and despair. As shown in the following quote from the consultations, such role models can also help people to adjust more easily and hopefully to treatment plans during their early episodes:

If only we'd known from another consumer that it wasn't always going to be like that. Because we developed this hope by seeing other consumers being well. You get this diagnosis from the doctor, and it's like what you've seen in your family and then you read about it and you go "My god, there's no hope, there's just no hope". Then when you find out there's these other consumers, they're doing ok, they've got jobs, it's just like amazing, because you believe. It's no good a psychiatrist telling you, but if there's another consumer in front of you. —Consumer

For young people with episodes of psychosis, if they know there's someone they can talk to who has already been through it and they know that there's a way through it and that you do feel better, maybe not 100% but you do feel a bit better. If I had that when I first came here I know that I wouldn't have been so stubborn with the doctors. I would have eased myself up saying, "OK, we can try this", but because I didn't have that I think I was a bit more stubborn thinking, "I don't need help, I'm fine". —Consumer

More positive attitudes toward people with mental illness are fundamental to awareness and acceptance and thereby to effective relapse prevention. Positive attitudes are required at all levels: positive self-attitudes for people who have mental illness, positive attitudes of families and carers, and positive attitudes among service providers and the community in general. Stigma and discrimination are internalised by people with mental illness and this impacts negatively on their sense of self-worth and wellbeing.

With stigma we have our own stigma, you can't think lower of yourself than we do of ourselves. —Consumer

The attitudes of service providers, both clinical and non-clinical, are of major significance. The negative attitudes of service providers, particularly of clinical services, came through clearly in the *Evaluation of the Second National Mental Health Plan* and the MHCA report *Out of Hospital, Out of Mind* (Groom et al 2003). As a result, improving the attitudes of the mental health workforce is an identified outcome of the *National Mental Health Plan 2003-2008*.

People who work in acute have quite negative attitudes. —Consumer

It is possible that differences in attitudes between clinical and psychosocial support services may be due to different points of contact with consumers. In the consultations, it was repeatedly suggested that the acute care workforce has more negative attitudes toward people with mental illness because they only see people when they are acutely ill; they don't see them when they are well. It is well documented that greater familiarity and exposure can improve attitudes toward people with mental illness (Kolodziej & Johnson 1996). For mental health care providers, seeing consumers during periods when they are well, rather than only when acutely unwell, may greatly improve attitudes through recognition that the people they work with are actually well much of the time and that there is considerable scope for recovery.

Clinicians and providers of acute services only see people when they are having an acute episode. They don't see them when they are well. So, they only think of them as being in relapse or being discharged. They don't see the different levels of wellness. It's a pity they

don't see them when they are well, to see the real person. These are the real people we see and work with. —Psychosocial rehabilitation provider

At the more macro level, there is ongoing need to reduce the societal stigma associated with mental illness. Some major initiatives have occurred in this area, with considerable effort targeting the media, and there appears to be progress in this regard (Steering Committee for the Evaluation of the Second National Mental Health Plan 2003). However, there is still much more to be done to eliminate the stigma of mental illness. Negative attitudes, stigma, and exclusion are powerful risk factors for relapse as they limit the opportunities for people with mental illness to be involved in the activities they need to stay well.

Recognition of early warning signs

Recognition and awareness of early warning signs and of the risk and protective factors for mental health are fundamental to relapse prevention. This awareness needs to be at individual, family and service levels. There are two types of monitoring that are relevant to recognition of early warning signs: direct monitoring, where the presence or absence of symptoms is ascertained; and indirect monitoring, where situations are assessed to determine the presence or absence of risk and protective factors (van Miejel et al 2002a). Both types of monitoring are essential for a comprehensive and holistic relapse prevention approach.

People with mental illness generally report that with experience they are able to detect their early warning signs, and that they rely heavily on these indicators to know when they are at imminent risk of relapse, even though early warning signs can vary and do change over time. Symptom and reality checks are essential tools to monitor mental health status. Most consumers develop their own symptom checks, but there are standardised measures of early warning signs that can be applied (see Birchwood et al 1989).

I think people who go through a re-emergence, repeat of a cycle of an episode, are aware of that illness anyway so they can catch it so that it doesn't become a full relapse. —Consumer

For many it's very individual. I know whenever I start to change my head gets itchy inside and I know something's going on and something's changing. —Consumer

If I'm too happy, if I'm too creative, if I'm too optimistic then I have to say, "Hey this is not good". —Consumer

Many family members also are able to detect early warning signs, although some state they have trouble distinguishing these from natural variations in behaviour (van Miejel et al 2002a,b). For consumers who lack insight into their early warning signs, family members or significant others can be effectively trained to contribute to symptom checks. Awareness of early warning signs is fundamental to relapse prevention.

My children are my barometer; they say, "Mum you're laughing and that wasn't funny" and they sort of know my symptoms and they do a symptom check and tell me, "I notice you did this, you did that". —Consumer

To start with I was well enough to realise something was wrong, so I told my flatmate. Then two hours later I changed my mind and isolated myself in my room. I was listening to voices telling me not to leave the room and not to talk to people. So, then he had to call the CAT team. —Consumer

Awareness of potential risk and protective factors for relapse

The most well researched and widely accepted risk factor for relapse is not taking medication as prescribed. An emphasis on the importance of medication was evident in the consultations, particularly from representatives of clinical services.

Maintenance medication is routine practice. It is essential that people understand the importance of treatment adherence. —Clinician

Medications can be, however, a vexed issue as they often have unpleasant side effects and, when people are feeling well, they prefer not to take them.

Sometimes you are better off on no medication because of what the medication does - once my doctor even admitted that, but only once. —Consumer

Techniques that encourage people to take their medication effectively are, therefore, essential for relapse prevention. This can include psycho-education to better inform people about their mental illness and the role of medications in its management. It can also include the use of behavioural tailoring to ensure that medication is not accidentally forgotten. Primarily, though, it is essential that the concerns of consumers around their medication are taken seriously and that clinicians work with consumers to develop the most appropriate medication regime and to review this regularly to ensure that it meets current needs.

I've been searching for 13 years. I think I've finally found a reasonable mix but I take four different drugs. —Consumer

A more holistic approach that goes beyond a focus on medication and a medical treatment model is also required for effective relapse prevention. Risk and protective factors need to be explicitly identified, and deliberate attempts made to reduce the risk factors or their impact, and increase the protective factors. Despite the lack of scientific evidence, most consumers and their families become aware of their relapse triggers, as well as the positive things in their lives that help to keep them well.

All the domains of life—environmental, physical, social and emotional—are a source of both stress and support. Stress is generally a risk factor and social support is a protective factor. Environmental stressors include inappropriate housing; environmental supports are good public transport. Some of the major physical stressors are sleep disturbances, poor physical health, poor nutrition, and harmful alcohol and other drug use; physical supports are relaxation and fitness. Social stressors come from isolation and poor social relationships; social supports are good relationships of all kinds. Emotional stressors come from feelings of hopelessness, despair, and poor self-esteem, whereas emotional support can come from finding hope and meaning in life.

It is all the elements, you have to get it all in balance. You need to rebuild the physical by doing activities - walking, gym, swim, ride, just anything. You've got the mental side of things to look at. You've got the social side of things to look at. Then the emotional side of things to look at and the spiritual side of things to look at. They're all questions that come up when you experience voices or hallucinations, or mental illness or depression and the like, so you need to learn to rebuild all of those elements. —Consumer

Anticipation and planning

Anticipation of potential future scenarios and appropriate planning are essential to relapse prevention. Many of the consumers spoken with in the consultations had plans that

incorporated maintaining their wellness and preventing relapse. However, these were rarely developed in partnership with service providers and were not comprehensive. Plans tended to evolve in an ad hoc way, with people learning over time through their own experiences and those of other consumers what types of activities help them to prevent a relapse.

It's a process. It's trial and error. You do all these things to try and distract yourself. Over time you know what works, you get an understanding of the illness. It's a balance of a whole lot of things that you learn to do. —Consumer

Planning is what empowers people with mental illness to make the decisions they choose, rather than have decisions made for them. Planning needs to be undertaken when the consumer is relatively well and able to make such decisions. It needs to be undertaken on several levels: daily plans, wellness plans, relapse and crisis plans.

I am a person with a disability. I have a psychiatric disability. I continuously work at having an overall plan for my psychiatric wellbeing. I also have daily plans and strategies. I believe in planning ahead as much as I am able to. —Moe Armstrong, Speaking Out

People with mental illness may need daily plans to ensure that they undertake the everyday activities they need to keep them well and prevent relapse. These plans may involve behavioural tailoring to ensure that maintenance medications are taken. They may also involve prompts to ensure that symptom and reality checks are undertaken. Plans need to be comprehensive and ensure that protective factors such as exercise, sleep and social activities are undertaken, and that risk factors like stress are minimised or effectively coped with.

Lists are important in terms of what do I have to do today. Do I have to go and have a coffee with someone or do I have to go and exercise. Just like everybody else does, it's just that the consequences of what can happen if you don't maintain your mental health can be a lot more severe. —Consumer

More general wellness plans are also required. These identify the risk and protective factors that are currently impacting on mental health, and the actions to be taken in response to them. Relevant risk and protective factors need to be identified for all the domains—environmental, physical, social and emotional. Relapse plans tend to focus on reducing stress and stressful activities, sleeping and eating properly, exercising, and making social contact with other people. However, goals for change and growth also need to be determined, as well as the facilitators and barriers to attaining these goals.

Planning and goal setting are not new concepts and have been well developed in the chronic illness management literature. For example, Figure 4 presents a diagram of the illness management action process as applied in other chronic illnesses. These processes are equally valid for mental and physical illnesses, and the mental health field has much to gain from examining the chronic illness management field (see Von Korff, Glasgow & Sharpe 2002).

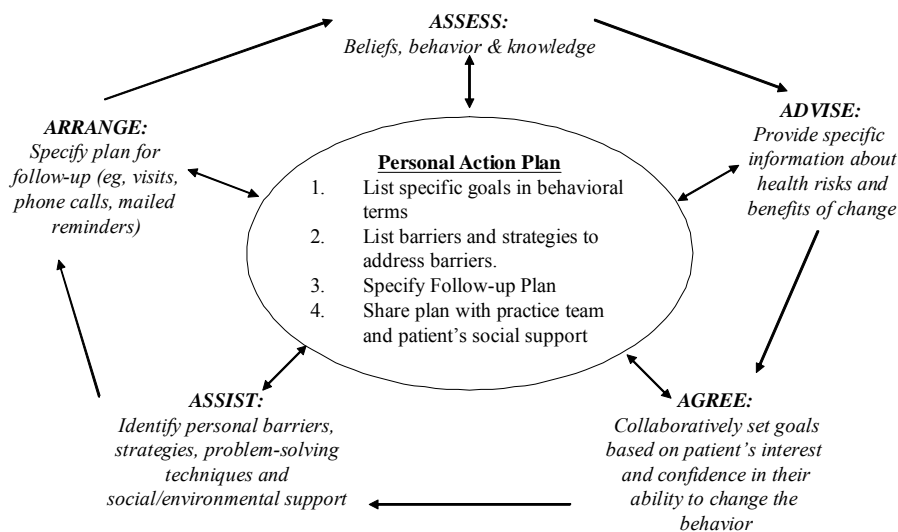


Figure 4. Illness self-management action process (Glasgow et al 2003)

People at increased risk of relapse also need emergency or crisis plans, detailing what needs to be done if they become acutely unwell. During an acute episode, the ability of someone to make decisions is often taken away from them. It is essential, therefore, for consumers to be proactive and make these decisions when they are well. Decisions regarding the care of children and pets can be particularly distressing for people experiencing an acute episode, but planning ahead for such emergencies can help ensure that the decisions of consumers themselves are upheld, rather than what a service provider might deem appropriate or practical at the time.

I've got one on the fridge – there's a map of how to get to the hospital, my case manager's number, the things I need to have looked after if I am away for awhile – like looking after my cat. If I get out of control he [my flatmate] can grab that, he knows all my current contacts and he can put it all in place. He knows it's what we agreed and he doesn't have to worry that he's doing the wrong thing because it's what I've put down. —Consumer

This doesn't guarantee that all will be trouble-free during a future episode, but does generally act to empower consumers in crisis situations.

Many times it's happened to me, and to my staff, where someone's in the midst of a full-blown psychotic experience and we'll pull out their wellness plan and they'll say, "You bastards have learned how to make my signature!". —Psychosocial rehabilitation services provider

Related to planning are self-will, responsibility and perseverance. Many people in the consultations, as well as their families and carers, noted the need for hard work and persistence in order to stay well. Persistence is required to achieve goals and to maintain the activities needed to prevent relapse (such as maintenance medication and exercise). It also entails a realisation that relapse prevention is something that you can do yourself: that your recovery is your own responsibility and that waiting around for services to provide the answers to your problems or for a miracle cure is not the way to get well and stay well (Walsh 1996). Furthermore, services must support self-will and responsibility rather than encourage dependence. Larry Davidson (2004) maintains that the statement, "You can do it -

we can help”, captures the approach that services need to adopt to support self-determination and recovery.

I've never stopped searching to get well. It's that thing of if you want something, you just keep searching, searching, searching, searching. So I don't see it as luck: I see it as you just keep going until you find the technique, you find the book that works, you find the medication that works. It took seven years for me to find the right medication to keep me stable, and without that I couldn't have done CBT, I couldn't have done support groups. So, whether that's luck or whether it's persistence. —Consumer

An effective relapse prevention plan will tailor the development of awareness, acceptance and planning to each person's unique needs, taking into account their age, personal circumstances, level of insight, cultural background, and experience of mental illness. It is not appropriate for services to inflexibly impose a standardised 'relapse plan'; rather, it is essential to routinely make sure that all the factors that may prevent relapse for a particular individual are comprehensively but sensitively considered.

That to me is the crux of the whole matter, the system treats the problem and not the person ... they don't see the person they only see the problem and fixing it and they don't do a very good job. —Consumer

Relationships and communication

Essential to effective planning is good communication, between all the parties involved—the consumer, their family and carers, clinical service providers, rehabilitation and support services. Awareness and planning are based on openness, trust and communication. Wellness and relapse plans need to be explicitly negotiated with the other people involved who need to be aware of their roles and agree to their part in the process. For example, family members are often an important aid to undertaking a symptom or reality check. However, for this to work both the consumer and the family member have to agree to this arrangement and make clear the expectations and boundaries.

