Editorial

On quality of mental health care: Is Australia getting it wrong?

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In being Clinical Director of a large Child and Youth Mental Health Service, there are constant nagging questions to be considered about the quality of care we provide every day. Are the right clients being seen? How many potential clients are there out in the community with similar problems to those that are brought to us, who just cannot get to care? Perhaps no-one has recognised there is a problem, the professionals concerned (if there are any) never thought to seek further consultation or referral, everyone was put off by the waiting lists, the distances to be covered are just too long. Are there groups of clients who do not get to see us and really should? Are there groups of clients for whom we do not have the skills? Are the clinical assessments accurately telling us what needs to be done to change situations to the client family’s satisfaction? Do clinicians accurately diagnose the collection of problems? Does the right therapy exist in our service for the specific set of problems presented to us? Are we training the right set of therapeutic skills? Are clinicians able to utilise the skills we are training? What actually does go on in the clinical consulting room?

We do try to address many of these issues. In our service we have had the good fortune to gain specific funding, for instance, to set up community outreach services for young people involved in the juvenile justice system (CYFOS), we have a clinical team working in the local Youth Detention Centre, we have a collaborative program with the Drug and Alcohol service (MHATODS). We provide good orientation programs for new staff, and regular staff update sessions – often with responsibility for organising the presentation sessions being taken by community teams themselves (‘in teaching we learn’). We have ongoing focused therapy training for various groups, and are planning update training courses in specific modalities such as Interpersonal Therapy. But I still have nagging questions about what actually does go on in the clinical consulting room?

Of course we have clinical accountability. Regular supervision occurs with senior practitioners in the service, and some form of supervision is available in an ongoing manner for all staff. Even with new consultant psychiatrists, who theoretically have ‘jumped through all the hoops to become good safe practitioners, I provide 12-18 months of what we call ‘transition to consultanthood’ – which allows us to talk about clinical, interpersonal and administrative issues, and gives me both insight into the consultant, and some security in their ability to manage. In addition to supervision, we have an electronic record keeping system (which does occasionally provide feedback), and we have written notes, we have regular team discussions about both new and follow-up cases, and of course we have the Health of the Nation Outcome Scales for Children and Adolescents and the Strengths and Difficulties Questionnaires, and other scales to tell us about our outcomes. But I still have nagging questions about what actually does go on in the clinical consulting room?
Do we provide enough time, and in particular thinking time, for our clinicians? Are they accurate enough in the response to the sequence of minute issues brought up in sessions, voice inflections, body language, and other indicators of therapeutic alliance? In applying sometimes formulaic therapeutic interventions are they still able to assist the young client, and/or their family, to gain a sense of meaning? When we apply evidence-based practice to the consulting room and the individual case do we really get to the essence of solving clinical problems? What is the evidence for that? Are we really being effective and efficient if certain clients keep on coming back? This is a real question based on a real case. Recently I did an internal review of a long-term case with a young person with a mix of intellectual, speech and conduct problems in the context of a separated mother with bipolar disorder, and a dysfunctional extended family. Several therapists had spent about two years each on the set of problems not to mention the inpatient admissions, the case review sessions, and the ongoing angst about the emerging diagnosis. The therapists had been caring and supportive to the family, and certainly responded to all the crises in an appropriate manner. But the case had been part of our service for 11 years. Is that an efficient use of time and very scarce resources? Had we actually achieved any change? By what yardstick do we measure these things?

As a service we have adopted the complexities of promotion, prevention and early intervention (PPEI) - we are ‘early adopters’ -, and allocated considerable resources to training clinicians in somewhat new ways of thinking, as well as setting up specific programs. As examples, we now have a very active (and prize winning) program for children of parents with mental illness (KOPING), a superb collaborative program for the families of young children with multiple problems (Future Families), and a wide range of regular education programs for professionals in the community (which attract large crowds). Like all clinicians, ours moaned about the new national direction in the Second Mental Health Strategy (Oh no, not something else we have no time to do! On top of everything else...!). Now there is an integration of some of the ideas about mental health promotion not just being a Public Health program, but able to be utilised in the consulting room. But then is it? There I go again with that hard question about what actually does go on in the clinical consulting room?

The question is not just academic, or the foible of an ageing child psychiatrist. We have two circumstances where new money is being supplied to develop new teams. In response to the very adverse report of the CMC enquiry, recurrent funding has been supplied to the Department of Child Safety to buy in clinical services for the (often very troubled) young people under their care. Across Queensland (and based on equity of access) there will be nine new teams of about ten staff, with a strong focus on clinicians, a half-time psychiatrist position for each team, an a half-time evaluation position for each team. Such riches! Leaving aside the question of where we suddenly get 90 staff from, the central question is how do you respond to a challenge like this? How do we ensure that we have the skilled staff to do what may be very complex clinical work with the particular socio-economically deprived group represented? How do you develop a system of access and care to ensure that we not only do a good job for the young people and their families or foster families, but are also seen to be responsive and doing a good job for the Department of Community Services (DoCS). Funnily enough we began back to front looking at the demands of outcomes at the clinical level, the service level, the interagency level and the Ministerial level. Evaluation has driven the clinical and administrative process! This led us to provide clear parameters of functioning at all of the levels. But I am still pondering that essential question, and it has seemed to me through all of the meetings we have had, all of those clinical questions are brought into sharp relief. Well, of course, we could just supply a group of trained clinicians and sort of do ‘more of the same’, but we have felt this to be a fantastic opportunity to apply our best consensus knowledge, draw on evidence-based practice, and try to do the very best we can. It could, of course end up over time with us all just doing ‘more of the same’, but that would be a great shame.

Another fantastic opportunity, and one more relevant to this journal, and the processes that Auseinet has tried to drive in Australia, is that
provided by North Lakes, a new comprehensive suburb 35 minutes north of Brisbane. Again with new recurrent money to build a Child and Youth Mental Health Service from the ground up (alongside community health and adult mental health), we are being challenged to think through what we need to consider to build the very best service we can. We are using the PPEI framework and, in a series of workshops with broad representation from services and the community, looking at the kinds of collaboration we will need to ensure we can both manage the preventive frame (from Universal through Selective to Indicated approaches) as well as the pressure of clinical work in what will become a catchment of 150,000 people with a wide range of socio-economic backgrounds. And of course we must make it sustainable. I am not yet sure what we will end up with, but even with my long-term commitment to PPEI, I will have to ask all of those difficult clinical questions.