I know it's ok to do this because it's what we've agreed. Earlier on there was lots of conflict because I would say I thought there was something going on and he would get really angry with me. But over time, he's realised that I am his best barometer. He knows that I can tell when he can't and now we talk about it and he trusts me to let him know when he's not well. It has made a big difference, but it has taken a long time to get to this. —Family member

Both formal and informal relationships are important. Family members and carers are highly motivated to build trusting relationships and have frequent contact and opportunities to do so. However, service providers can be less willing to take the time to invest in relationship development and good communication. This is somewhat surprising given the level of evidence attesting to the importance of the therapeutic relationship in terms of positive outcomes (Horvath & Greenberg 1994). Trust and effective communication between service providers and consumers and their families and carers are fundamental to good continuing care, but something that is generally elusive in the mental health care system.

Furthermore, it is necessary to regularly revise and revisit relapse prevention plans and this requires long-term ongoing relationships. Life situations are constantly changing, and all the consumers and carers contacted during the consultations emphasised the “learning process” and the “always changing” nature of the factors related to ongoing mental health. Relapse prevention plans will soon be outdated if they are not regularly reviewed and updated; these

are not static documents, but rather dynamic tools for the recovery process and must be responsive to changing life circumstances and developmental needs.

Alternatives

People who have experienced mental illness, and their families and carers, need a wide range of service alternatives that can be tailored to their personal context and that address their particular risk and protective factors for wellbeing. However, very few local areas adequately provide the range of services that are needed to support people who have experienced mental illness in the community. Better provision of community support services, along with the development of effective partnerships and communication strategies between different services and sectors is an urgent need in most jurisdictions. The entire range of evidence-based psychological, pharmacological and psychosocial support options needs to be available and accessible to enable people with mental illness to find the techniques that best support their recovery.

In the national consultations, consumers and their families and carers argued that there are few rehabilitation and recovery-focused services provided by the mental health care system. This perception is confirmed by a study that showed that only 19% of people with low prevalence mental disorders in Australia had received any type of rehabilitation services in the past year; a much higher proportion of people perceived a need for such services, but were unable to access them because the services were either not available or were unaffordable (Jablensky et al 1999, Jablensky et al 2000).

Non-government organisations and self-help groups have attempted to fill this void. In the national consultations, consumers and carers of all ages noted the immense value of non-government organisations and support groups in providing psychosocial support services that were otherwise unavailable. These types of services include social, recreational and vocational programs, which help people to reclaim these essential supports for recovery. However, this sector is greatly under-resourced, and unable to meet the high level of need for such services.

The rehabilitation we have to do ourself. They throw us out of hospital to nothing. We got together to do it ourselves. —Consumer

Accommodation

Fundamental to wellbeing is having appropriate accommodation and shelter (WHO 1986). A comprehensive range of accommodation options with varied levels of support needs to be available for people who have experienced mental illness, and options need to be suitable to people of difference ages, cultural backgrounds and personal circumstances.

The need for housing to be secure, safe and stable has been recognised in NSW through development of the *NSW Framework for Housing and Accommodation Support for People with Mental Health Problems and Disorders* (NSW Health 2002b). This report notes that although appropriate accommodation is critical, many people with mental illness are unable to afford stable housing or make their own housing choices, and frequently have problems accessing appropriate housing and difficulty maintaining tenancies because of disruptions caused by their illness.

Some people are discharged from hospital after an acute episode with little follow-up to ensure appropriate accommodation in the community, which leaves them open to neglect, abuse and homelessness (Groom, Hickie & Davenport 2003). People with complex needs,

those who have co-occurring alcohol and other drug problems, and people who have been forensic patients have even greater difficulty obtaining and keeping appropriate housing.

Of major concern is the level of homelessness experienced by people with mental illness. An unintended consequence of the deinstitutionalisation that has taken place over the period of the *National Mental Health Strategy* has been an increase in the number of people with mental illness who are homeless or inadequately housed. Data collated by the AIHW on supported accommodation programs show that mental illness, directly and indirectly, is a major contributor to homelessness (AIHW 2003).

Homelessness and inappropriate housing expose people with mental illness to a wide range of risk factors for their mental and physical health and wellbeing. These include violence and abuse, harmful alcohol and other drug use, poor nutrition and sleep, severe social isolation, lack of amenities for self-care, disease, and even exposure to the elements. All of these are major stressors that are highly likely to compromise mental and physical wellbeing and pose additional challenges for providing continuing care (see Shern et al 2000).

In contrast, safe, secure and stable accommodation is protective of health, including mental health (Thomson, Pettigrew & Morrison 2001). Appropriate accommodation not only removes the risks associated with unsuitable accommodation or homelessness, but also provides a base from which a person can focus on their recovery. It enables people to develop links with organisations and services within their community, and allows them to channel their energy into other factors supportive of their ongoing wellbeing (such as education or employment).

I've lived in some bad places, put up with all kinds of bad stuff. I couldn't go back to that now. Where I am now makes the difference. I can feel ok, I can do things, I'm doing ok now.
—Consumer

Appropriate housing poses unique challenges for different demographic groups. For example, there are gender differences in housing needs—women are more likely to live independently, whereas men seek out housing arrangements that are more dependent (Cook 1998).

Affordable housing in safe neighbourhoods is essential for single women and women with children (Blanch, Nicholson & Purcell 1998). Families need comprehensive accommodation services that “build resilience to help compensate for the stresses of poverty and disadvantage” (NSW Health 2002b p12). Teenagers and young adults need accommodation options that match their life-stage, and that do not increase their risk in other areas (such as sexual abuse and harmful alcohol and other drug use). For older people, age-related health problems, such as mobility and self-care problems, make housing needs especially complex.

Accommodation is also a major issue for families and carers. Living with someone with recurrent mental illness can be a significant stressor for families, and there are times when they may not be able to manage. Respite and a wider range of community care options are urgently needed to support families and carers (Groom et al 2003).

It's ridiculous. It's either here or hospital. There's no in-between. It's either all on or all off.
—Carer

Another worry for carers is that they will become ill or too old to continue to care for their family member. This is a very real fear common for all people caring for someone with a disability.

I worry what will happen when I'm gone. It's up to me to keep her safe and protected. It's my reason for being here, but I'm not going to be here forever. What will happen then? —Carer

Employment

Another environmental factor that can affect relapse is employment. Employment is a complex issue for people with mental illness: it can be a stressor that precipitates relapse or a source of meaningful activity and an essential source of economic wellbeing. Employment is fundamental to how most people define themselves in western societies, and appropriate and supportive employment has many protective elements: it “increases people’s satisfaction and self-esteem and breaks the cycle of poverty and dependence. Work also provides an opportunity to socialise and communicate.” (NSW Health 2002a p13).

People with mental illness report that work gives them a sense of pride, self-esteem, financial freedom to do things that others can do, the capacity to financially support others, the opportunity to build things, the chance to be more independent from others, a sense of being a part of the whole, and a sense of integration rather than isolation (Clarke 2004).

Work is how we measure ourself in society. The first thing we do when we meet each other at parties or out or socially - it's a matter of 'Well what do you do?' If I don't do anything then I am more likely to be viewed as a 'mental illness' - as a schizophrenic or bipolar - and I'm more like to measure myself that way, if I don't have some form of meaningful activity.
—Psychosocial rehabilitation provider

Work can also be a major source of stress, and flexible and appropriate employment options are essential to preventing relapse. There is considerable untapped capacity for employers and organisations to contribute to preventing relapse for people with mental illness by providing more flexible work arrangements and more supportive and less stressful workplaces (Berry & Butterworth 2004).

It's important to have people helping you understand what going back to work means - you've changed - it's ok to not work - I don't work fulltime anymore. —Consumer

This job helps me. It allows me to get involved. If I went back to my other job I wouldn't last any time. —Consumer

The 9-5 grind is a meat grinder. We learn that we can't do that. —Consumer

I have changed my career - I had the most spectacular blow up at work. I find getting back on the horse is the worst thing. —Consumer

Rehabilitation services for people with mental illness often focus on vocational rehabilitation and there is a growing body of knowledge in this area (see Rogers 2003, Waghorn & Lloyd 2005). A recent review of 18 randomised controlled trials concluded that supportive employment was the most effective approach (Crowther, Bond, Huxley & Marshal 2001). Notably, pre-vocational training that aims to assist people to acquire the skills and work habits that will make them able to be employed was found to be no more effective in helping people obtain competitive employment than standard community and hospital care. In contrast, supported employment models, where the vocational services are highly integrated with psychiatric support through multidisciplinary teams, have highly successful employment outcomes (Cook et al 2005).

Vocational and pre-vocational programs need to be flexible and non-threatening - by that I mean they don't threaten somebody's disability support pension, because that's one of the biggest barriers to vocational activity. These are the events that have a huge impact - safe, affordable secure accommodation, meaningful activity - these are the core elements of

wellness – for everybody. We just focus on symptom amelioration. The too hard basket is the whole of life picture. —Psychosocial rehabilitation service provider

Economic wellbeing

Closely related to employment is financial security, which is protective of health for all people. In contrast, financial problems are a significant source of stress. Many people with mental illness have reduced financial capacity, often through inability to sustain full-time paid employment, and must subsist on disability support pensions and illness benefits. Financial planning and budgeting can also be compromised by some of the symptoms of mental illness, such as disorganisation. Furthermore, behavioural factors, such as smoking cigarettes, can cause financial difficulties for people on limited incomes. Families and carers report that budgeting and finance are major concerns, and that it is difficult to obtain effective support in this area.

My son is on a pension, which is deposited fortnightly by Centrelink into his bank. He then takes a little bit of money out each day, until it is all gone. So, the bank charges him for every one of these transactions. Last month the bank transaction fees were \$26 out of his pension. How is that fair? —Carer

Financial hardship has flow-on effects to many other risk and protective factors as it can limit opportunities and increase risks, such as inappropriate housing. Help with financial organisation and budgeting can be essential to enabling a more stable lifestyle that is conducive to staying well and preventing relapse.

Education, art and other forms of meaningful activity

Having a reason to get out of bed and a meaningful structure to the day are essential to wellbeing for all people. Employment is an exceptional source of meaningful activity because it also confers other benefits, notably economic benefits. However, there is a wide range of sources of meaningful activity other than employment, and these are uniquely individual and vary according to developmental and cultural needs. Sources of meaningful activity can be severely disrupted by mental illness, however, because symptoms and lack of opportunities can interfere with participation in preferred activities.

Education is an essential activity for younger people who have experienced mental illness. Ways to minimise education disruptions and support for continued engagement in education are especially essential to ensure future options for young people.

Meaningful activity can come from social, recreational, hobby, volunteer and work-related sources (Smith 2000). Art and music are provided as sources of meaningful activity in many structured programs. However, it must be recognised that determining meaningful activity is an individual process. For some people, unstructured activities such as gardening or caring for a pet are important sources of meaningful activity. Providing rehabilitation programs that restrict opportunities to a few mandated activities does not provide the type of engagement in meaningful activity that is supportive of recovery and helps to prevent relapse.

You have to have real things to do. Things that make it possible to get up in the morning. And you have to find those things for yourself. Going to a basket weaving class every day is not what I need to stay well. —Consumer

Importantly, self-help groups can be a source of meaningful activity for some consumers, giving them a strong sense of purpose. For example, the Mental Illness Education program trains consumers and carers to go into schools and other organisations to tell their personal

stories and thereby help to reduce the stigma of mental illness and increase the public's mental health literacy. Participation in the program can become a major life focus for many consumers and carers as it provides meaningful activity, a sense of achievement, a sense of identity and social contact.

The MIE program is really important. I've got purpose, to build up my confidence and self-esteem, like mastering skills, remembering what to say next, doing all the admin. Doing this really helps to keep me to stay well. —Consumer

Harmful alcohol and other drug use

Harmful alcohol and other drug use is a major risk factor for relapse for people with mental illness (Ries & Comtois 1997). The co-occurrence of mental illness and harmful alcohol and other drug use is common, and can have significant social, emotional, physical and cognitive consequences that impact on treatment and relapse (see Teeson & Proudfoot 2003). People with mental illness are more vulnerable to harmful alcohol and other drug use for many reasons, which include attempts to self-medicate symptoms as well as lifestyle and social changes associated with mental illness (Bellack & DiClemente 1999).

Estimates of the proportion of people with a co-occurring mental illness and substance use disorder range from 50% to 90% (Baigent, Holme & Hafner, 1995). Australian data show that substance use problems are evident for 28% of men and 14% of women with anxiety disorders, and for 34% of men and 16% of women with affective disorders (Teeson, 2000). For people with psychotic disorders, 60% use tobacco, 22% are daily alcohol users, 23% use alcohol weekly, 9% have used psycho-stimulants, and 5% have used opiates in the past year (Degenhardt & Hall, 2000).

While the role of alcohol and other drugs in *causing* mental illness is unclear, their role in exacerbating current illness and precipitating relapse is evident. For example, while the effect of cannabis on the onset of psychosis has not been established, once mental illness has occurred, the use of cannabis is a major risk factor for relapse (Degenhardt, Hall & Lynskey 2003). Harmful alcohol use also has a marked impact on relapse.

My biggest problem for relapse is alcohol. If I don't drink, I'm fine. If I start drinking it all goes downhill fast. But even though I realise this, sometimes I still want to have a few drinks, but then it goes down a downward spiral. —Consumer

Harmful alcohol and other drug use impacts in many ways to increase the risk of relapse. It can mask or exacerbate symptoms and make diagnosis unreliable; it can also reduce compliance with treatment and reduce the effectiveness of prescribed medications (Bellack & DiClemente 1999). Harmful alcohol and other drug use often results in negative emotional states such as guilt and remorse, self-blame and loss of self-worth, as well as loss of control, negative lifestyle changes, and detrimental effects on sleep and physical health. Serious health and legal consequences can arise from some forms of substance use, including incarceration, and these are additional stressors that further increase the risk of relapse and impede recovery.

Effective interventions to prevent harmful alcohol and other drug use are imperative components of relapse prevention. Yet, co-occurring disorders have serious implications for mental health services. People with substance use problems can be excluded from standard treatments that have been developed for narrowly defined sets of symptoms, and staff rarely have the skills to recognise and treat more complex presentations (Teeson & Proudfoot 2003). The Australian Psychological Society argues that harmful alcohol and drug use is so common for people with mental health problems that all psychologists and other

professionals working in mental health should be skilled in assessing and dealing with substance use problems (through treatment or referral), and all professionals working in alcohol and other drug treatment services should be skilled in assessing and dealing with mental health problems (Rickwood et al. 2003, 2005).

The greatest challenge we face in mental health is alcohol and drug use. It is the norm, yet no services know how to effectively deal with it. —Clinician

Special mention of the impact of tobacco smoking is warranted because the rate of tobacco smoking for people with mental illness is two to three times the rate for the general population (McNeill 2001). This high rate of smoking has a number of negative health outcomes for people with mental illness and contributes to lowered life expectancy (Coghlan et al 2001a). The high cost of tobacco smoking adds to poverty and financial disadvantage (Ashton et al 1999), with heavy smokers at times needing to spend their entire disability support pension on their smoking habit. Furthermore, smoking can contribute to social exclusion because social venues are increasingly smoke-free. Importantly, however, interventions to reduce smoking behaviour among people with mental illness have begun to be developed and favourably evaluated (see Ashton & Weston 2002).