An emerging answer to both the DoCS and the North Lakes situations seems to relate to the quality of the clinicians we are able to employ. If we are looking for effectiveness and efficiency, with commitment to the clinical outcomes as well as provision of a sense of meaning for the young people and the families we see, then there is no substitute for highly trained, well qualified, experienced, and well supervised clinicians who have an ongoing fascination for the clinical process. One of the conundrums here is that if the clinicians are genuinely effective and efficient, then they will have time for reflection, and time to consider the wider range of programs necessary in a new suburb. If we are only able to employ young clinicians, or those who left a previous service because they were disaffected with the apparent daily clinical overload, we may well be in trouble.

So this brings me to the issue of quality and some of the pitfalls that may be emerging in Australia. There are more than rumours that nurse training may be reduced in universities to increase the numbers of available nurses and replenish the obvious need in our hospitals and the community. At one level you can see the logic, but does shorter training by implication mean that these people will come with fewer skills, and less experience? There is also more than just talk that the current graduate medical degree may be shortened to a two year graduate degree. Again you can see the logic given Australia is currently so short of primary care and specialist doctors. But does less training, and less time to reflect on a professional career, less time to weed out those who perhaps should not be practicing in one of the helping professions, mean that we get professionals who are less effective, less efficient, and more prone to give up under the sometimes intense pressures with which we all at times have to struggle. Leaving aside some of the current debates about professional incompetence (as if we can leave them aside with all the international media coverage) what is it about training that might protect professionals from burnout? Personally, I believe it is something to do with quality of training, the building of commitment and a passion for what it is that we do, a thorough knowledge of what it means to be ethical, and learning how to be both effective and efficient. Sometimes surviving a lengthy and somewhat arduous training is important to the quality of the end result.

Which brings me to the final area I want to discuss. I have recently had the privilege to bring together a Consortium to complete an application for the proposed National Youth Mental Health Foundation (I am sure we are one of many groups to tender). Again this is a fantastic opportunity to address issues to do with literacy in young people and access for those young people with mental health problems. It is also a fantastic opportunity to provide training to general practitioners, and allied health professionals who may have the opportunity to work in primary care with GPs. It is also an opportunity to consider carefully the models that can be promoted, improved, or developed as initiatives to improve service access for young people. And the stated framework is one of PPEI! Hurrah!

But there are some questions emerging for me about the program. It is three and a half years of funding, and therefore whoever gains the large grant will have the enormous task of building in some sort of sustainability to the Foundation and its programs. Another issue is that there are already many groups – State and Territory based as well as national – whose work already impinges on the area. Somehow all of these
groups will have to be drawn together – a ‘joining of the dots’ I have heard it called. But the question in mind is about quality. The pointy end of this whole process is that young people deserve the very best of care that can be made available, which includes the quality of engagement, the optimum development of a therapeutic alliance, and the ability to do effective, efficient and meaningful therapy to solve the problems presented by the young person. I have been a general practitioner, and we have recently been working with general practitioners to provide an audit of their ability to recognise mental health problems. What emerged from this process was the tremendous pressure that GPs are under to provide a rapid throughput of casework. We are asking a lot of GPs, even those committed to mental health issues who have trained through the Better Outcomes in Mental Health Care program, to expect that they will be able to make time to do a quality job. And coming back to my repeated question, how will we be able to assess just what occurs in the consulting room? I wish the successful tenderers every success in developing this massive venture. At the pointy end, the challenge may be to develop the quality of general practice mental health care and allied health care in primary care, or the quality of care in some innovative youth access programs. But we still must continue to improve access to care in dedicated mental health services and ensure that the professionals there are able to deal with the most serious of mental health issues in a timely, effective and efficient way because they are experienced, well trained and well supervised. The focus of the exercise really is the whole system and its quality.

Which brings me finally to this issue of AeJAMH, where it will be abundantly clear that we do have some very good quality articles. We have two thoughtful guest editorials which record the changes occurring in our mental health system. Lynne Freidli reflects on the launch of the UK National Framework for Improving Mental Health and Well-being. She notes that ‘tackling discrimination and social exclusion have received a stronger focus than promoting mental health’ thus far in England, and that this fine focus may have stopped the wider lens view of what factors in a society may be toxic to mental health and well-being. There are high hopes that there will be a refocusing on ‘how we live’, and its impact on ‘care of children, care of the self and social relationships’. Jennie Parham reflects on the recent Dublin conference ‘Mental Health Promotion: Going from Strength to Strength’, and her discussions with colleagues in the UK, who believe that Australia may be 10 years ahead in the development of preventive activity in mental health. Jennie rightly asks why we in Australia may not feel that this is so. After reviewing the current status in Europe, and then in Australia, she examines the ‘report card’ for Australia against a recent WHO framework document, noting that the complexity of our federation makes for difficulty in the translation of national policy into practice, concluding that considerable effort is still necessary to maintain the momentum we have with regard to mental health and its promotion against the pressure of the need for clinical service.

Two articles (Reid et al. and Maybery et al.) address the two sides of the care coin. Darryl Maybery and colleagues’ research on children of parents with a mental illness, reminds us of the need to develop and improve support and coping mechanisms such as ‘problem focused coping, developing adaptive cognitive styles, fostering social skills with peers and siblings’. However the children in the research also provide us with a challenge - to enhance the natural supports of the child, that is the peer group, especially in times of crisis when a parent is newly ill.

Joanne Reid and colleagues report on ‘the other side of the coin’ in a timely, challenging article based on phenomenological research on the needs of parents of adult children with mental illness. In recent years, we have heard so much about the children of parents with mental illness, that this is a refreshing reminder of a contrasting area of need. In focusing on psychoeducation, they address educational needs, barriers to accessing information and support, and other unmet carer needs, including the need for managing stress and emotional needs. My own experience is of being bailed up after Rotary forums where desperate parents frequently bewail the system which attempts to lock them out of the information system while expecting them to provide ongoing support and care. This paper is a timely reminder to think again.
Janice Chesters and colleagues explore the perspectives of fifteen residents about a supported housing program for people recovering from low prevalence mental health disorders, and address the importance of such accommodation in the community. The semi-structured interviews provide a sometimes poignant richness of comment. Overall, supported accommodation provides a treatment and living place, but more than that a venue in which to put together the right ingredients to help facilitate recovery.

Phillippa Farrell and Trish Travers report on Healthy Start, a program designed to build the capacity of the childcare workforce to promote the mental health of children. The research demonstrated increased awareness of risk and protective factors and referral sources, as well as levels of confidence in discussing mental health issues with parents, immediately after the training, but this was sadly not sustained over time. The crucial role of childcare workers, the needs they have for education, and the lessons learned from the program are explored.

Sarah Stewart provides a welcome exploration of how culture may mediate the inter-relationship between interpersonal trauma and suicide. In this very thorough review of the literature, she explores abuse, domestic violence and culture, considers these across a number of specific cultures, and notes there are gaps in our understandings of how culture mediates the inter-relationship between interpersonal violence and suicide. Sarah rightly challenges our current understandings about suicide and takes policy to task on the issue of domestic violence.

Finally, in a supplement to this issue of AeJAMH, Geoff Waghorn and Chris Lloyd provide an in-depth exploration of employment and mental illness, looking at education and employment opportunities as human rights, the disease burden of mental illness, and the inter-relationship of specific illness and employment. This comprehensive study goes on to look at the implications for the psychiatric disability support sector, and the development of policy. They comment: ‘although a range of promising vocational services and programs are available in Australia, the forms in which these are provided are the result of service systems evolving over time’. They then recommend six priorities for policy makers and funding providers which emerge from the study.
Guest Editorial

Promoting mental health in the United Kingdom: a case study in many parts

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… for Mack, who excels at the art of connecting.

Keywords
mental health promotion, public mental health, well-being

For while the tired waves vainly breaking,
Seem here no painful inch to gain,
Far back, through creeks and inlets making,
Comes silent, flooding in, the main.
Say not the struggle nought availeth. Arthur Clough

As this journal goes to press, England will be launching its first National Framework for Improving Mental Health and Well-being. The reasons why we haven’t had a strategy in England until now are, of course, primarily a matter for English colleagues to reflect on, along with a number of uncomfortable trends that we share with many other Western countries: the declining mental health of our children, the escalation in prescribing rates for antidepressants and the steady rise in stress related sickness absence. More broadly, however, the presence or absence of national strategies in the United Kingdom and elsewhere raises some interesting questions about what needs to be in place to achieve improved public mental health.

Public mental health takes a population wide approach to understanding and addressing risk and protective factors for mental health and well-being and has been defined as the art, science and politics of creating a mentally healthy society (Friedli, 2004; Scottish Executive, 2004).

In the UK, the term public mental health is beginning to take precedence over mental health promotion:

public mental health (of which mental health promotion is one element), provides a strategic and analytical framework for addressing the wider determinants of mental health, reducing the enduring inequalities in the distribution of mental distress and improving the mental health of the whole population. (Friedli, 2004)

This may be a tactical, rather than a conceptual shift, as public health is enjoying a renaissance, stimulated by a series of Treasury reports on the economic benefits of prevention (Wanless, 2002; 2003) and the recent launch of Choosing Health, the English public health White Paper (Department of Health, 2004).

Over the past decade or so, mental health promotion has inspired strong commitment, gained an impressive range of advocates and is beginning to lose its marginal status, hence the title of an international conference held in Dublin earlier this year: Mental Health Promotion: Going from Strength to Strength (http://www.charity.demon.co.uk/dublin/). What might be called the mental health promotion movement has contributed to a marked shift in the debates about mental health, from a
The extent to which public mental health will achieve better outcomes for people with severe and enduring mental health problems is an open question. In England, tackling discrimination and social exclusion have received a stronger focus than promoting mental health for all, notably with the publication of *Mental Health and Social Exclusion* by the Office of the Deputy Prime Minister and *From Here to Equality*, the National Institute for Mental Health’s (NIMHE) strategy for tackling stigma and discrimination on mental health grounds (NIMHE 2004; Social Exclusion Unit, 2004). Reasons for this include:

- the pressing need to address barriers to inclusion for people with mental health problems;
- lack of awareness of the relevance of mental health promotion to improved health and quality of life outcomes for people with mental health problems; and
- most stakeholders work within or use mental health services.

The launch of the national mental health promotion framework can be seen as an effort to provide greater leadership and support for a population-wide approach to improving mental health.

Notwithstanding these developments, public mental health could hardly be described as mainstream. What is needed then, to support the mental health promotion community and perhaps more critically, what do those of us committed to public mental health need to do to strengthen both the quality and status of mental health promotion theory and practice? This was subject of a plenary at the Dublin conference, where the differences between the UK and Australia provided a basis for reflecting on these issues (see Jennie Parham’s guest editorial in this issue: Parham, 2005).

Based on what is happening in the UK and Europe, it seems to me that developing the *art of connecting* is a key strategy (see Figure 1), and that this needs to focus on three areas:

- public debate and engagement;
- policy and emerging ideas; and
- the values underpinning our practice.
Public debate and engagement

The focus on stigma and discrimination has tended to preclude a wider debate about factors that are toxic to mental health, whether or not one has a diagnosis. We have a wealth of data on public attitudes to mental illness, but very little on public knowledge of what harms and hinders mental well-being; the mental health equivalents of smoking and car exhaust fumes.

The extent of control that individuals have over factors that potentially damage their mental well-being varies considerably and in many cases will be very limited. But greater public awareness and understanding of mental health as a resource to be protected and promoted could contribute significantly to reducing structural barriers. For example, prior to the widespread introduction of smoke free workplaces, many people had no choice but to work where they were exposed to second hand smoke. As awareness of the dangers of passive smoking increased, demand from unions and employees contributed to the adoption of workplace smoking policies. Rather than perpetual hand wringing about the public’s stigmatising attitudes, perhaps we should focus on building the same public demand for mental health and well-being as has been achieved for smoke free public spaces.

Emerging ideas

Many different disciplines and intellectual traditions can (and should) contribute more centrally to our thinking: we need to form alliances with colleagues concerned about the environment, violence and political conflict, the rise of fundamentalism, human rights, civil liberties and the implications of bio-science. Three areas of very specific relevance to mental health promotion also merit attention – the economics of well-being, health assets and ongoing debates about evidence.

The economics of well-being challenges the equation of economic growth with life satisfaction and reminds us of the cost of economic growth, notably the psychosocial impact of inequality and materialism (Layard, 2005; Marks & Shah, 2004; New Economics Foundation, 2004). It draws on robust evidence that the structure and quality of social relations are fundamental to well-being and provides a context for analysing how the drivers of economic growth undermine individual and community efforts to remain or become connected. The focus is less on individual psychological and cognitive attributes and more on the relationship between the organisation of society and how we feel. In the UK, a cross government Whitehall Wellbeing Working
Group has been established to explore how policies might change with an explicit well-being focus (DEFRA, 2005). This is an interesting development in the current political climate, where the rhetoric of civic engagement, participation and inclusion coincides with a simultaneous discourse of suspicion, intolerance and vilification of more and more sectors of the population. A contradiction that will not be unfamiliar to Australian readers.