Physical health

Physical health status affects the ongoing mental health and wellbeing of people with mental illness (Kisley & Goldberg 1997). Furthermore, mental illness has been shown to profoundly affect physical health status. A large study from Western Australia (Coghlan et al 2001b), revealed that death rates from all main causes were higher for people with mental illness and the overall death rate was 2.5 times higher than the general population of Western Australia.

People who have experienced mental illness can have compromised physical health for a number of reasons. They are less likely to receive appropriate health care compared with those without mental illness, and it is an indictment of our mental health care system that people who have been involved with mental health services have often had their physical health needs overlooked. Furthermore, behavioural factors such as smoking, harmful alcohol and other drug use, obesity, poor diet, inadequate living situations (such as homelessness), and poor self-care as a consequence of illness symptoms, can make people with mental illness vulnerable to physical health problems.

In contrast, being in good physical health, sleeping well, eating well, exercising, and avoiding harmful alcohol and other drug use are important for maintaining wellbeing. In the consultations, many consumers mentioned the importance of “getting the basics right” to prevent relapse, by which they meant the fundamental sources of wellbeing in terms of sleep, nutrition, physical fitness, and access to physical health care. These are things that are fundamental to the wellbeing of all people, but assume greater significance for people who are more vulnerable to mental health problems because they have previously experienced an episode of mental illness. Notably, good sleep patterns are very important for wellbeing, and disruption to sleep is often one of the first signs of relapse (Birchwood et al 2000).

I know I've got to go back and get the basics right. I've got to sort out sleeping first, and make sure I eat, get back into some walking. It's so easy to let things slip, but it's so important for me. I have to stay on top of these things. —Consumer

A growing body of research shows that exercise is protective of mental health, particularly in relation to alleviating depression (Hutchinson, Skrinar & Cross 1999; Tkachuk & Martin 1999). Many of the consumers in the consultations mentioned the unique benefit of exercise for staying well and of the need to increase their level of exercise when they noticed early

warning signs. Exercise can benefit in at least two ways: by increasing the production of neurotransmitters that improve mood and as a form of distraction.

I need to make sure that I have my walk every day: if I stop doing that I start to become unwell. —Consumer

The role of nutrition in relapse is not well understood, but good nutrition is likely to be protective. For example, there is strong evidence that improving nutrition in socially disadvantaged children has positive physical and mental health consequences (WHO 1999). Moreover, poor nutrition is a risk factor for many physical health problems, which in turn, can exacerbate mental health problems.

Ensuring access to physical health care is also imperative. Many of the more disadvantaged people with mental illness, particularly those who are homeless, do not have access to general health care and routine health checkups, and this can be detrimental to their physical and mental wellbeing. Dental care is also often lacking and this can be a factor that contributes to social exclusion.

The impact of physical health on mental health requires considerably greater recognition than it currently receives. Of special significance is obstetric care for women, as pregnancy can increase vulnerability to a range of risk factors, and the postpartum period has clearly been identified as a time of increased risk for relapse of schizophrenia and bipolar illness (Altshuler et al 1996, Leibenluft 1996). People who have previously experienced mental illness need their potentially increased vulnerability to physical health problems and procedures identified and sensitively responded to so that physical health issues do not precipitate mental health problems, and vice versa.

I have to have an operation on my knee soon and I know that the anaesthetic will make me unwell again. The last time I had an anaesthetic I was in the psych ward for months. I know that will happen again, but no-one will listen. No-one is interested on the effects for my mental self. I guess their take is that if I get psychotic after the operation then that's not their problem and the psych services will deal with it if it happens. They don't care, it's not their problem, but I know what's going to happen and I don't want the operation and to go through it all and so much. I just want someone to realise what is going to happen and to stop it now. —Consumer

Social relationships

Social relationships are protective of mental health for all people. People with mental illness are, however, less likely to have such protective relationships, and when their social links are poor their recovery is compromised and they are at heightened risk of relapse (Pevalin & Goldberg 2003). People with mental illness can become isolated at all the levels by which social connection is derived—intimate relationships, family, friends, workplace and leisure acquaintances, and community contacts. People with histories of hospitalisation are at particularly high risk of social isolation, and have poorer social relationships than those who have been treated through primary care (Kent et al 1995).

People have different social needs across the course of their lifespan. For example, it is especially important for younger people to be able to mix with their peers as the establishment of good peer relationships is fundamental to wellbeing in adolescence. Yet, peer relationships can also be a risk factor if peers are involved in anti-social behaviours or harmful alcohol and other drug use.

You need to re-establish social contacts that aren't the same as they were in the past, for instance you couldn't have bad habits or drug taking if you're used to that kind of culture. That kind of culture isn't going to help your mental health so you will need to break off those - the marijuana and whatever else is circling around – and build up relationships with people that don't have that and that's where peer support can be effective, but it is a matter of recognizing that this person is no longer going to be helping my wellbeing and I'm going to have to say, "Well, I'm not going to have anything to do with that", or change some relationships so that you're not dependent on that. —Consumer

The lack of an intimate relationship is major risk factor in adulthood, and the experience of separation or divorce adversely affects wellbeing (Richards et al 1997). Adults whose marriages have not survived, and those who have lost their employment, lack important sources of social support. For older adults, loss through death becomes a significant risk factor for mental health.

Women tend to be involved in more relationships than men throughout their lives, generally having multiple relationships of different types, and consequently, their need for social skills is greater (Mowbray, Nicholson & Bellamy 2003). However, it is important to note that while good social relationships are protective of mental health, family (and other) relationships can at times be conflicted or even dangerous. For women, in particular, the potential for violence in partner relationships is a risk factor that must be recognised.

Rebuilding social relationships is essential to maintaining wellness and preventing relapse. Peer support and self-help groups are invaluable in this regard, because they provide a safe and non-judgemental place for social interaction (Nikkel 1994). After an episode of mental illness, some people need to rebuild their basic social skills as their symptoms can interfere with these. Self-help groups can provide a safe environment in which to do this. Support groups help in many diverse ways, but importantly they provide access to people with shared experiences, a sense of belonging, role models and inspiration (see Pepper 2003). Throughout the consultations the importance of social relationships, derived from self-help groups, as well as from family and other sources, was repeatedly emphasised as essential for relapse prevention.

I don't know what I'd do without the support of the others in the group. When I get to the point where I feel like I can't cope, they come to the rescue in so many ways. Sometimes it's just a phone call, sometimes they bring over something to eat. It makes all the difference. It stops me thinking that I'm the only one with this and I find new energy to keep going on. —Carer

Violence

People with mental illness are more likely to have histories of physical and sexual abuse, and this is especially true for women. Studies have shown that 20-50% of women in psychiatric settings have histories of past physical or sexual assault (eg, Rosenberg, Drake & Mueser 1996). Violence can be from partners (Mowbray et al 2003), family members, police and relative strangers. Violence, threat of violence and fear of violence are serious stressors with a major impact on wellbeing. Determining and eliminating exposure to violence are essential as the trauma of a violent attack is a potential trigger of relapse. Of special significance, unsafe housing arrangements may expose people to violence, reinforcing the importance of safe and appropriate accommodation for people with mental illness.

Resilience

The value of positive mental health, hope and fighting spirit in promoting wellness and preventing relapse is well documented (Vaillant 2000). In contrast, feelings of hopelessness, poor self-esteem and lack of meaning in life are risk factors for relapse (Birchwood, McGorry & Jackson 1997). People gain positive mental health from feeling hopeful, having confidence, and having a sense of control (Birchwood et al 1993).

This is how far I've come. This is what I do to maintain myself. If I get sick, then I get sick. But I know how to maintain myself now. I know I'm strong. Let it be, let it happen.
—Consumer

Resilience derives from many diverse sources, and these can vary according to individual temperaments, circumstances, life-stage and cultural background. Resilience can come from finding meaning in life and engaging in meaningful activity, having supportive social relationships, and having a sense of spiritual wellbeing (Myers 2000). It is increasingly being recognised that spiritual wellbeing can have a vital role in recovery for some people (Wilding 2003). Regardless of their source, the impact of factors that increase resilience should not be underestimated for preventing relapse.

Repeatedly, throughout the consultations, consumers and their families and carers mentioned the importance of humour for their wellbeing. Humour was a benefit that was often gained from belonging to self-help and peer support groups and other supportive relationships.

Here we don't have to be PC [politically correct]. We can say the most terrible things and just crack ourselves up. —Consumer

If you didn't have friends to laugh with, you couldn't get through it. —Consumer

Wider range of treatment options

A wider range of treatment options needs to be available for people with mental illness. People in the public mental health care system, in particular, often have only a limited range of therapeutic options and do not have access to psychological therapies and psychosocial approaches.

For example, despite its established success, few people with mental illness have access to cognitive behavioural therapeutic (CBT) approaches. Many people in the consultations revealed that they found learning such skills (often through self-help approaches) was critical in staying well. CBT approaches help to prevent relapse by enabling people to disengage from habitual, dysfunctional ways of thinking (Teasdale et al 2001). They are most useful in treating the depression and anxiety that are frequently comorbid with psychotic illness (Jablensky et al 1999).

It wasn't until I did more than just take medication that I found ways to stay well. The medication was really important to start with. I needed the medication to get me stable to be able to start to try out and learn other techniques. But it has been learning some cognitive techniques and learning to meditate and making sure that I practice these things every day that have really made the difference for me for staying well. —Consumer

Mindfulness-based cognitive therapy integrates the elements of CBT with meditation-based stress reduction and is geared to preventing relapse for people who have recovered from episodes of major depression by enabling them to become more aware of their negative thoughts and feelings and to change the way that they relate to them (Segal, Williams &

Teasdale 2002).

Access and early intervention

Effective relapse prevention requires early intervention through access to appropriate supports and services. This means, firstly, the development of effective personal coping skills and illness self-management strategies in response to early warning signs. Secondly, it requires a service system that responds to early warning signs, not just acute crises. Furthermore, relapse prevention needs to commence during the earliest stages of treatment; as part of the ongoing process of continuing care that needs to be put in place at the outset. Relapse prevention requires a different service response. It requires truly listening to consumers and their families and carers and taking their concerns seriously. If intervention is early enough, it should not require an acute service response. The aim is to prevent crises in the form of rehospitalisation and police intervention. This is not, however, the experience of many people seriously affected by mental illness.

It's not the consumers who you need to ask about whether they are having a relapse; it's about whether the services can respond at that time and whether they take what consumers say about the state of their health when they go to be admitted to a service. A friend of mine went to an acute ward and knocked on the door and said 'Can you please admit me' and they said 'No go away' and there was a bit of a scene and she threw an ashtray through a window, so they called the police and the police took her to the station and she was interviewed and then the CAT team came down and assessed her and she was admitted to hospital. This is not an uncommon story. —Consumer

Essential to relapse prevention planning is the ability of the mental health care system to respond quickly and effectively and over time. Currently, there tend to be two parallel service systems within most jurisdictions in Australia: an acute, crisis-focused health system and a completely separate set of psychosocial rehabilitation and community support services. There needs to be a “middle level of service response” that fits somewhere between acute clinical services and non-acute support services, as well as better ways to “join up” or integrate the clinical and non-clinical service approaches.

There is an urgent need for respite, time-out, and safe places that consumers can go to when they are starting to feel unwell, but do not need the full response of the acute system. Increased availability of step-up and step-down facilities is essential. Too often, people are discharged from a hospital admission to no service response whatsoever. Due to the demands on hospital beds, consumers may be discharged while still experiencing their current episode. Consumers need better supported accommodation options for re-entry to the community after a hospitalisation. Similarly, there is a need for more supported community options for people who are beginning to become unwell again, but do not require hospitalisation.

A background paper developed by the Northern Territory Government (2003) identifies the following as some of the different types of community support options required to provide effective continuing care in the community: assertive community treatment; mobile intensive treatment teams; mobile crisis teams; hospital at home; group crisis residences; family sponsored homes; crisis apartments; and day hospitals.

Relapse unfolds, it doesn't usually happen overnight, usually over a period of days to weeks, but people still need a timely access to some point of the service that understands and is a collaborator in the process that is being described and has the knowledge and skills to know what those general and specific interventions can be. There's a permeability about re-entry that is really critical. So often family members will say 'Oh, I phoned up the mental health

service', and the family member wasn't satisfied because the mental health service said 'get the person to come in', and has not appreciated the issues that the family has picked up which is something is changing here that needs some supported direction beyond what the family member can provide themselves. —Clinician

The role of psychiatric disability support services

Special mention needs to be made of psychiatric disability support and rehabilitation services. This sector is well-developed in some jurisdictions, for example Victoria and some area health services in NSW. In these areas, this sector is able to provide significant support for people in the community that helps to prevent relapse and supports recovery. Other jurisdictions have very little in the way of psychiatric disability support and these types of services are few and fragmented; in such areas access to this essential component of relapse prevention is severely restricted and people are more likely to be unsupported when in the community and experience the revolving door of readmission to hospital.

Here it's either in hospital or out – there is nothing else in between. —Consumer

Psychiatric disability support and “rehabilitation refers to the services and technologies that are made available to people with disabilities so that they might learn to adapt to their world” (Curtis 2001). Many of the alternatives covered in the previous section are the domain of psychiatric disability support and rehabilitation. For example, many accommodation services, employment, education and social programs are provided through the psychiatric disability support and rehabilitation service sector, and often by non-government organisations.

In Victoria, Psychiatric Disability Rehabilitation and Support Services are part of Primary Care Partnerships. They link with community health, local government and a range of other specialist providers to ensure continuity of care for service users (Clarke 2003). Key workers and program managers provide community links with drug and alcohol services, community health and employment, education, housing and homeless services. This type of approach is needed to ensure that the array of service alternatives that is needed to support someone who has been seriously affected by mental illness in the community are in place and working effectively together.

A vital aspect of the psychiatric disability support sector is that key workers work with people with mental illness at all stages of their illness: through periods of illness as well as during the process of developing wellbeing and recovery (Clarke 2003). As such, they are ideally positioned to contribute to continuity of care for people across the course of their illness and to have an important role in preventing relapse.

This sector is recognised in some jurisdictions as a functional component of comprehensive support services that can respond to the complex and diverse needs of people with a psychiatric disability. However, for most jurisdictions the capacity of this sector needs to be substantially increased. Even areas where such services are available, there are often long waiting lists which makes access problematic. Better ways to more fully integrate this sector with clinical and acute services also need to be developed to ensure continuity of care across services and sectors.