Health assets or salutogenesis is an approach to public health that focuses on assets and resilience, rather than solely on deficit and vulnerability. It aims to maximise assets within a community, not just to reduce need. In mental health terms, it is the equivalent of measuring positive mental well-being, as opposed to surveys of psychiatric morbidity. This is important because strategies that focus on need may (inadvertently) reduce health assets, for example through fostering high levels of dependence on professional input; conversely, an intervention that enhances health assets, for example social networks, may have no impact on disease. In other words, interventions to improve health may be entirely independent of interventions to prevent disease:

Salutogenesis asks, “What are the causes and distribution of health and well-being in this group, community or country population”. Epidemiology asks “what are the causes and distribution of disease and early death in this group, community or population”. (WHO Europe, 2005)

Emerging research on health assets can help in making a robust case for the importance of mental health and well-being, both in ethical and in public health terms. It can also contribute to current debates about evidence and effectiveness: who is defining success and what measures are they using? The demand for evidence-based practice is likely to remain fundamental, but questions about what counts as evidence are growing louder. Factors informing these questions include a growing emphasis on:

- the impact of psychosocial factors on health, for example social capital, social inclusion and quality of life;
- public/patient involvement and the need to take account of consumer views in deciding what success looks like; and
- user led research, drawing on people’s own expertise in living and coping with mental health problems.

Mental health promotion can contribute centrally to the development of measures and methodologies that can capture a wider range of domains than symptoms, and a wider range of stakeholder perspectives.

Values

Faced with the relentless pressure to ‘do and deliver’, it is never easy to reflect on the values underpinning our practice. This is particularly true in an environment unsympathetic to intellectual work: we look longingly across the Channel in that respect. But a robust debate about first principles has never been more pressing: one of which might be that neither prevention nor cure necessarily result in health. For mental health promotion, this means considering whether mental health problems are like polio. Are the characteristics, attributes, insights and experiences associated with, for example, what we call schizophrenia or depression, to be eradicated?

This question is central in considering some of the potential problems with ‘raising awareness’ campaigns. At root, these invite the public to adopt a medical explanation for their problems and to seek medical help, while also, usually through case studies or first person accounts, highlighting the consequences of the disorder: stigma and exclusion. They do not invite reflection on economic and environmental causes. Public health warnings rarely include ‘inequality and injustice seriously damage your mental health’ or ‘fear of foreigners really screws you up’. The reinterpretation of problems as medical suggests that we’re not well, but always, already, potentially (medically) sick. The data used to support our case for the importance of mental health: one in four (lifetime prevalence), one in seven (point prevalence), every family in the land etc., reinforce the myth that mental health problems are a random misfortune, as opposed to a consequence of risk factors that are well understood and strongly associated with social and material deprivation (Melzer, Fryers & Jenkins, 2004; Rogers & Pilgrim, 2003).
Conclusion

It’s been said that the mental health equivalents of drains and clean water are respect and justice. For our own mental health we need to be heard, believed, understood and respected. Justice is about the distribution of the good and bad things in life in a way that is felt to be fair. There is overwhelming evidence that inequality – a key indicator of injustice – erodes mental well-being and that this is one of the key pathways through which deprivation impacts on overall health.

In the UK, we are still recovering from an eighteen year period in which community resources and infrastructures for challenging inequality were systematically dismantled. In this period of potential recovery, mental health promotion needs to build alliances with those communities who are already critical of ‘how we live’ and its impact on care of children, care of the self and social relationships. Of course public mental health needs resources and strategic influence, but it also needs a grass roots movement, one which mobilises against global and local trends that are toxic to the mental health and well-being of all of us. A National Framework for Improving Mental Health and Well-being in England that can contribute to this would be well worth waiting for.

References


Notes

1. To date, Northern Ireland (DHSSPS, 2003; Friedli, 2004) and Scotland (the National Programme to Improve Mental Health and Well-being http://www.wellontheweb.org/well/well_MainTemplate.jsp?pContentID=77&p_applic=CCC&pMenuID=157&p_service=Content.show&) are the only countries in the UK that have a mental health promotion strategy.

2. The WHO European ministerial conference on mental health, in Helsinki in January 2005, brought together all 52 countries in the European region of the WHO. Organised in partnership with the European Union and the Council of Europe, the conference’s declaration and action plan will drive the policy agenda on mental health for the coming years (WHO, 2005a, 2005b).


Guest Editorial
Promotion and prevention ‘report card’: Is Australia getting it right?

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Keywords
mental health promotion, prevention of mental disorders, international mental health policy

The last decade has witnessed an increasing international momentum in addressing mental health promotion and prevention of mental disorders. Positive mental health ‘is a state of wellbeing in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community’ (WHO, 2001). Mental disorders are found in people of all ages, regions, countries and societies, and are present at any point in time in 10% of the adult population. Furthermore, ‘the social and economic costs of mental ill health for societies are wide-ranging, long-lasting and enormous. Mental health promotion and prevention of mental disorder can be effective in leading to health, social and economic gains’ (WHO, 2004a).

It is widely recognised and understood that treatment interventions alone cannot significantly reduce the burden of mental illness and mental disorder. Positive mental health cannot be achieved by treatment alone because mental health is not about the absence of illness. Several international agencies and organisations acknowledge mental health promotion and prevention of mental disorders as a key priority. These include World Federation for Mental Health, Clifford Beers Foundation, World Health Organisation (WHO) and the International Union of Health Promotion and Health Education (IUHPHE). Mental health promotion and prevention has become the focus of an international conference World Conference on Mental Health Promotion and Prevention of Mental and Behavioural Disorders which began in 2000 and is held every second year. WHO (2004a, 2004b) has recently released two international policy documents on mental health promotion and prevention of mental disorder.

Australia is part of this worldwide movement. Recently, I had the privilege of attending and giving a keynote presentation at a conference in Dublin called Mental Health Promotion: Going from Strength to Strength (as mentioned by Lynne Friedli in her editorial in this issue: Friedli, 2005) which brought together people from the five nations of the United Kingdom and Ireland, along with several international colleagues. Before and after the conference, I met with some of these colleagues in their respective countries. One of the most consistent remarks made to me on my travels was how far ahead Australia was in comparison to the United Kingdom and Europe. ‘At least 10 years’ was the most common response. Since returning to Australia, I have spent time reflecting on Australia’s progress in addressing mental health promotion and prevention in the context of the international arena. Back in Australia, why doesn’t it feel like we’re 10 years ahead? Are we getting it right?
International developments

Before providing a somewhat subjective assessment of Australia’s progress so far, I will give a brief snapshot of some of the developments happening in various parts of the world including the United Kingdom, Europe and Australia.