The role of the acute and specialist mental health system

A fundamental reorientation of approach to treatment is required in acute clinical settings. This can be the first opportunity to commence relapse prevention, yet one that often goes unrealised. All too frequently the acute response focuses on ameliorating current symptoms and early discharge, with no follow-up into the community. It was noted during the

consultations that the emphasis in acute settings was on admission, and too little time was devoted to discharge planning. When discharge plans were part of routine practice, they were often delayed by several months after the discharge.

It was noted earlier that attitudes toward the recovery of people with mental illness were especially negative in acute mental health settings. This was a strong finding of the evaluation of the *Second Mental Health Plan* and the *Out of hospital, Out of mind* report of the MHCA (Groom et al 2003). A great deal of emphasis needs to be put on changing attitudes of the workforce in acute settings, and some suggested strategies are rotating staff around acute and community settings, and ensuring the inclusion of consumer consultants in acute settings, as they provide positive role models for consumers and staff alike.

The importance of maintenance medication in preventing relapse was noted earlier, yet people in the consultations, particularly general practitioners, reported experiences of people being discharged from hospital with only three days' medication and no GP appointment. Given that it could take three or more weeks to obtain an appointment with the GP, this was a period of significant risk. It was argued that a major impact on relapse could be achieved by ensuring that an appointment was made prior to discharge to see the GP in the first few days after discharge, and that other necessary supports were put in place to ensure that the person was able to attend this appointment.

An ongoing role for the acute and specialist mental health systems in continuing care is critical for people with mental illness who require a high level of support in the community. Continuing care for many people seriously affected by mental illness is provided by general practice (Jablensky et al 2000), but GPs need to be supported by specialist mental health services in this regard.

I'm not going to agree to take on a mental health client if I know that I'm going to have to spend four hours on the phone getting a response from acute care when I need it. —GP

The CLIPP Project (Consultation Liaison in Primary Care Psychiatry) is a large GP shared mental health care initiative developed and evaluated in Victoria over the last eight years (Meadows 2003). The project involves, firstly, the development of psychiatric liaison attachments to general practices involving collaboration and consultation from sector psychiatrists. The second aspect involves the transfer of a selected group of psychiatric services clients into shared care, with GPs using the channels of communication and collaboration developed in the liaison attachments.

Importantly, the CLIPP model uses the concept of a 'relapse signature', involving recognition of early warning signs of relapse, to simplify clinical monitoring. This model of service delivery provides a supportive mechanism for mental health service clients to be reintegrated into general health care within a seamless service delivery structure. The program processes have been comprehensively reported (see www.health.vic.gov.au/mentalhealth/publications/clipp/) and provide an effective model of collaboration between general practice and psychiatry to support people with a high level of need in the community and ensure that relapse prevention takes place.

The role of case management

Many people with a history of mental illness have a complex array of needs that must be considered. Case management is one of the major types of community aftercare that is used to provide ongoing management of chronic or recurring illness. Active case management is especially important for people who have been repeatedly hospitalised for mental illness. Too often these people experience a 'revolving door', a recurring pattern of discharge and re-

admission to hospital because they are not adequately supported in the community. The more chronic and disabling the experience of mental illness, the more a case management approach to continuing care is required for people with mental illness, and their families and carers.

There are many different models of case management (Chamberlin & Rapp 1991), but the major approaches are assertive community treatment teams and case workers with individual case loads. In assertive community treatment, services are usually provided by a community team on an ongoing and intensive basis (Bond et al 1990). The effectiveness of the assertive community treatment approach in reducing relapse in terms of hospitalisation has generally been established (eg, Bond et al 1990, Chamberlin & Rapp 1991, Solomon 1992).

Most case management programs in mental health, however, typically involve a single case manager working with a consumer. The role of the case manager is to undertake assessment, monitoring, planning, advocacy and linking of the consumer with rehabilitation and support services (Intagliata, 1982). Its function is clearly illness management and relapse prevention.

Evaluations of the effectiveness of individual case management have been somewhat contradictory (eg, Borland, McRae & Lycan 1989; Goering et al 1988; Nelson & Sadeler 1995). Importantly, where significant reductions in hospitalisation have been found the staff to consumer ratio has been 1:9-20. Studies that have not reported reductions in hospitalisation have reported higher caseloads, and it has been argued that in programs where the ratio is 1:20-40, case managers do not have sufficient time to provide the individualised support that is required to help people adapt to community living (Harris & Bergman 1988). There is also wide variation in the philosophy and practice of case management, and the relationship between the case manager and consumer is seen as fundamental to success. The principles of effective case management have been extensively studied, and are presented in Table 3 as they apply for mental health services.

Table 3. Principles of effective case management

1. Case managers should deliver as much of the “help” or service as possible, rather than making referrals to multiple formal services.
 2. Natural community resources are the primary partners (eg, landlords, employers, teachers, art clubs, etc).
 3. Work is in the community.
 4. Both individual and team case management works.
 5. Case managers have primary responsibility for a person's services.
 6. Case managers can be para-professionals. Supervisors should be experienced and fully credentialed.
 7. Caseload size should be small enough to allow for a relative high frequency of contact (no more than 20:1).
 8. Case management service should be time-unlimited, if necessary.
 9. People need access to familiar persons 24 hours a day, 7 days a week.
 10. Case managers should foster choice.
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Source: Rapp & Goscha (2004)

There is a great deal of unmet need in Australia for case management (Groom et al 2003). The lack of a case manager was mentioned repeatedly in the consultations as a major barrier to recovery. This is even more pronounced in regional, rural and remote areas, and there were many stories of people being discharged from hospital with no discharge planning and no aftercare. Even in regions where case management models were available, often the case manager had too large a caseload to provide effective relapse prevention.

I currently have 40 people on my list. My understanding is that best practice is about 12 clients. With 40 I can barely get around to seeing them every 2 weeks. I certainly don't have the time to put in place all the psychosocial supports that they need, even if they were available. —Case manager

The majority of people who have been seriously affected by mental illness do not have a case manager. Consequently, the functions of the case manager fall to other people—the consumer him/herself, family and carers, and general practice. Notably, many carers find their ‘case management’ role a significant burden and feel that they are completely unsupported in this role: they do not have access to resources, supports, services or even appropriate information about their family member. Carers feel that they are forced to assume a case management role, without the authority, skills or resources to do so. While case management is not a panacea, there is an urgent need for more case management within the mental health system, to ensure that people seriously affected by mental illness are connected with the clinical and psychosocial supports that they need to remain in the community.

I am the only case manager my son has and they don't even tell me when he is discharged from hospital. All of a sudden he is back at home and I have to manage as best I can, which is not good enough. —Carer

The role of primary care, including general practice

The role of primary care, particularly general practice, in mental health care is now well recognised. Most mental health care is delivered through general practice and other primary care services, with GPs providing mental health care to 75% of those seeking such help (AIHW 2002). Many people who have been seriously affected by mental illness manage their illness with only the support of a GP; for other people the GP will form an essential part of a wider team of mental health service providers. GPs can provide ongoing mental health care in several different ways: through direct care, shared care, and referral to specialist services. An established and ongoing relationship with a health practitioner is a vital tool for continuing care, and the place of primary care and general practice in relapse prevention needs to be more fully explored and supported.

There seems to be growing evidence of GP clinics being engaged with by the mental health team and growing levels of secondary consultation and improving understanding and knowledge. It's probably not relapse prevention – it's more about information and understanding and being able to identify premorbid or prodromal conditions. But, primary care are fearful of being equipped with the knowledge of being able to identify prodromal syndromes. If you identify, what's your duty of care, that's what they're fearful of, where are the services to provide the follow-up response. —Clinician

General practice has a role in the continuing care of all people who have experienced mental ill health, irrespective of the severity and chronicity of the mental illness. For those people who have experienced an acute episode that has required hospitalisation, effective discharge planning involves engaging the GP in the person's ongoing mental health care. The GP, case manager and psychiatrist comprise a health support team that can provide a high level of support to people within the community.

The GP's role is also critical for the many people who are discharged from acute settings into the community without a case manager and only infrequent, if any, contact with a psychiatrist. A case manager may not be assigned, either because this function is not deemed to be necessary, or because there is no capacity to provide one. In these situations, the GP

(with the family and carers) may need to provide a case management-type function by ensuring that the necessary support services are put in place.

There are also many people who have been seriously affected by mental illness who have never been hospitalised and have managed their condition within the community, often without the support of specialist mental health services. For such people, the GP may be the only point of contact for health care and is, therefore, an essential ongoing source of health support, information, and referral.

To effectively engage general practice in relapse prevention, there are many supports that need to be in place. Firstly, GPs need to be available and easily accessible to people who have experienced mental illness, and this is not always the case. GP services are insufficient in many areas, particularly rural and remote areas, but even some urban areas are under-serviced. Even when GP services are available, they are not accessible in a timely manner because of the high level of demand on their services.

I have to book in 3 weeks ahead to get to see my doctor. By then it's too late. Sometimes I just book in ahead anyway, so there's an appointment if I need it. —Consumer

My son has moved to a new area and he can't get onto the doctor's books. They are all full and won't take any more patients onto their books. I keep trying and keep phoning and asking but I've got nowhere. Our only option is the emergency room. —Carer

GPs also need to be skilled in providing mental health care, and they vary in their ability, training and interest to do so. Two major initiatives have recognised the role of general practice in mental health care: the *National Primary Mental Health Care Initiative* which came into effect in June 1999, and the *Better Outcomes in Mental Health Care Initiative* in 2001. These initiatives aim to promote and encourage quality primary mental health care through education and training and other capacity building strategies and responding to the barriers to providing mental health care that are commonly expressed by GPs. It is essential that these initiatives continue to support GPs in providing mental health care, and that special emphasis is placed on the training and support needs of GPs providing services in rural and remote communities, Aboriginal and Torres Strait Islander communities, multicultural communities, and to younger and older Australians with mental health care needs.

A major strength of general practice in relation to relapse prevention is the importance of an established and ongoing relationship between health care provider and consumer. If such a relationship is in place, relapse prevention can be implemented much more effectively. Where such a relationship is not in place, it is an important first step to attempt to develop it. The ability to discuss the factors that affect relapse and put a relapse prevention plan in place is optimised when a consumer has a GP who knows them and their circumstances and with whom they have developed a trusting relationship. This can be especially important for young people who do not like to talk about their personal issues to people with whom they have not established a relationship (Rickwood, Deane, Wilson & Ciarrochi, in press).

Relationships with patients can be, however, quite complicated for family GPs who also provide health care to family members and carers. At times, the family or carer's need for information or intervention may conflict with the health needs or requests of the consumer. In such situations, active relapse prevention plans are a vital tool to enable the GP to provide support to all parties without crossing confidentiality boundaries. For example, if it has been previously agreed by the consumer that the role of the family member in terms of early warning signs is to inform the GP who is then expected to provide some form of early intervention, the conflicts at such a time may be minimised. Monitoring early warning signs

and early intervention responses can raise complex issues regarding privacy and communication. Effective and explicit communication strategies between the consumer, family and carers, and the GP, as well as careful and respectful planning are imperative to avoid conflict.

Another strength of primary care for relapse prevention is a focus on providing holistic care, addressing both physical and mental health. People with mental illness often have compromised physical health and it is essential that their physical health needs are recognised and met. Physical and mental health are inseparable and affect each other in complex ways; good physical health is conducive to good mental health, and vice versa. The holistic approach to health care provided by services provided within a primary health care network, with ongoing monitoring of physical as well as mental wellbeing, is essential to prevent relapse.

Particular emphasis is placed on the role of medication in relapse prevention and GPs have an important function in prescribing and monitoring psychiatric medication and encouraging people to appropriately maintain their treatment programs. To do this, GPs need training and support, particularly around dosages and the side effects of psychiatric medications and ways to minimise these. The ability to consult with prescribing psychiatrists and to have easily accessible information about medications is essential. GPs also need skills to encourage effective use of medicines, and techniques such as behavioural tailoring and motivational interviewing may be relevant (Miller & Rollnick 1991).

In relation to medication, an important part of the recovery process for many consumers is minimising their medication or coming off it completely. GPs have a highly relevant role in this process, by seeing the person frequently throughout this process and monitoring progress. After the psychiatric medication has ceased, it is critical for the GP to continue to work with the person to monitor wellbeing to ensure a timely response if the need for medication re-emerges. Coming off medication is a fearful time for many family members and carers, and a period of heightened risk for relapse. The support of the GP to the family and carer, as well as the consumer, is essential to allay fears by ensuring that appropriate supports and early interventions are in place.

I came off my meds a couple of months ago. My doc helped me to come off them slowly and now I'm off them completely. Yeah, my family doctor, not the psychiatrist. She'll keep an eye on things, so if I need to have something to help keep me stable, then I'll have to have something. But I'm going really well and if I keep up the hard work I hope I'll be able to stay off the medications. —Consumer

Psychological, as well as pharmacological, treatments are recognised as being important for relapse prevention. Effective cognitive behavioural skills are particularly emphasised as an important component of relapse prevention for many people, and some GPs have developed the skills and interest to provide CBT themselves. However, all GPs need to understand the usefulness of cognitive behavioural skills for their mental health patients and encourage the learning of these skills by referring to allied health services that can provide CBT. This requires partnerships with allied health professionals to ensure that such referral pathways are in place.

The holistic approach of general practice also enables the GP to incorporate a broader view of the psychosocial and environmental impacts that may affect relapse. An understanding of a patient's personal and family situation is essential to ensuring that supports are in place to prevent relapse and sustain wellness. This may include referral and liaison with many other community agencies and it is important that the GP is effectively integrated within their

community through a primary health care network to be aware of and able to ensure access to psychosocial and psychiatric rehabilitation support.

Of special relevance is the need for GPs to be able to meet the needs of consumers across the lifespan. This requires an understanding of the different impacts on mental health across the lifespan as well as the diverse service sectors that need to be engaged depending on the life-stage of the consumer. For example, for young people who are at risk of further episodes of mental illness, working effectively with the school and family is essential. *MindMatters Plus GP Initiative* aims to bring schools and general practice together to develop better referral pathways and networks of care for young people with high support needs for mental health and wellbeing (see www.adgp.com.au).

Older adults who have experienced mental illness also have unique needs where GPs require special skills and understanding. Older adults often have complex physical health needs, as well as their mental health needs, and partnerships with the aged care sector and home and community care may be required. Furthermore, older people who have had a lifetime of experience with mental illness are a particularly vulnerable group who require a high level of ongoing support in the community.

POPULATION GROUPS WITH SPECIAL NEEDS

There are several population groups within Australia that are of special significance and have additional needs in relation to mental health care. While the issues covered elsewhere in this paper also apply to these population groups, separate mention is provided here to highlight some of the unique features of relapse prevention in terms of the 4As of awareness, anticipation, alternatives and access for these population groups.

Across the lifespan, the population groups of children and adolescents and older people require special mention. Historically, the mental health care system in Australia has not been geared to their needs and it is, therefore, necessary to draw attention to some of the differences from mainstream adult-focused services for people at these stages of the lifespan.

Of primary historical and cultural importance to Australia are Aboriginal peoples and Torres Strait Islanders. Issues relevant to their unique and pressing needs regarding continuing care for mental health and wellbeing are emphasised here. People who come from culturally and linguistically diverse backgrounds also have distinctive needs that must be recognised. Another exceptional challenge for mental health care is being responsive to issues of distance and access in Australia, and responding to the needs of people living in rural and remote communities.

Children and adolescents

Understanding relapse prevention from the developmental viewpoint of children and adolescents is complex. Children and adolescents are usually at an earlier point in the developmental trajectory of mental illness, although the onset of mental health problems and mental illness appears to be occurring earlier in the lifespan. Nevertheless, for most children and adolescents mental health interventions are focussed on indicated prevention and early intervention (NSW Health 2001), rather than continuing care for recurrent or chronic mental illness. Consequently, relapse prevention must be considered within this developmental context.

The mental health system has developed with a focus primarily on adults, although international policy has recognised the importance on focusing initiatives on the infant, child, adolescent and family mental health sector and have acknowledged that this area needs dedicated planning and implementation to ensure that the needs of these population groups are not overshadowed by those of general adult mental health services (AICAFMHA 2003). A fundamental barrier to including these groups under the general umbrella of mental health is that the adult focus of the mental health sector is reflected in the language that is used to communicate within and about the system. Unfortunately, this paper is also bound by such language, as terms such as 'rehabilitation', 'recovery', 'consumer' and 'carer' derive from the adult-focus of mental health. This can lead to alienation of the child and adolescent mental health sector.

Despite differences in terminology, the elements of relapse prevention still apply for child and adolescent mental health although they are framed in different terms. It needs to be emphasised that childhood and adolescence are times when the opportunities for successful outcomes in terms of relapse prevention are maximised. Consequently, much of the focus of child and adolescent mental health services is on building resilience and enhancing wellbeing. Effective child and adolescent mental health services operate within a preventive

and holistic framework; arguably more so than is current practice in many of their adult-focused counterparts.

We work within a protective behaviours framework. We don't do 'rehabilitation' and we don't focus on illness. We concentrate on strengths and opportunities, particularly opportunities to remain in school and to stay connected to family and positive influences.
—CAMHS clinician

Children and adolescents have very specific needs around awareness of their mental health status and their potential for relapse. Diagnostic labelling is often avoided for young people, as it may be firstly, inaccurate, and secondly, unduly stigmatising and limiting of future options. Identity development is a central issue during adolescence, and incorporating mental illness into the adolescent sense of self may not be a positive step. For relapse prevention, this means that awareness and acceptance have to be encouraged in a developmentally appropriate way. The focus needs to be on promoting wellbeing rather than preventing illness; consequently, awareness and monitoring of warning signs, if appropriate, must be framed within a positive wellness focus that aims to maximise opportunities rather than impose limitations.

While the health behaviours of children are often determined by their parents or guardians, the health behaviours of adolescents become increasingly under their own control. Encouraging positive health behaviours that promote mental health, and encouraging early help-seeking behaviour in particular, are issues of concern. Young people seek mental health help in different ways as they mature, and these changes need to be understood in order to provide services that they are prepared to use (Rickwood et al in press). The availability of mental health resources that are acceptable and accessible to young people is a priority. In this regard, the Headroom website (www.headroom.net.au) and resources developed by young people for young people are essential. A resource entitled 'Keeping yourself well after mental health problems' has been developed as part of the Headroom project specifically related to relapse prevention for young people. Youth-friendly services of all types are required to remove the stigma of seeking mental health help and encourage adolescents to access them, and there is currently a paucity of such services, especially outside large urban areas.

Peer support is optimally important for adolescents and the development of effective peer-based programs needs prioritisation. However, it is important to caution about the nature of such programs, as the development of a 'deviant' peer group can encourage persistence of a mental health problem (National Crime Prevention 1999). Positive peer group interactions are essential for young people, and such an approach has been targeted specifically to young people who have experienced mental health problems through programs such as 'Amigos'. Innovative work is being undertaken by Adolescent Services - Enfield Campus (ASEC) in South Australia and the Early Psychosis Prevention and Intervention Centre in Victoria (EPPIC) around training peer consultants to provide mental health information, hope and role modelling for young people. Importantly, AICAFMHA has been successful in proposing the development of a youth participation strategy for mental health to the Federal government.

It is a special challenge to be the parent of a young person with a serious mental health problem. Increasing independence from parents is a developmentally appropriate goal of adolescence and this, along with occasional adolescent rebellion, makes the parent/carer role especially complex. While parents need to be involved in the continuing mental health care of their adolescent children, they need extra support to negotiate the issues that arise. For example, parental monitoring of symptoms may or may not be appropriate: for some families this will be a source of conflict. Increasing adolescent independence must be recognised and

facilitated by all the parties involved in providing continuing care. This can be a particularly vexed issue in areas where, through lack of services, parents have to provide a lot of input into continuing care.

If only we had a case manager. It is not appropriate for me to be acting like the case manager, but there is no-one else to do it. He gets angry that I interfere and tells me that it's none of my business and I should leave him alone. But if I don't get involved to find services and try to get help, then we end up in crisis, which can be very bad. I have to try to stop that happening. If I don't try, then it will happen and we all end up with the police and hospital. In the end he will end up in jail if I don't keep on it. I think he would accept it much better if someone else, who was not his mother, took this role. —Rural carer

To implement developmentally appropriate relapse prevention interventions, an understanding of a person's developmental stage within the lifespan is essential to understanding their mental health needs. Age is an imprecise indicator of developmental stage, but in general terms, *Action Plan 2000* notes that the developmental needs of children aged 5-11 years are around the social and physical environments that provide education and socialisation experiences, as well as family factors. For adolescents aged 12-17 years, developmental needs are about entering secondary school, puberty, an increasing need for independence, peer relationships, and identity and sexual orientation issues. For young adults aged 18-25 years, the concerns are around identifying as an adult with personal and social responsibilities, developing intimate relationships, and embarking on career and vocational pathways. It is during this young adult life-stage that the prevalence of mental health problems and mental disorders peaks.

Clearly, there is large variation across the developmental needs of children and adolescents. Furthermore, young people with mental health problems may be developmentally immature for their chronological age. Providing services based on inflexible age criteria is, therefore, not appropriate, and services need to be flexibly organised around the developmental needs of young people.

There is huge variation in the developmental needs of children and young people. Some are still at home with their parents and go to school, some have left home and are no longer at school, some even have families of their own. Services that are provided solely on an age basis, whether it is up to 18 years, or even the 15-25 year approach, are not able to meet the needs of these hugely different levels of maturity. —CAMHS clinician

It is essential to recognise the interconnection of mental, physical, social and emotional health and development for children and adolescents and to be aware of the risk and protective factors in their lives in all of these domains (Raphael 2000). Relapse prevention and 'rehabilitation' programs need to take a multidisciplinary and integrated approach to considering all these domains. A primary focus needs to be on family relationships and education and vocational needs. It is important to work within a learning framework and to consider what learning and developmental opportunities are being provided by the interventions being put in place. For young people who have been seriously affected by mental illness, intervention programs that work holistically within all the developmental domains, such as day programs and hospital to home transitions, can help to prevent early mental health problems from becoming entrenched (McEntee & Hilton 2002).

There are additional risk factors for young people with mental health problems (Resnick et al 1997). Risk-taking behaviour around alcohol and other drug use and sexuality are common, and support services need to deal with these issues. Illicit substance use is a major risk factor of special concern for young people, and strong partnerships between mental health and drug

and alcohol services need to be routine. Appropriate accommodation for young people is also a challenge: it is especially inappropriate to house teenagers with mental health problems with older people who have more chronic mental illness or who have established drug and alcohol problems.

At maximal risk are young people who are involved with the justice system, particularly those who have been incarcerated. These young people often have social and emotional problems and other issues related to their incarceration that add substantially to their risk of future mental health problems.

Young people from Aboriginal and Torres Strait Islander backgrounds and from culturally and linguistically diverse backgrounds also have additional risk and protective factors related to culture, identity and belonging that need to be identified and considered.

The children of parents with mental illness are another group of young people who have unique risk factors: the COPMI project is a national initiative that is investigating the best ways to meet the needs of these young people, many of whom may have significant mental health problems themselves. A document has recently been published outlining the *Principals and actions for services and people working with children of parents with mental illness* (AICAFMHA 2004) along with development of a website of supporting documents (see <http://www.copmi.net.au>). These initiatives are not only important to these children, but are highly relevant to the ongoing wellbeing of their parents.

It is important for mental health service planners and policy makers to recognise that the types of services accessed by children and young people with ongoing mental health problems can be quite different to those for adults. For example, while primary care provides a first point of contact for most people seeking mental health help, for children and young people primary care “includes care from services such as general practitioners, school counsellors, paediatricians in some instances, community health centers, and other community-based health, maternal, child, family and youth health and welfare services” (Raphael 2000 p40). Furthermore, much of the demand for a mental health service response for children and adolescents is for community services (rather than hospital and emergency services), and waiting lists for community clinics and other community services are a barrier to implementing effective relapse prevention approaches.

Raphael (2000) argues that a comprehensive mix of clinical and support services is required to address children and young people’s individual physical, emotional, social, cultural and educational needs and provide for all age groups spanning across childhood, adolescence and early adulthood. Children should receive services in the least restrictive, most normative and stable environment that is clinically appropriate—where possible, in their local community. Services should be integrated and coordinated, with partnerships and linkages with other agencies for children and specialist mental health services, to ensure continuity of care across the service system and through young people’s developmental transitions. Mechanisms for joint planning, developing and coordinating services should be developed that include young people in ways that match their developing maturity.

Finally, it must be acknowledged that the transition to adult services can be traumatic for a young person who has been in the child and adolescent mental health system, and these transitions must be undertaken sensitively (Raphael 2000). In some instances, young people must move to the adult system as soon as they turn 18 years of age, and such transitions may not be appropriate to their developmental maturity and particular needs. The development of more flexible and individually-tailored interfaces between child and adolescent, youth, and adult-focused services, both clinical and non-clinical, needs urgent attention: a better

understanding of developmental needs, and the planning of services accordingly, will benefit people at all ages across the lifespan.

Older adults

At the other end of the lifespan, older adults also have unique needs in relation to relapse prevention. Older people living in the community tend to have the best mental health across the lifespan, but those in aged care and other supported accommodation settings are at increased risk of mental health problems (DeLeo et al 2001). Older adults may have experienced a lifetime of chronic or relapsing mental illness, or had recent onset of mental illness as the result of a significant stressor such as bereavement or physical ill health. Generally, however, mental illness in older age tends to be more chronic in nature. To ensure appropriate relapse prevention for older adults, consideration must be given to the chronicity of the mental illness as well as developmental needs at this stage of the lifespan.

Differentiating mental disorders from ‘normal’ aging has been one of the more important achievements of recent decades in the field of geriatric health (US Surgeon General 1999). Appropriate diagnosis of physical and mental conditions is essential at this stage of the lifespan, but there are many factors that can impede this. Consequently, depression, Alzheimer’s disease, harmful alcohol use, anxiety, late-life schizophrenia, and other conditions can go unrecognised, untreated or misdiagnosed, with severely impairing and sometimes fatal outcomes (US Surgeon General 1999). Better diagnosis of both mental and physical health conditions and greater awareness of mental illness symptoms among older people are priorities.

Older adults who have experienced a lifetime of chronic or relapsing mental illness have special needs. These people are often “uniquely disabled by a combination of personal, social, mental and physical health disadvantage” (Jolley, Kosky & Holloway 2004 p27), having spent a large portion of their adult life in mental hospitals. With the move toward community care, these older people have been discharged into the community, but are at risk of not having their needs met because of the lack of effective partnerships between psychiatry, rehabilitation and aged care. The Royal College of Psychiatrists has produced guidelines to highlight the special needs of these people, who they call ‘graduates’, to define and encourage good practice in the management of mental disorder for people who have suffered from enduring or episodic severe mental disorder throughout adulthood and are now reaching old age (Jolley, Kosky & Holloway 2002). As noted earlier, the notion of ‘recovery’ can be, paradoxically, traumatic for these people, and needs to be sensitively approached along with the related issues of relapse prevention and rehabilitation.

I don't know why you think I am going to recover now. I've been sick all my life and in and out of hospital for 40 years. I've had every sort of drug and a whole lot of different psychiatrists and doctors and none of them have done any good. And now you tell me that I'm supposed to recover. —Consumer

To facilitate understanding of the risk and protective factors for relapse in later life, it has been argued that successful ageing is contingent upon three elements: avoiding disease and disability, sustaining high cognitive and physical function, and engaging with life (Rowe & Kahn, 1997). These are, therefore, factors to be considered in terms of providing support and rehabilitation services for older people to reduce risk and increase the protective factors for mental health. Common risk factors for mental health for older adults are bereavement, social isolation and poor physical health. Bereavement is a well-established risk factor for depression, and peer support groups have been found to be helpful in this regard (US Surgeon General 1999). Social isolation is a significant problem for many people who have

experienced mental illness, and one that becomes particularly acute with ageing. Finding appropriate ways to engage older people with each other and with the wider community through day programs and social activities need to be prioritised.

Support groups for older people with mental illness and their families are likely to be helpful in that participating in such groups can reduce feelings of isolation, increase knowledge, and promote coping efforts. Little research has been undertaken on the efficacy of support groups for older people, however, and has generally been limited to support for carers and those who have been widowed, rather than to older people who have experienced mental illness.

Maximising physical health through appropriate diet, exercise, sleep, medical check-ups and medication review is also paramount. The essential role of general practice is evident in this context for older people. GPs are the main source of health care for older people and often the only health contact that older people actively seek (AIHW 2002). Dealing with the complex array of physical and mental health problems of older people with mental illness is a special challenge for general practice.

There is a high risk of suicide associated with mental illness for older people, both those who have long-term illness and those who have a late-onset disorder. While suicide is a serious risk at all stages of the lifespan for people with mental illness, it requires special consideration as a psychosocial risk factor for wellbeing in old age (De Leo et al 2001).

In terms of timely access to clinical and non-clinical services to support the wellbeing of older adults who have experienced mental illness, aged care and disability support services for older people are not geared toward those who have experienced mental illness; rather, they are more suited to the frail aged and those with dementia (AIHW 2003). An understanding of psychiatric disability is, however, being recognised as an increasing priority for services provided for this age group. Currently, however, availability of and easy access to services for older people with mental illness are often lacking, and these people's complex needs are not being met by the mental health, general health, disability or aged care sectors.