The UK experience

Lynne Friedli has provided insights into the UK experience in her guest editorial in this issue (Friedli, 2005) highlighting the development of England’s first National Framework for Improving Mental Health and Wellbeing. As Friedli (2005) notes, ‘the only countries in the UK that have a mental health promotion strategy are Northern Ireland and Scotland’.

What is notable about the UK experience is that there is a broad policy landscape for mental health promotion which traverses a range of different sectors. Policies include National Service Framework: Mental Health (Department of Health, 2004a); Action on Mental Health: A Guide to Promoting Social Inclusion (Social Exclusion Unit, 2004); Choosing Health: Making Healthy Choices Easier (Public Health White Paper: Department of Health, 2004b); and Social Care Green Paper, Independence, Wellbeing and Choice: Our Vision for the Future Social Care of Adults (Department of Health, 2004c). It is interesting to note that although there is a separate National Suicide Prevention Strategy for England, it is also integrated into the Service Framework for Mental Health.

The National Institute for Mental Health (England) was established to support the implementation of the National Service Framework and assist in service improvement. It has eight development centres, aligned to the eight health authorities in England. Each development centre has responsibility for supporting implementation of the National Standards, of which Standard One is Mental Health Promotion and Standard Eight is Suicide Prevention. However, implementation and investment in mental health promotion fluctuates across the country.

Colleagues in England commented that the lack of country wide strategic coordination of activities had stalled progress in England. Perhaps the launch of the new Strategic Framework may alleviate this problem.

Scotland, on the other hand, has developed a very comprehensive approach to mental health promotion. A significant investment has been made by the Scottish Executive (2003) in establishing the National Program for Improving Mental Health and Wellbeing in Scotland. The National Program has four main aims: raising public awareness of mental health and mental illness and promoting positive mental health and emotional wellbeing; eliminating stigma and discrimination; preventing suicide; and promoting and supporting recovery. There are six priority areas covering population groups and settings. The policy is supported by a national program of support activities including collecting and disseminating the evidence base, research and evaluation, establishment of learning networks, and communication strategies.

In the process of developing their national program, Scotland undertook an international review of mental health policy and their conclusions were that Australia was leading the way in policy development. Scotland is also looking to Australia for implementation models and a number of colleagues from Scotland will be visiting Australia in the near future to examine and explore some of our initiatives.

The European experience

By far the most significant development in Europe is the Implementing Mental Health Promotion Action (IMHPA) network. With the participation of 28 countries and co-financed by the European Commission, the Ministry of Health, Welfare and Sport (The Netherlands) and the National Research and Development Centre for Welfare and Health (STAKES) of Finland, the IMHPA network provides a European platform that combines support for policy priority setting and the dissemination of evidence-based knowledge on prevention and promotion in mental health. The IMHPA network has been engaged in three main activities since April 2003: the development of a European Action Plan for mental health promotion and prevention of mental disorder, (Jané-Llopis & Anderson, 2005); the compilation of a web-based registry of evidence-
based interventions for promotion and prevention in mental health across Europe; and the development of a set of training initiatives, including a training manual for primary health care professionals.

The Netherlands has an extended system for mental health promotion and prevention within health services, clinics and NGOs. Many of these services have specialised promotion and prevention teams targeting mental health, financed by municipalities or the national health insurance system. Emphasis has been given to building the capacity of the workforce in the Netherlands: workforce development programs addressing mental health promotion and prevention have been developed and implemented.

Finland has been implementing the European Early Promotion Project since 1997. The national project has trained more than 2,000 primary health care nurses in half the country’s municipalities between 1997 and 2002. The training program included a manual on the identification of risk factors and focussed interventions to be used in primary care and with those working in day care and social services.

These are just some examples of developments in Europe and are by no means comprehensive, but they provide a flavour of the activity.

The Australian experience

At a policy level, Australia has developed national policy in mental health promotion and prevention: The National Action Plan for Promotion, Prevention and Early Intervention for Mental Health 2000 (Commonwealth Department of Health and Aged Care, 2000a). This complements the National Mental Health Plan: 2003-2008 (Australian Health Ministers, 2003). Other national policies which have a direct impact on mental health promotion and prevention in Australia include:

- LiFe: The National Framework for Preventing Suicide and Self-Harm;
- The National Strategy for Aboriginal and Torres Strait Islander Peoples Social and Emotional Wellbeing 2004-2009;
- Framework for the Implementation of the National Mental Health Plan 2003-2008 in Multicultural Australia;
- National Drug Strategy; and
- National Crime Prevention Strategy.

These strategies link the mental health sector with Aboriginal and Torres Strait Islanders, general practice and primary care, multicultural health services, drug and alcohol services, and local government.

The Australian Government has also invested in a number of national initiatives which support the implementation of mental health promotion and prevention strategies in a range of different sectors. These include, but are not limited to:

- Auseinet;
- MindMatters;
- Mindframe National Media and Mental Health Initiative;
- beyondblue: the national depression initiative;
- Better Outcomes in Mental Health Care Initiative;
- COPMI National Project;
- ResponseAbility; and
- CommunityMindEd.

These national projects and initiatives support the implementation of promotion and prevention in a range of sectors including health, media, journalism, education, and community services.

At the state and territory level in Australia, there is also a range of initiatives in place. Most jurisdictions have developed policy or an action plan to guide the implementation of promotion and prevention, funding commitments, and coordination mechanisms. Most have also made significant investments in initiatives and programs to implement evidence-based PPEI approaches.

Australia’s ‘report card’ - the current status of progress

In a briefing paper, produced for the WHO European Ministerial Conference on Mental Health in Helsinki, (WHO, 2004c), a number of challenges were identified in addressing the future implementation of mental health promotion and prevention activities. These challenges provide a framework I think is useful for assessing progress in this area. The key components for effective implementation of mental health promotion and prevention include:

1. Development of a comprehensive strategy for mental health promotion and prevention of mental disorder.
2. Establishment of infrastructure to support implementation. This includes organisational infrastructure, policies at the local level, capacity building, and workforce development.

3. Inter-sectoral linkages and collaborations. Mental health is a shared responsibility. It is not only an issue of mental health or public health, but also one of public policy. There is a need to engage support from other sectors such as social welfare, employment, housing, education, and criminal justice sectors.

4. An environment which facilitates a climate of respect for and protection of basic civil, political, economic, cultural, and social rights.

How well does Australia fare using this framework as a guide? Clearly, the perception of countries outside Australia is one of admiration. Is that consistent with the perception of Australians themselves? Do we see our progress the same way as the rest of the world sees us? Following is a subjective analysis of Australia’s progress so far, based upon my experience of leading Auseinet (Australian Network for Promotion, Prevention and Early Intervention for Mental Health: www.auseinet.com) for the past four years, and upon dialogue and interactions with many colleagues working in the area.