Subsequently, an unreasonable burden falls on family and carers. Late-life mental disorders pose special difficulties for the family members who assist in providing care (Light & Lebowitz, 1991). Carers may be old and frail themselves, or have other demanding responsibilities. There is an urgent need for appropriate respite and day care alternatives for older people with ongoing mental health problems.

I am caring for my elderly father as well as my brother. They both have schizophrenia. I also have two kids to look after and I'm a single mother. I don't have a life at all for myself. It all revolves around them. There's no-one else ... this is a full-time job, but I don't get paid.

—Carer

It is important to recognise that the cultural and linguistic diversity of Australia's older population is increasing, and due to different 'waves' of migration there are cohorts of older people from culturally and linguistically diverse communities that will peak in their aged care needs at different time points. Consequently, the ongoing mental health needs of these older Australians from different cultural groups must be considered (Klimidis & Minas 1998). Older people from Aboriginal and Torres Strait Islander backgrounds who have experienced mental illness are likely to be profoundly disadvantaged in multiple ways that increase the likelihood of relapse.

Aboriginal peoples and Torres Strait Islanders

There are special challenges with regard to all the aspects of relapse prevention identified in this monograph for Aboriginal peoples and Torres Strait Islanders³. Fundamentally, this issue must be considered within the broader context that the emotional and social wellbeing of Aboriginal peoples and Torres Strait Islanders is a significant health concern for Australia and a source of national shame. Culturally appropriate mental health care is not widely available in most jurisdictions and the provision of basic health and community services is an urgent and basic need for Aboriginal communities. It must be noted that Aboriginal peoples and Torres Strait Islanders comprise diverse groups of peoples who live in a variety of urban, rural and remote, traditional and other settings (Swan & Raphael 1995). It is, therefore, overly simplistic to make statements that apply to all Aboriginal peoples and Torres Strait Islanders. Furthermore, the issues described in many other sections of this paper, especially for rural and remote communities and issues related to socio-economic disadvantage, also apply.

A recent major initiative addressing mental health is the *National Strategic Framework for Aboriginal and Torres Strait Islander Mental Health and Social and Emotional Wellbeing 2004-2009*. This document presents the specific challenges for mental health care for Aboriginal peoples and Torres Strait Islanders. Holistic health care is prioritised, recognising the integrally interrelated states of physical health, sexual and gender identity, family relationships, education, employment, community relationships and spirituality for Aboriginal and Torres Strait Islander communities and peoples.

In terms of awareness of mental health status, the *Ways Forward* report reflected on the holistic nature of health and mental health within an Aboriginal context (Swan & Raphael 1995). The construction of mental illness is a cultural concept developed mostly within a western context and it is a frustrating reality that many of the assessment tools used by clinicians have little or no cross-cultural validity. Consequently, the expression of early warning signs and symptoms of recurrent mental illness for Aboriginal peoples and Torres Strait Islanders is unexplored. Furthermore, construction of the sense of self for Aboriginal peoples and Torres Strait Islanders is complex and incorporates the family and extended clan group, alongside an elaborate set of relational bonds and reciprocal obligations. It may also incorporate a profound sense of continuity through Aboriginal Law and Dreaming. It is unknown how awareness and acceptance of having a mental illness, and of thereby being at increased risk of recurrent symptoms, translates within an Aboriginal or Torres Strait Islander context. A first step for preventing relapse for people from Aboriginal or Torres Strait Islander backgrounds is understanding the narrative of their personal construction of self and of their symptoms of mental illness.

Stigma toward people with mental illness is evident within Aboriginal and Torres Strait Islander communities. This can be inadvertently perpetuated by health care providers who cannot speak the Aboriginal language and use short-hand forms of verbal and non-verbal communication.

We really need to stop using the term 'rama rama' to refer to people with mental illness when we come out to the communities. It really means something like crazy and we wouldn't use

³ Please note that the development of this section was strongly supported by a draft document by the Sheldon Remote Mental Health Team (2003) entitled, *Leave Only Footprints. Cultural Sustainability and Mental Health in a Remote Aboriginal Setting*. Sheldon Remote Mental Health Team, Alice Springs.

such terms when referring to people in town, would we? But we allow short-cuts like this out in the bush, because we don't have ways to communicate these things better. —Remote health worker

Anticipating potential relapse and planning for such an event entails working within existing relational bonds and community supports. It is likely that the less individualistic nature of Aboriginal and Torres Strait Islander communities is a major strength upon which to draw. People from an Aboriginal or Torres Strait Islander community who have experienced a mental illness may still be well integrated within that community and able to draw upon its supports. Planning for relapse prevention needs to be flexible and work through a wellbeing focus, rather than a specific illness or crisis focus. Nevertheless, it is important that Aboriginal peoples and Torres Strait Islanders be given opportunities to express their preferences should a crisis arise and that these choices are respected and upheld.

Aboriginal families can be more accepting of illness. There are more extended networks. For example, there is not so much concern where children go because of all the family networks. —Aboriginal health representative

Hospital care can be a particularly inappropriate response for Aboriginal peoples and Torres Strait Islanders experiencing mental illness, especially for those who live in remote communities and in a more traditional lifestyle. A study of Aboriginal peoples in Central Australia reported that 90% wanted alternatives to hospital care, compared with 47% of non-Aboriginal people (O'Kane, Briscoe & Fowler 1999). Similar results were found for the Top End (Nagel, Mills & Adams 1996). Being taken out of their community and placed in a city hospital as the result of a mental health crisis is a significant added trauma.

Timely access to mental health services of any type is, however, a major problem for many rural and remote Aboriginal and Torres Strait Islander communities. Treatment and support services are often not available to enable any attempt at early intervention for recurrent mental health problems. Until issues around basic levels of service provision are addressed it will be difficult to implement relapse prevention in these communities.

We are so backward in treatment because we don't have the same resources. A lot of the consumers I work with talk about just getting treatment, medication treatment, any treatment. There is no psychotherapy. And we've been pushing for a long time to get more information about other therapy. We've got such diverse populations and basically it's all medication orientated. —Consumer/carer advocate

Fundamentally, there is an urgent need for a more culturally appropriate response from mainstream mental health and health providers. It has been estimated that only 10% of non-Aboriginal practitioners feel confident working with Aboriginal mental health (Westerman 2002). Based on a model developed by Cross and Bazron (1989) and adapted to the Aboriginal Australian context, Westerman defines cultural competence as ranging between: aversion, incompetence, blindness, precompetence, competence and proficiency. There are very few mental health workers who are able to attain levels of cultural competence or proficiency. The experience of many Aboriginal communities is that the majority of mental health professionals will fall into the cultural precompetence level, defined by Cross and Bazron as including those who are aware of their own personal limitations regarding cross-cultural communication. While the intention to provide a quality service exists, the workforce is often frustrated by a lack of knowledge as to the most appropriate manner to deliver services, and is often unaware of their lack of understandings and limitations.

It is also the case that there is high turnover of health care providers within Aboriginal and Torres Strait Islander communities, particularly those that are rural and remote. This means that cultural competence does not have time to develop and communities are continually exposed to new workers who are not able to develop the necessary skills or confidence. High turnover of service providers also means that linkages and partnerships between service providers do not have the opportunity to develop and consolidate, yet these linkages are essential to relapse prevention.

Mental health care is carried out in many communities by the families, local clinic, Aboriginal health workers and community supports (Sheldon Remote Mental Health Team 2003). Ongoing mental health care requires acknowledgement and respect for the interconnectedness of kinship, culture, law, land and spirituality, as well as the effects of invasion, colonisation and ongoing cultural stress. Cultural consultants or Aboriginal mental health workers act as guides to the culture and ensure that health interventions are carried out in culturally appropriate ways. The *Ways Forward* report recommended that there be a minimum of two Aboriginal mental health workers, a male and a female, in each region, but this target has not been achieved. Aboriginal mental health workers are essential for relapse prevention, as they have extensive knowledge of the client's family and circumstances, the community, supports and traditional practices, and are able to connect people with the types of supports they require. Furthermore, the role of Aboriginal mental health worker provides an opportunity for community people to have a real job in their community and these types of opportunities are essential for the wellbeing of communities.

The job of Aboriginal health worker is a real job in the community that people can aspire to. They can get training and better money. They think, 'We want that job', because it has a bit of status and is better than sitting around on CDP and getting paid to do nothing. —Community mental health worker

There are some quite specific mental health interventions that could be better developed for people of Aboriginal and Torres Strait Islander backgrounds. For example, it has been suggested that a more narrative therapy approach is required; this approach enables people to tell their stories which may improve communication with Aboriginal clients and enable better understanding of the richness and complexity of their lived experiences (Wingard & Lester 2001). There is also need to explore the cultural translation of therapies that have been shown to be efficacious for preventing relapse in western settings; for example, cognitive behaviour therapies.

We call it Bush CBT. We use it a lot in bush work. It is our way of doing CBT work with people in the communities. I don't think you'll read about it anywhere, it probably hasn't been documented anywhere. That would be a really useful thing – to have some resources to do BCBT – it would be a really useful project for someone to properly develop those. —Aboriginal health worker

It is important in some communities to be able to incorporate traditional healing practices in order to provide a culturally appropriate approach to relapse prevention. For example, many Aboriginal people in Central Australia would consult a traditional healer or Ngangkari in the first instance, and these people may provide an opportunity for early intervention.

A Ngangkari is a very clever person – they know all about sickness – they can look inside and see their sickness. They can look and see that someone is unhappy or mad or something is wrong with their head, from looking at their face ... and they will touch his head and hold it tightly, and pull something out of his head, it might be a stone or a stick, or a mamu (bad spirit) inside making him crazy. Then at night when the Ngangkari is asleep, his spirit might

go to that young fella's place and go inside his head and fight with that mamu and pull it out and get rid of it. That young fella will wake up and think, "Oh I'm happy, I'm feeling good, my head is no longer heavy – that mamu is going". (Thomas 2000 p5 cited in Sheldon Remote Mental Health Team 2003)

Cultural stress, grief and trauma have unique impacts on the mental health of Aboriginal peoples. A manifestation of these issues is increased risk of suicide and self-harm (Swan & Raphael 1995). It is, therefore, essential that mental health services work in partnership with life promotion programs within Aboriginal communities.

It must be recognised that some Aboriginal people have experienced a long history of mistreatment by mainstream health and welfare services. These people have understandably become mistrustful and fearful of contact with such services. In the mental health context, people can be especially fearful of having a "psych file", as there are examples of these being used against them by lawyers, particularly in relation to the removal of children. This can provide a strong reason to avoid contact with services.

I have seen things written in files that are racist and have gone against people. People are worried about stuff being written in their files that will be used against them. —Aboriginal health representative

For most Aboriginal and Torres Strait Islander communities, relapse prevention is best placed within an ongoing process of community development as determined by the community itself. This applies equally to urban, rural and remote communities. Many communities experience very high levels of stress in all domains: economic, environmental, physical, social and emotional stress. These sources of stress need to be addressed for all members of the community. Improving the general health and wellbeing of Aboriginal and Torres Strait Islander communities will improve the health and wellbeing of individual members and contribute to preventing relapse for those community members who have experienced mental illness. Only when the economic, environmental, physical, social and emotional wellbeing of communities are improved will there be real opportunities for relapse prevention for Aboriginal peoples and Torres Strait Islanders who have been seriously affected by mental illness.

People from culturally and linguistically diverse backgrounds

Australia has a culturally and linguistically diverse population, with many residents born overseas and originating from non-English speaking countries. Australia is also home to refugees, who have a unique and often traumatic experience of migration. Considering relapse prevention within a multicultural context requires understanding the differences that arise through cultural and linguistic diversity.

A factor that has an overriding impact in terms of relapse prevention for people from culturally and linguistically diverse backgrounds, particularly those from non-English speaking backgrounds, is that they are less likely to access mental health services. There is a marked reluctance among many people from culturally and linguistically diverse backgrounds to voluntarily access both hospital and community-based mental health services (McDonald & Steel 1997, Minas et al 1996). This lower level of service use is not related to lower levels of need, but rather to difficulties in understanding and accessing mainstream systems of care and lack of access to services that are culturally safe and appropriate.

Stigma, lack of information about mental illness and mental health services in appropriate and accessible formats, and poor communication and cultural differences between clients and clinicians have been reported as major barriers to timely access to mental health services (Long et al 1999). Lack of access negates the early intervention and ongoing partnerships with service providers that are essential for relapse prevention. Furthermore, lack of early intervention contributes to the reality that people from some culturally and linguistically diverse communities are overrepresented among involuntary admissions and forensic populations.

The stigma of mental illness has a particularly strong impact in some cultures and is a significant barrier to early and effective access to services. While stigmatisation of mental illness is universal, the importance of privacy related to such matters is stronger in some cultural groups than others (Raphael 1997). Reducing the stigma of mental illness is, therefore, a priority in many transcultural contexts to encourage and support consumers and their families and carers to access the services that they need to manage risk of further illness.

The role of families is of primary importance in many culturally and linguistically diverse communities and approaches to relapse prevention must recognise this. In many transcultural contexts it is the family, rather than the individual, that must be the level of focus for interventions to encourage awareness of mental health, anticipation and planning related to preventing relapse, and access to the range of clinical and non-clinical supports that may be required to support someone at risk of further episodes of mental illness.

Consumer participation and empowerment have been identified as being essential to relapse prevention, yet there are unique challenges to involving consumers, carers and communities from culturally and linguistically diverse backgrounds in mental health (Sozomenou et al 1999). There is a relatively small number of consumers and carers from culturally and linguistically diverse backgrounds acting as advocates and educators in mental health. Due to the great diversity of community groups and languages, diverse feelings around participation rights within community groups, and community discrimination around mental health as a public concern, additional supports need to be put in place to increase participation. Involvement needs to be facilitated at all levels: from community advocates to participation in individual illness management plans. Importantly, the development of self-help groups that support consumers and carers from different cultural and linguistic groups needs to be prioritised to provide social support, information, role models and advocacy.

It is very hard and lonely here. I do it all on my own. Sometimes I wonder whether I should take my son home. In my country there would be more people to give us support. There is a different system there where there is much more support for people like him. He might even be able to get a job. Here there is only me: I have to do it all. It's very tiring, but I can't ever give up. —Carer

The role of the general practitioner and other primary care providers has been highlighted for transcultural mental health care (Mihalopoulos et al 1999). GPs are often the first and only point of service contact for many consumers from culturally and linguistically diverse backgrounds and their families and carers. This relates partly to the pronounced impact of stigma, but also to other barriers that limit access to mental health services and other community services. Consequently, for ongoing monitoring and illness management for people who have experienced a mental illness, the GP may play an even more important role in a transcultural context, and this requires additional skills and supports for the GP.