Comprehensive strategy

Australia does have a strong national policy framework in place. The National Action Plan for Promotion, Prevention and Early Intervention 2000 and its accompanying monograph Promotion, Prevention and Early Intervention: A Monograph, were released by the Australian Government in 2000 (Commonwealth Department of Health and Aged Care, 2000a, 2000b). At the time, it was a landmark policy on mental health promotion and prevention. In a national consultation conducted by myself and Debra Rickwood in 2001 (Parham & Rickwood, 2003), it was evident that there was strong support for the national policy from a range of different sectors and settings. Scotland released its policy in 2003 (Social Exclusion Unit, 2003), WHO in 2004 (WHO 2004a, 2004b), and the European Action Plan was released in 2005 (Jané-Llopis & Anderson, 2005). Many of these action plans and policies have been influenced by the Australian policy. More recently, Australia has added to this area in the development of policy for relapse prevention and recovery. This soon to be released policy Pathways to Recovery: A Framework for Preventing Further Episodes of Mental Illness will provide a platform for the development of recovery oriented services in Australia.

However, Australia, unlike the UK and Europe, has a federated system of government which includes three levels of government. At the national level, the policy platform is strong and is complemented by other national strategies and action plans. By contrast, at the state/territory level, policy development is less consistent. Most of the jurisdictions have developed policy and/or action plans for mental health promotion and prevention but not all are operational.

Overall, the progress in this area is substantial and significant but could be strengthened further, particularly at the state/territory level.

Establishment of infrastructure to support implementation

Australia may be regarded as having the best policy in the world, but what about implementation? Again, some of the challenges for implementation derive from having a number of levels of government and others from the tensions within the health system between ‘treatment’ and ‘prevention’. The consultation on the National Action Plan for PPEI identified implementation as one of the key issues to be addressed (Parham & Rickwood, 2003).

The Australian Government has made a significant investment and commitment to the promotion and prevention agenda in mental health. This is demonstrated by promotion and prevention being a key platform in the National Mental Health Plan 2003-2008 (Australian Health Ministers, 2003), the establishment of the National Mental Health Promotion and Prevention Working Party to guide policy development, and funding a range of national initiatives which either provide models for implementation or support implementation in a range of sectors and settings. Furthermore, the Australian Government has taken risks in investing in initiatives and projects that build capacity and address structural/systemic issues
(i.e. MindMatters, Better Outcomes in Mental Health Care, Auseinet, beyondblue) or that build partnerships with other sectors (i.e. MindMatters, Mindframe Media and Mental Health Initiative, ResponseAbility, CommunityMindEd). Most of these initiatives are developing international reputations and putting Australia on the global map.

At the state/territory level, the picture is a little different. The key drivers of this agenda (i.e. those with the funds to invest) are largely Departments of Health and/or Human Services and their respective Mental Health and Public Health Units.

There is acknowledgement at the jurisdictional level of the importance of investment in promotion and prevention. The big question is ‘Who is responsible?’ The answer quite often is ‘mental health is everybody’s business’, that is, it’s a shared responsibility. Sometimes, that can mean no responsibility. It would appear that despite good intentions and goodwill, progress seems slow at the state/territory level.

There are a number of reasons for this. From mental health’s perspective, there are a number of significant challenges. These include an under-funded and under-resourced mental health service system; a workforce that is predominantly trained in the medical model; and service models that are oriented to treatment rather than early intervention.

At a recent hearing of the Senate Select Committee on Mental Health in Australia, Auseinet presented to the hearing that other countries (particularly in the UK) were commenting that Australia is leading the way in mental health policy development. In the midst of all the ‘doom and gloom’ they were hearing, there was a good news story. However, good policy alone does not lead to effective implementation. Infrastructure does need to be put in place to support it, which includes organisational support, funding, workforce development and capacity building.

Implementing a promotion and prevention approach in mental health services requires a multi pronged approach that needs to include:

- Service reorientation;
- Workforce development;
- Attitudinal and cultural change; and
- Provision of a range of service levels to enable appropriate referral pathways.

Some of these strategies require additional funds in an already under-funded environment.

From a public health perspective, there is a need to make more effective linkages between physical health and mental health. In Australia, mental health has, largely, taken the responsibility to lead the promotion and prevention agenda, despite the national policy being signed off by both mental health and public health. Clearly, in England now with the release of the White Paper and the launch of the Framework, public health is rising to the challenge of providing leadership in this area.

The level of collaboration and partnership between mental health and public health fluctuates, but there is enormous potential for the expertise of those working in public health to be utilised to progress the mental health promotion and prevention work.

Implementation of PPEI at the jurisdictional level is largely determined by the level of infrastructure in place and in some cases, the energy and commitment of 'champions' or 'advocates.'

Overall, evidence of infrastructure to support implementation in Australia is progressing but patchy and based on champions. It needs to be embedded more in sustainable structures and systems.

**Inter-sectoral collaboration and partnership**

Achieving positive mental health requires the contribution of a range of sectors and settings. As Jané-Llopis states ‘many of these potential partners are not aware of the benefits they can gain from investing in mental health promotion’ (WHO, 2004c). She further states that ‘the health sector can provide leadership by engaging in active promotion and advocacy for mental health and by encouraging other sectors to join in multi-sectoral activities, sharing goals and resources’ (WHO, 2004c).

There is a real need for mechanisms to be put in place that facilitate the participation of other sectors in a meaningful way (i.e. memorandums of understanding, joint planning groups, collaborative partnerships).
Some of the best examples of inter-sectoral partnership in Australia are demonstrated in the area of suicide prevention. There are many projects that have multi-sector input and many of the state/territory plans for suicide prevention are whole of government.

VicHealth, the Victorian Mental Health Promotion Foundation, has a strong track record in working with many of the sectors outside of health, which they identify as some of the ‘key drivers of mental health’ as well as developing resources and workforce development programs that support the development of collaborative partnerships.

In general, this is the area that needs the most strengthening. There is a lot of energy for and commitment to addressing mental health issues from sectors outside health that needs to be harnessed and utilised. Non government organisations, in particular, are essential partners in ensuring accountability in mental health. Strengthening the NGO sector will be an important factor in the development of recovery oriented services as they are the primary vehicle for the provision of housing, rehabilitation, employment and support services.

Overall in this area, progress has begun but there needs to be greater investment and strengthening.