The cultural competence of service providers, both clinical and non-clinical, is essential to relapse prevention for people from culturally and linguistically diverse backgrounds. Health

providers need to be culturally sensitive in their assessment, diagnosis and management of clients. While these are areas of continuing need, some relevant resources have been recently developed including a revised, national version of the Cultural Awareness Tool (CAT), which is available to facilitate practitioners' understanding of their clients' explanatory model of their presenting problem (WA Transcultural Mental Health Centre 2003).

Working in a transcultural context requires 'awareness, knowledge and skills' (Gabb 2000). This means, firstly, an explicit awareness of the cultural values involved in the relationship between service provider and client. There is then the need to understand significant events and experiences that impact on wellbeing: a process that is especially relevant for those with experiences of torture, trauma, displacement and loss. Finally, there are specific skills required for working with people from diverse cultural and linguistic backgrounds, such as working with interpreters and being aware of verbal and non-verbal communication differences. While training in cultural competence is recognised as a necessity in many services, in others, and particularly in some of the support services sectors, there is little provided in the way of such training.

Risk and protective factors vary across culture, as well as by age and gender (US Department of Health and Human Services 2001). Poverty, immigration, violence, racism and discrimination are some of the risk factors that disproportionately affect racial and ethnic minorities, especially refugees. Fundamentally, opportunities and access to the basic living requirements that promote wellbeing, such as accommodation, work, education and leisure activities, can be reduced for people from culturally and linguistically diverse backgrounds.

Conversely, protective factors such as spirituality, community and family support can be stronger in some communities, and these can be drawn upon to support the wellbeing of people who have experienced mental illness. It is important to encourage community members to talk with each other about their experiences in order to begin to develop shared understandings of the environmental and social factors that comprise the risk and protective factors for mental health within their communities (Loughhead 2003), and to determine ways to impact on these to reduce the stressors and improve the supports that will facilitate the wellbeing of people who have experienced mental illness.

Rural and remote communities

As a large country with a relatively small population that is concentrated in a small number of major urban areas, issues related to distance and isolation mean that rural and remote communities in Australia have an additional set of challenges in terms of relapse prevention. Rural communities are not homogeneous and each has a unique set of factors contributing to the social and emotional wellbeing of its members. Importantly, many rural and remote communities are home to significant populations of people from Aboriginal and Torres Strait Islander backgrounds, and some have a large proportion of people aged over 65 years (ABS 2002). While facing complex challenges in terms of mental health care, rural and remote communities have less access to services than urban centres.

A common barrier to relapse prevention in rural and remote communities is fear of stigma, which reduces awareness and acceptance of mental illness, partly because it is difficult to maintain privacy in small and more insular communities. Along with 'rural stoicism', stigma makes it more likely that rural people will withdraw rather than seek help from appropriate mental health and support services (Hoolahan 2002). Improving community attitudes toward mental illness and encouraging appropriate help-seeking behaviour are, therefore, priorities in smaller and more remote communities.

Everybody here knows everybody else's business. If I get to the doctor, it will be all about town before I get out the door. —Consumer

Access to mental health and community services is a serious concern in many rural and remote communities (AIHW 2002, 2004), and has a substantial impact on planning for, and providing the support services that are required for preventing relapse.

There is no such thing as discharge planning here. You get shoved out the door, often before you are well enough and ready, and then there is nothing ... no contact, no follow-up, no services, nothing. They just wait for you to come back in again. Then it is the same thing all over again. —Consumer

Frequently, mental health care in rural and remote communities is provided through community health centres, hospitals in major regional centres, and a small number of GPs. Many communities have no resident mental health services and must rely on visiting services or travelling to communities where services are available. Lack of accommodation is, therefore, a highly related issue, including accommodation for visiting service providers as well as for consumers and their families and carers. People requiring services often have to travel away from their families and communities, which becomes an additional stressor and denies people an important source of social support. Transport and accommodation are major barriers to providing early intervention and continuing care.

One of the main reasons we can't get services to come out here is lack of accommodation. The few places there are to stay are booked up, and they are also expensive. It costs more to stay out here than it does to stay in town. Who is going to pay accommodation prices like that for this sort of place. If we had more accommodation at decent rates, we might be able to attract some more services to come out here. —Remote area service provider

Families and carers are at increased risk in rural and remote communities because, like consumers, they also lack services and support. They often have to provide ongoing support to their family member in the absence of any community support services and with no access to crisis services. This can be a very heavy burden, and there is a great deal that needs to be done to support families and carers in their continuing care role in rural and remote communities.

Special attention needs to be given to general practice within rural and remote communities. The GP is often the only source of continuing care for people who have experienced a mental illness in rural and remote locations (AIHW 2002, 2004). However, waiting lists are long, there are often low rates of bulk billing, and there is a focus on crisis rather than continuing care and relapse prevention. Initiatives to support GPs working in rural and remote communities to provide relapse prevention through continuing care are essential.

Although they are important in all communities, the role of non-health services and community agencies is paramount for supporting relapse prevention in rural and remote communities. Schools, the police, businesses, publicans, the local newspaper—all the members of the community—need to work in close partnership to provide a positive attitude toward and an integrated network of support for those members of the community who are particularly vulnerable because they have been seriously affected by mental illness.

The coppers here are great. If they see _____ wandering around, they pick him up and bring him home. It helps keep him out of trouble. They keep an eye on him and bring him home to Mum. —Family member

The development and implementation of new technologies that overcome issues of distance and isolation are essential to providing continuing mental health care within rural and remote communities. Initiatives such as the Commonwealth telepsychiatry initiative, whereby Medicare rebates were introduced to enable people with mental illness living in rural and remote areas to participate in telepsychiatry consultations with their psychiatrist, need to be sustained and expanded. Internet technologies also enable opportunities to provide information about mental health and mental illness and to connect people living in rural and remote communities with support groups (Christensen, Griffiths & Evans 2002).

In terms of planning interventions around the risk and protective factors that affect relapse, it must be noted that rural and remote communities are often more exposed to risk factors for mental health. For example, rural communities have more economic problems, higher unemployment rates, higher suicide rates, more domestic violence (Sheil 1997), and poorer physical health than urban areas (Mathers, Vox & Stevenson 1999). There are environmental and occupational hazards, sparse infrastructure and risk-taking attitudes to health, illness and behaviour (Wainer & Chesters 2000). Social polarisation has occurred in some areas as a consequence of the closure of services and changes to agricultural and industrial practices (HREOC 1998).

There is a general lack of opportunities and alternatives to support mental health and wellbeing and thereby reduce the risk of relapse in many rural and remote areas. This can be particularly pronounced for younger people who lack social, employment and educational opportunities. Consequently, people who are more vulnerable to the stressors of life by having previously experienced a mental illness may be at greater risk of relapse in rural and remote communities because they are more exposed to stressors, and the services and opportunities that support rehabilitation and recovery are not available.

Alternatively, there are protective factors available in many rural and remote communities that are lacking in more urban settings. Rural people are less likely to report unhappiness than their urban counterparts, and women from rural and remote areas report lower levels of stress than women from metropolitan areas (AIHW 2002). Rural communities can be more socially connected; specifically, health professionals and community service providers can work more closely together as they often know each other well and have an investment in the health of their community (Hoolahan 2002). Paradoxically, lack of traditional services and resources can be an asset, as services have a capacity to change and adapt more quickly; something that is difficult to achieve within more established service systems (Curtis & McCabe 1990). Finally, the open spaces and slower pace of rural communities provide an environment that can be very supportive of mental health and wellbeing compared with overstimulating and hectic urban environments. It is important for rural and remote communities to identify their strengths and work together to enhance the ability of these protective factors to support the people within their communities who have experienced mental illness.

Forensic populations

People with mental illness are significantly over-represented in the criminal justice system. Estimates suggest that people seriously affected by mental illness are three or four times more prevalent in prison populations than in the general community, and the vast majority of prisoners have had some type of mental health problem (eg, Fazel & Danesh 2002, Herrman et al 1991, Brinded et al 2001). There are many reasons for this higher prevalence, including people with mental illness coming to the attention of the police when they should be receiving treatment. Repeatedly throughout the consultations, consumers and carers reported

incidents of not being able to get a mental health service response until the situation had escalated to the point where a police response was called in.

*My parents finally call the police. It's like using a sledgehammer to crack a nut. —
Consumer*

Many of the crimes committed by people with mental illness are minor, and they should be diverted from the criminal justice system to the mental health system (Ogloff 2002). However, in some jurisdictions there are few alternatives to the criminal justice system for people with mental illness because of a lack of appropriate mental health services.

Not only are there many people with mental illness in the criminal justice system, but incarceration itself has serious negative impacts on people's mental health, as well as the sources of mental health and wellbeing, such as employment, accommodation and social relationships. Consequently, there is an urgent need for the issue of relapse prevention to be taken up in the criminal justice system.

There is a pressing need for the criminal justice workforce to have an understanding of mental health issues. This includes training for prison officers, community services officers, and probation and parole officers. Specialist mental health care needs to be provided within correctional institutions and corrective services, and strong links must be forged between mental health services, drug and alcohol services, and correctional services to ensure that the needs of people with this complex array of problems is met (Ogloff 2002).

Essential for relapse prevention are systems to help people to re-enter the community after incarceration. Currently, people are released from prison without medication or referral to mental health services, and even without such fundamental supports such as transport, housing and food (Borzycki 2005). People who have been incarcerated have trouble with finding and keeping appropriate accommodation, employment and re-establishing social relationships. The lack of these supports means that there are multiple and cumulative risks for mental health as a consequence of incarceration.

There is an urgent need for pre-release preparation and post-release follow-up into the community. A major Australian report of interventions for returning prisoners to the community states that a "significant challenge in terms of prisoner reintegration is therefore likely to be the development of programs that can simultaneously address alcohol and other drug use, mental wellbeing, and chronic physical ill-health" (Borzycki 2005).

The problems of continuity of care and disadvantage that are documented elsewhere in this document are heightened for forensic populations and this is an area that is neglected in terms of relapse prevention.

WHAT DO WE NEED TO DO TO INCORPORATE RELAPSE PREVENTION INTO CONTINUING CARE?

Relapse prevention must become a routine component of continuing care for all people who have been seriously affected by mental illness. It needs to be incorporated alongside rehabilitation as one of the tools within a recovery oriented mental health care system. Relapse prevention should commence at the earliest possible opportunity, even during treatment of the first episode, and then be adapted according to each person's changing needs across the lifespan, across the course of their ongoing experience of mental health and mental illness, and across changing life circumstances.

Relapse prevention initiatives are currently incorporated within some mental health services, however, the approach needs to become routine practice and to do this change needs to occur at many levels of the mental health care system. Comprehensive implementation of the elements that enable effective relapse prevention is required.

The actions required to implement relapse prevention are apparent and have been listed as outcomes in the *National Mental Health Plan 2003-2008*. They comprise many of the components that make up good clinical care and effective aftercare and continuing care. These include: real participation and partnerships with consumers and their families and carers; access to services and service responsiveness; workforce development; and ongoing monitoring, evaluation and research. While the required outcomes that would enable the implementation of relapse prevention are evident in the *Plan*, what is not made explicit is how these outcomes apply specifically to a focus on preventing relapse, which will be considered here.

Empowering consumers and their families and carers through participation and partnerships

Real consumer and carer participation in the planning and delivery of mental health care is a central feature of relapse prevention. Consumers and their families and carers must be the driving force behind the reform of continuing care through the development and implementation of relapse prevention plans and the service responses that support them. Participation must occur at all levels, which means that consumers, supported by their families and carers, must be actively involved not only in the planning and evaluation of services, but also in the planning of their own treatment and continuing care.

People with mental illness require information and support to enable them to accept and understand their health condition. This information needs to support people to effectively self-manage their mental health, make health care choices, and interact with a variety of services to obtain the clinical and psychosocial support they need. Families and carers require similar information. This means having easily accessible information about mental health, mental illness, and illness management that is available in a diversity of developmentally and culturally appropriate formats. Particularly important in the context of relapse prevention, is understanding early warning signs and the risk and protective factors for ongoing wellbeing.

While ‘expert’ information is relevant, peer support is critical for many people coming to terms with living with a mental illness. Peer support, for both consumers and their families and carers, can provide essential information, fellowship, role models, mentors and advocates.

Consumers need to become skilled in participating in their own continuing care and ensuring that appropriate service supports are put in place for them. They need to expect that continuing care plans, which incorporate relapse prevention within a recovery focus, will be a routine component of mental health care. The input of consumers and their families and carers to these plans must be recognised as fundamental and thereby legitimised and actively engaged. Plans need to be developed in a timely manner through true partnerships, and the information shared as appropriate and agreed to by the consumer.

Plans must be supported and developed at a number of levels. In-patient mental health services must negotiate effective discharge plans with consumers, their families and carers, as well as with the health and psychosocial support services the consumer will require in the community. Mental health services, more generally, need to support the development of relapse and wellness plans that are reviewed at regular intervals and driven by the changing needs of the consumer.

Crisis plans may also need to be developed depending on the nature of a person’s mental illness; in some jurisdictions these have been incorporated in the form of Advance Agreements, which set out the consumer’s choices for care and treatment if he or she becomes acutely unwell and unable to make decisions at the time. Advance Agreements are a mental health adaptation of Advance Directives, which are also referred to as ‘Ulysses agreements’ or ‘living wills’. Advance Directives typically apply in palliative care contexts, being a document that is created when a person is well that defines the medical treatment the person wishes to refuse should they become so unwell that they are unable to refuse consent to treatment. They developed in response to technological advances that can keep people alive and are a witnessed document that is legally binding in some jurisdictions.

There is also need for plans that support and enhance the capacity of people to self-manage on a daily basis and for the longer-term. Plans need to cover daily wellness needs, such as using behavioural tailoring to ensure effective medication use and mapping out daily wellness needs in terms of exercise, nutrition, sleep and social activities. Longer-term plans also need to be made to set out goals that support recovery.

The development of illness management techniques that empower consumers and facilitate communication between consumers and service providers must be prioritised and encouraged. Approaches such as the Expert Patient Program⁴ have been developed in the United Kingdom to help people with long-term health conditions to be better able to self-manage their health needs.

Collaborative Therapy is a comprehensive therapeutic framework that provides a tool for empowering consumers and enhancing communication between consumers and services (Castle & Gilbert 2003a,b). It enables consumers, clinicians and other services to work systematically and collaboratively toward optimal mental health outcomes. The approach prioritises consumer participation and continuous improvement. An important component is the Collaborative Treatment Journal, which is a small pocket journal held by the consumer that can be used to chart stressors, early warning signs, supports, and other factors that influence the course and management of their mental health. The journal places the consumer

⁴ See <<http://www.expertpatients.nhs.uk/>> (Accessed 11 April 2005)

at the centre of their recovery by facilitating communication between themselves and the other people and services involved in their continuing care. Randomised controlled trials of Collaborative Therapy are taking place in Victoria, ACT and South Australia (see Gilbert et al 2003). This approach is congruent with 4As, and provides a promising model that can be used to implement relapse prevention within continuing care models for people seriously affected by mental illness.

It is vital that the role of families and carers in relapse prevention be recognised and supported. Family support is essential to preventing relapse and the needs of families, and especially of the children of people with mental illness, must be acknowledged and services put in place to enhance their ability to support consumers while protecting their own wellbeing. Initiatives to include families and carers in treatment and relapse planning are essential. Support and training, for example in recognition of early warning signs, is also important for families and carers. Mental health services must become more responsive to the needs and concerns of families and carers as they often are the first to realise when early intervention needs to take place.

Service access and responsiveness

Relapse prevention is based on the availability of timely and appropriate service responses from diverse service sectors. This requires appropriate supply, organisation, deployment, education and training of the mental health workforce. Firstly, the distribution and composition of the mental health workforce has to be responsive to population needs for continuing support, and innovative solutions to encourage greater supply and equity of access must be developed. In most jurisdictions, and almost universally in rural and remote areas, the capacity of both clinical and community support services needs to be increased.

Fundamentally, mental health care services need to be able to respond outside acute and crisis situations. This calls for a different type of service response, with a lower threshold of service need required to enable people to get an effective response when they are experiencing their early warning signs. A wider range of service responses and varying levels of care are required – from acute inpatient care to a range of supported accommodation options, as well as support for self-management within the community.

When you pick up early warning symptoms ... people need to be back in the system, but not back in the acute end. —Clinician

Early intervention has been recognised as a function of the mental health care system that requires innovation and action. Early intervention requires a mental health care system geared toward acting quickly and effectively, with minimal invasiveness and in a non-stigmatising manner, recognising the rights and needs of consumers and their families and carers. Primary care, and general practice in particular, are fundamental to effective early intervention by being in a position to recognise changes in the mental health status of consumers and ensuring that there is an appropriate and agreed service response. This requires strong partnerships with specialist mental health services who must respond when primary care services identify a need. Many jurisdictions have Memorandums of Understanding between their Divisions of General Practice and public mental health services and these linkages are constantly being developed and improved. However, in many jurisdictions there is still some way to go to achieve the type of early intervention responses that are required.

The strengths of the specialist mental health, primary care and psychiatric disability sectors need to be brought together and, while retaining their distinctiveness, recognise and enhance their synergy. This would encourage true partnerships to develop, thereby enabling seamless

transitions from acute care to follow-up and support services, and back to acute care if necessary.

The issue is around return pathways. We need a semi-permeable membrane, a lower threshold back into a higher level of care. —Clinician

Relapse prevention needs to commence in the treatment phase of the first episode and be ongoing, possibly for the entirety of a person's life. Delivering mental health care that is responsive to the many, diverse and changing long-term needs of consumers and their families and carers, requires working within complex systems of service delivery. This means developing models of integrated care, whereby innovative funding and service delivery methods support the coordination and delivery of continuity of care across episodes of illness, across the lifespan, and across services and sectors. This is a challenging task necessitating expanding service frameworks within and beyond the health system, to incorporate mental health and primary care, as well as disability, accommodation and welfare services, and education, employment and other sectors that impact on the recovery of people with mental illness. Models of these expanded and integrated frameworks are being developed in some areas and these approaches need to be encouraged and more widely adopted.

Inequities regarding access to some of the support services that are essential to recovery and impact on risk of relapse must be eliminated; in particular, access to disability services, accommodation, and domiciliary care need attention, but also access to employment, education and training, and income support. It is essential that barriers to support services and all discriminatory practices that restrict access for people with mental illness be removed.

There is need for more outreach and assertive community treatment options, particularly to reach people who are socially and economically disadvantaged, such as homeless people with mental illness and those with complex comorbidities, such as harmful alcohol or other drug use. Strong partnerships are essential and effective partnership models are beginning to evolve in some areas, particularly between mental health, drug and alcohol, and accommodation services. However, further development of partnership models is required, along with ways to sustain and embed partnerships as standard practice.

They are assertive outreach staff - they don't take referrals, they find people, their job is to link people with existing services. 80% of their target group are people with a serious mental illness who are in caravan parks and rooming houses and such like. We also have outposted to work with those people an RDNS nurse, so the three of them go out. For a while we also had a mental health clinician, so it was a team of four people. They would just visit people and say 'how are you going' and make sure they were ok. The nurse got to see they were ok, the clinician got to see they were ok, the two linkage people made sure they were getting the supports – the generic mainstream supports from the community that they needed. It worked really well, it was a great model. I think it had a big impact on people who were isolated and people didn't have to exhibit relapse signs, severe signs, before they got support.

—Psychosocial rehabilitation service provider

It is important to recognise the role of the community sector, and non-government organisations in particular, which are a major source of continuing care and support for people in the community. In most jurisdictions, services that impact on the risk and protective factors for relapse and that provide accommodation, psychiatric rehabilitation, and support services to consumers and their families and carers, are provided mostly by the non-government sector. However, while the demands on non-government organisations have increased significantly over the past decade, their funding base remains limited. This inequity needs to be addressed if these organisations are to have the resource base that enables them to

effectively provide services for consumers and carers. Access to psychosocial and psychiatric rehabilitation services will be facilitated by better resourcing and improved coordination and integration. Considerable effort needs to be applied to building up the community support and non-government sector to enable these services to meet levels of population need and to be integrated within a broader and more comprehensive mental health care framework that is easier for consumers, their families and carers, and services providers to access.

Workforce development

Positive attitudes, hope and expectations of recovery need to prevail within all the services provided for people with mental illness. This requires eliminating stigmatising attitudes and practices, and education of the many and varied workforces that provide clinical and psychosocial services. All service providers need to maintain a positive attitude toward people with mental illness, and their families and carers, and this will require innovative work and training practices that enable the mental health workforce to develop and maintain an optimistic approach to treating and supporting people who have been seriously affected by mental illness. Two innovations in this regard are peer consultants to acute and clinical services who provide positive role models of people coping well with mental illness, and the rotation of staff through different service settings, particularly acute care staff into community settings, so that they have opportunities to see people coping effectively in the community.

One of the things they need to do is to rotate nursing staff through acute wards, community and NGOs. Then they get to see people who aren't sick all the time. They won't get those negative impressions. —Consumer

Workforce development also needs to focus on supporting a more holistic and comprehensive approach to mental health care that emphasises a bio-psycho-social understanding of mental health (see Engel 1980), recognising that the factors that affect mental health and mental illness occur in biological, psychological and social domains. This means an emphasis on updating the knowledge and skills of service providers, as well as increasing their ability to work within partnership models and systems of integrated care.

Mental health services must reorient to routinely work within frameworks that not only aim to reduce the clinical manifestations of illness, but that support the empowerment of consumers and encourage personal capacity building and support self-management. This will entail training the diverse components of the mental health care system to interact effectively, so that specialist mental health services, primary care services, allied health services, psychosocial services, and inpatient and community services, all recognise each other as equal partners in the provision of continuing care and communicate effectively with each other. It also means accepting the central role of consumers and their families and carers, and being open to innovation and change as new evidence becomes available in this dynamic field.

I was very lucky, I've hit a stroke of luck in this new mental health service and outpatient unit. A social worker happened to pick up my file and decide to have a look through it and she could not believe what she saw, she thought, "My god, this person has been in the system for nearly 20 years and she's only ever seen a psychiatrist", and so she got the team together and said, "Right this woman has really not had any treatment except drugs". I was so lucky, I felt really humbled, I got offered a social worker to work with me. What I liked about it was then I knew what was going to happen, I had this process going. She got me to see this psychologist who has taken me through a whole lot of stuff – stuff I'd never done before and that has really helped. —Consumer

The importance of primary care must be highlighted. As reform of the mental health system has progressed and mental health care has moved increasingly from institutionalised care to care within the community, primary care has become an essential community resource: supplying information about mental health and wellbeing to the general community, meeting the increasingly complex and diverse mental health care needs of patients, as well as being the gateway to specialist health care and many allied health services. This is an extremely demanding role, one that requires a high level of support and continual learning. While there are many initiatives underway enhancing mental health care within primary care, these need to be expanded and prioritised to ensure that primary care, including general practice, has the capacity to fulfil its essential role in continuing care for people seriously affected by mental illness.

Information: monitoring, evaluation and research

Underpinning the implementation of any intervention or innovation is the need for information at different levels, and this also applies to relapse prevention. There is, firstly, a need to be able to identify programs that are related to relapse prevention and to monitor their uptake and implementation. The effectiveness of relapse prevention programs needs to be evaluated and their safety and quality monitored. Such monitoring requires high quality information systems that can generate relevant data in a timely manner. As noted earlier, it is currently not possible to identify people with psychiatric disabilities in many of the data collections outside the mainstream health sector, and this limits understanding of the utility of these services for people with mental illness.

Secondly, the evidence base around the factors that affect relapse needs development. There is currently little scientific evidence related to the risk and protective factors for relapse and the efficacy of psychosocial interventions, mainly because there has been little research interest in the area (see Jorm et al 2001). Such research needs to be encouraged and targeted. Research funding is a politicised process and advocacy is required from the mental health community to ensure that when such areas of research need are identified, concerted effort is applied to ensure that the resources are made available to undertake it.

We need to recognise the imbalance of research. We shouldn't assume that things that aren't well researched are not effective ... We're not going to get research dollars to look at the efficacy of psychosocial interventions as opposed to medical interventions, because you can't sell them. —Clinician

ISSUES FOR CONSIDERATION

To summarise, the following is a list of possible issues for consideration in order to progress the implementation of relapse prevention within continuing care for Australia's mental health care system.

For people who have been seriously affected by mental illness, the major issues relate to being empowered to incorporate relapse prevention as a tool within their own journey of recovery. These issues include:

- having information and support to accept and understand their health condition in ways that are developmentally and culturally appropriate;
- developing understanding of the following topics:
 - early warning signs of relapse, including symptom and reality checks
 - risk factors for relapse, including relapse triggers
 - protective factors for relapse and wellness needs
 - effective clinical services and approaches
 - effective psychosocial and psychiatric rehabilitation services
 - illness self-management tools;
- being the central force in their own treatment planning and continuing care;
- expecting services to engage them in continuing care planning that is regularly reviewed and comprises, as appropriate to the individual consumer's circumstances: discharge plans from acute and inpatient care; ongoing relapse prevention and wellness plans; crisis plans; as well as support to develop self-management plans; and
- being fully involved in the planning and evaluation of mental health services and empowered to advocate for service development and quality improvement.

For the families and carers of people who have been seriously affected by mental illness many of the issues are similar to those for consumers, but relate more specifically to their role in supporting the consumer while maintaining their own wellbeing. This includes:

- having information and support to accept and understand the health condition of the consumer, and their role in supporting the consumer's ongoing wellbeing;
- being involved in treatment planning and continuing care as appropriate and agreed by the consumer;
- ensuring that appropriate continuing care planning takes place and is regularly reviewed and that their role in this is explicitly acknowledged and negotiated;
- being able to advocate for service development and having their role in the planning and evaluation of mental health services recognised; and
- having family and carer support services in place to maintain their own wellbeing.

For primary care services, including general practitioners, the major issues are related to:

- understanding and negotiating their role in the continuing care of a person who has experienced mental illness, particularly their role in relation to recognition of early warning signs and agreed early intervention responses;

- ensuring that the physical health needs of people who have been seriously affected by mental illness are met;
- providing integrated and seamless continuing care pathways by working in effective partnership with specialist mental health services, other primary care services, allied health services, and providers of psychosocial and psychiatric rehabilitation services; and
- being actively involved in discharge planning and continuing care plans.

For case managers, the major issues are:

- coordinating the development of relapse prevention plans in collaboration with consumers and their families and carers and other relevant parties;
- regularly reviewing plans;
- ensuring that clients receive all the clinical, psychosocial and rehabilitation services they require to maximise their recovery;
- providing integrated and seamless continuing care pathways by working in effective partnership with specialist mental health services, primary care including general practice, allied health services, and providers of psychosocial and psychiatric rehabilitation services;
- identifying gaps in the services required to prevent relapse and advocating for the development of these services;
- having positive attitudes that support a recovery orientation; and
- keeping up-to-date with emerging evidence regarding the factors that reduce risk of relapse and enhance resilience.

For providers of non-clinical psychosocial and psychiatric rehabilitation support services, the main issues are:

- providing a service response that is able to meet community demand for support services;
- being recognised as an essential component of continuing care, and thereby included in relapse prevention planning;
- providing integrated and seamless continuing care pathways by working in effective partnership with specialist mental health services, primary care, allied health services, and providers of other psychosocial and psychiatric rehabilitation services;
- having positive attitudes that support a recovery orientation;
- training workers to have the appropriate skills and knowledge to provide services that prevent relapse and support recovery;
- removing any barriers to accessing disability and psychosocial support services for people with mental illness; and
- developing a more coordinated, comprehensive and integrated set of community and non-government services.

For providers of clinical services, the main issues relate to:

- making relapse prevention a routine component of treatment and continuing care;
- prioritising consumer participation, and that of families and carers if appropriate, in treatment and relapse prevention planning;
- ensuring continuity of care beyond the acute episode by providing integrated and seamless continuing care pathways through working in effective partnership with primary care including general practice, allied health services, and providers of psychosocial and psychiatric rehabilitation services;

- implementing effective and comprehensive discharge planning to provide continuity of care through ensuring that the necessary pathways and appointments for follow-up care are in place prior to discharge; and
- having positive attitudes that support a recovery orientation.

For service managers, workforce planners, and policy makers the issues relate to developing a mental health care system that can support relapse prevention initiatives and provide continuity of care across the course of an episode of illness, across the lifespan, and across service sectors. This means:

- developing service responses that support early intervention by having a lower threshold for gaining access to services;
- providing a diverse and appropriate mix of clinical, psychosocial and disability support services that can meet population needs;
- providing developmentally and culturally appropriate services and ensuring that service providers are trained in developmentally and culturally appropriate approaches;
- resourcing services, particularly the non-government sector, to a level that enables capacity to implement relapse prevention initiatives;
- providing outreach and assertive community services to meet the needs of consumers who are most disadvantaged and least able to access services;
- ensuring that all services work within a recovery orientation and that workers have a positive attitude toward people with mental illness, as well as their families and carers; and
- implementing training programs to update workforce skills so that workers in all the sectors that are involved in continuing care are able to work within integrated care pathways that prioritise the needs of consumers and their families and carers and are based on current knowledge of the factors that affect relapse.

Finally, the whole community has a role in preventing relapse. This includes:

- understanding the impact of everyday actions, particularly stigma, on the wellbeing of people who have experienced mental illness and their families and carers;
- refusing to allow discriminatory practices or stigmatising views of people with mental illness; and
- becoming more accepting, inclusive and supportive of people with mental illness within our communities.

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