Respect and protection of civil rights

Creating a mentally healthy society involves eliminating stigma and discrimination. In Australia, the most frequently discriminated against include people with mental illness and mental disorder, Aboriginal and Torres Strait Islanders, refugees and detainees. They are the subject of a number of Royal Commissions occurring in Australia at this time. beyondblue: the national depression initiative, has certainly had an impact in Australia on reducing the stigma of depression and raising public awareness. There are a number of models of mental health literacy being implemented in Australia and the Rotary seminars have certainly assisted in that process. VicHealth has developed and implemented a major mental health promotion campaign ‘Together we do Better’, aimed at addressing one of the important social determinants, social connectedness.

Overall, Australia has not done very well on this dimension it would seem. There is a need for a more coordinated, strategic national approach.

Summary

In summary, there is a growing worldwide movement to address mental health promotion and prevention of mental disorder. Australia has led the way in the development of policy and in innovative initiatives and projects. In these areas, we are getting it right. However, in the area of sustainable implementation of evidence-based practice, engaging stakeholders from other sectors outside health and reducing discrimination, Australia has still a long way to go.

Despite the ‘pressures’ in the health system in Australia, there is a sense of urgency about ensuring that mental health promotion and prevention remains on the agenda, that progress increases and we do not lose the distinct advantages we currently have with an innovative, cutting edge policy platform. Otherwise, the rest of the world will catch up and benefit more from the investment Australia has made so far.

References


http://www.imhpa.net


http://www.euro.who.int/document/mnh/ebrief08.pdf
The psychoeducation needs of parents who have an adult son or daughter with a mental illness

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Abstract
Since deinstitutionalisation, parents of adults with mental disorders are increasingly utilised as a resource for their relatives’ care. This study used a general phenomenological perspective to capture people’s experiences. Semi-structured in-depth interviews were conducted with eight parents who were members of the Schizophrenia Fellowship of Southern Queensland to explore their perceptions of their psychoeducation needs. The themes that emerged included the usefulness of past experiences with psychoeducation, educational needs, barriers to accessing information and support, and other unmet carer needs, including the need for managing stress and emotional needs, recognition and inclusion of family members in decision-making, and negotiating the best care for their family member within the health care system. This study adds to an increasing body of knowledge that advocates for the greater inclusion and involvement of families in the care and treatment of their relatives. Further research into the needs of families, in particular barriers and supports in accessing information and services, is recommended.

Keywords
carers, psychoeducation, mental illness, supports, barriers

Introduction
Since deinstitutionalization, parents of adults with a mental illness have become a primary resource in their relatives’ care, often responsible for providing housing, financial assistance, emotional support, case management, and advocacy for their son or daughter (Parker, 1993; Solomon, Draine, Mannion & Meisel, 1998). Families, therefore, need information, support, education, and skills training to cope and reduce their burden (Solomon et al., 1998). Clarifying carers’ needs for education and support has shown to not only increase carer satisfaction but improves perceptions of mental health professionals and participation in family treatments (Ascher-Svanum, Lafuze, Barrickman et al., 1997).

Family psychoeducation developed to further complement and improve compliance with other treatments (Goldstein, 1995). Most family psychoeducation interventions aim to enhance knowledge by providing educational material about the aetiology, diagnosis, symptoms, and course of mental illness, as well as the treatment options, and resources available for housing and rehabilitation (de Groot, Lloyd & King, 2003). Family psychoeducation aims to address social isolation and stigma. This is achieved by directly increasing the size and complexity of the social network, by exposing the family to other...
families like themselves, by offering a forum for mutual aid, and by giving family members an opportunity to hear the experiences of other adults who have had similar experiences and found workable solutions (McFarlane, 1994). Programmes can provide therapeutic techniques to enhance coping, problem solving, communication, and crisis intervention skills (Gasque-Carter & Curlee, 1999; Goldstein, 1995; Goldstein & Miklowitz, 1995; Solomon, 1996; Winefield & Harvey, 1994). By better understanding the relevance of these programmes to the needs of family carers, future interventions may not only be more useful but effective.

Family interventions have been recommended for the treatment of schizophrenia (Lehman & Steinwachs, 1998). The literature has shown that these interventions can lead to improvements in relapse rate and outcomes, reduction of families’ expressed emotion, and enhancement of the problem-solving capacity of families (Bustillo, Lauriello, Horan & Keith, 2001; Dixon, McFarlane, LeFley, Lucksted et al., 2001; Penn & Mueser, 1996; Thornicroft & Susser, 2001). Family psychoeducation has important benefits for parental carers of consumers with schizophrenia including enhanced coping skills, adaptive capacities and satisfaction, and has shown to meet some of the educational and support needs of families (Barrowclough & Tarrier 1992; Biegel, Robinson & Kennedy, 2000; Dixon, Adams & Lucksted, 2000). As discussed by Dixon et al. (2001) and Solomon (1996), family psychoeducation can vary in a number of ways including the content of the information and the manner in which it is presented.

Previous studies have highlighted that valuing the subjective experiences and needs of parental carers cultivates a mutual appreciation and understanding when targeting interventions (Doornbos, 2002; Mohr & Regan-Kubinski, 2001; Saunders & Byrne, 2002; Tweedell, Forchuk, Jewell & Steinnagel, 2004). Therefore, this study aims to explore the personal experiences of families with psychoeducation programmes and other education on admission and in the long term as well as establishing what parental needs and barriers exist. The following research questions guided the study:

1. What role do family psychoeducation interventions play in meeting the educational and support needs of parents?
2. What other types of information and support are needed?
3. What barriers limit carer access to meaningful and useful information? and
4. What other unmet needs do parents feel are not addressed?

**Method**

The study design is based on a phenomenological approach, which emphasises the direct study of personal experience (Polgar & Thomas, 2000). In-depth interviewing was used to uncover the meaning of a lived experience by exploring participant responses to questioning (Seidman, 1991). The study asked for reflection on and discussion of issues relating to parents’ psychoeducational and family care giving needs and explored the personal experiences of families. The study met the ethical requirements of the University of Queensland and was supported by the Schizophrenia Fellowship of South Queensland (SFSQ).

**Participants**

Eight participants were recruited for the study. All were providing a major carer role to their son or daughter. The participants’ adult offspring had been diagnosed with schizophrenia, bipolar affective disorder or schizoaffective disorder. Several parents had more than one son/daughter with a major mental illness diagnosis. Seven of the eight participants were female and all were aged between 54 and 80. All participants resided along Queensland’s Gold Coast. The living arrangements of participants varied and appeared to fluctuate. Several participants did not live with their son/daughter, but visited them regularly at their homes or at inpatient treatment facilities, while other participants lived with their son or daughter. The sons/daughters of the participants were aged between 21 and 52 years. Seven were male and two were female.

**Procedure**

The selection of participants was purposive, as participants were deliberately approached with the help of a local carer support agency, the SFSQ. The researcher attended the SFSQ’s carer support meetings, gave a description of the study
and information sheet outlining the purpose and nature of the research. Carers were advised that they were under no obligation to participate in the study. Interview questions were formulated from the literature and through brainstorming with colleagues.

As one of the major aims of the study was to uncover the subjective experiences of the participants, data was collected through semi-structured in-depth interviews (see Appendix 1 for an outline of the interview schedule). For convenience, interviews were conducted at community locations before and after SFSQ carer meetings. Informed consent was obtained prior to conducting the interviews. Each participant was interviewed alone, unless they wished a spouse or family member to be present. Interviews were transcribed from audiotaped recordings. The computer programme NVivo (Qualitative Solutions and Research, 1999) was used to form a conceptual model of the links between the themes and concepts that emerged.

Rigour was ensured by the use of cross-check questions, participant checks, peer checks, and reflective journaling (Krefting, 1991). Throughout the interview, the researcher used paraphrasing and cross-check questions to ensure that the correct conclusions were made, without bias or distortion. Participants were sent a transcript of the interview and the encoded themes to clarify any conclusions, ensure the validity of the findings, and highlight any bias. The researcher also kept a journal of data collection and analysis experiences, which was used to judge the bias and limitations of the study. An independent colleague coded the data, which was then compared with the researcher’s coding scheme. Areas of agreement and disagreement were identified and discussed and categories were amended where appropriate.

Findings

The major themes that emerged from the interviews with the parents were experiences with psychoeducation, information and educational needs, barriers to accessing information and support, and other unmet needs.

Psychoeducation experiences

Participants discussed the usefulness of family psychoeducation, the inclusion of their son or daughter, flexibility and choice of programme, duration and frequency, and the location of the programmes as the most pressing issues.

Usefulness of psychoeducation. Participants showed mixed feelings about the usefulness of psychoeducation programmes in which they had participated. Some felt that psychoeducation programmes could not offer many new insights. ‘I doubt that anybody doing those programmes would know as much as I know’ (Participant 1). Others had found areas such as communication and coping skills were very useful. ‘Things like, the way you spoke, like I’ve heard it many times before, but when you, when it actually comes up, you know you should be using those skills’ (Participant 8).

Inclusion of family members. Participants shared ambivalence about whether or not the adult son or daughter with a mental illness should be included in the programme. They felt that their son or daughter may not recognise the importance of involvement due to a lack of insight into their illness. ‘They’ll say, I haven’t got that, there’s nothing wrong with me’, but that a chance to discuss issues with their son and daughter might be useful. ‘It’s good to talk in front of them, in my opinion, and say well this is what I see, even if you don’t. You’re entitled to say what you need to say’ (Participant 7).

Programme flexibility. Each of the participants was able to clearly articulate the format of educational programmes that would best suit their needs. Offering flexible programmes with alternate sessions was highly recommended by several participants. ‘I think they should be given at centrally located places and probably a variety of times, so perhaps they could run one course in the daytime and then an alternate one in the evening to accommodate everybody’ (Participant 2). When it came to attending programmes, another participant agreed that whilst they’d ‘probably work around it if it really looked good’ they would ‘probably be more inclined to go to something that was at a time that was suitable’ (Participant 8).

Home-based programmes. Participants dismissed the notion of holding psychoeducation programmes at a person’s home. Most participants thought that home-based programmes would be inconvenient and
negatively affect other family members, including their son or daughter with the mental illness.

If (my son) was home that would not be convenient, because part of the illness is that they don’t like strangers and they don’t trust strangers… they’re not comfortable with people coming into the house… and …I have a daughter who may not want to be involved and that would inconvenience her. (Participant 3)

Several participants also felt that home-based programmes would be unfair on the host.

I think you live under so much stress... but you like to go round and tizzy up a bit more if people are coming in to your home. So I think it’s better somewhere outside. (Participant 5)

**Barriers and supports**

As well as psychoeducation programmes, participants reported receiving information and support from many services and resources including health professionals, books, pamphlets, support groups, conferences, lectures, and the Internet to assist them with their carer role. Throughout this process participants identified a number of barriers and supports, which limited or encouraged their participation in programmes or access to information and services.

**Barriers to information.** Psychoeducation programmes that were held at night were not considered as convenient or accessible as ones held during the day. Due to difficulties of access to transport, fatigue and driving concerns, most participants agreed that night programmes would best be held at other times. Older participants found this of particular concern.

At our age now, we don’t like going out of a night time very much. Because we have eyesight problems and all that sort of thing, and you want to stay home because you get exhausted. (Participant 5)

Furthermore, participants identified access to programmes both for those who drive, ‘it’s a little bit far for me to travel at night... I’ve got a car, but its very dark, the road, you know, at night’ (Participant 6) and those who caught public transport ‘if they’re at night I won’t go out on buses’ (Participant 7). Another barrier to carer participation in educational programmes was the restriction felt due to the responsibility of caring for their son or daughter.

You can’t always just say, ‘Oh, well I’ll get up and go’. Like today, he was going for this interview, and I nearly went with him because, I thought he won’t be able to find where he was going. But I was lucky that someone else rang up and said that they would take him, so that let me come to the meeting, otherwise I wouldn’t have been here. (Participant 7)

**Attitudes of health professionals.** Doctors’ and other health professionals’ lack of empathy and understanding of carers’ needs was raised consistently throughout the interviews as one of the largest barriers to accessing information and support. One participant believed that she received no understanding from clinicians throughout her experiences as a carer, ‘I found them very cold...you don’t really get much empathy at all’ (Participant 6). Another participant reported a similar situation.

Well, I think with the health professionals, they become general public servants, we get the opinion they’ll... that it’s just a 9 to 5 job and then they go home. (Participant 5)

Parents spoke of the frustrations they experienced, particularly when they felt their intentions for their family member were being questioned ‘they must know we’re sincere and that we love our children to death’ (Participant 6). Overwhelmingly, participants believed that ‘everyone can do with more support when they’ve got anyone with any illness’ (Participant 7). Some participants believed that when they did feel empathy from staff, they found it gave them ‘the will to carry on’ (Participant 6).

Participants also highlighted that health professionals’ expectations of their level of understanding was another barrier parents faced when accessing information about their son or daughter’s illness and treatment. On admission, parents felt that more specific information from health professionals would have been useful. Several participants felt that health professionals ‘expect that you know what’s going on’ and therefore for many parents, information ‘wasn’t offered at all’ (Participant 2). Often the only information given to participants was from a brief discussion with a doctor or health professional. Participants spoke of the explanations and advice they had received on
symptoms, diagnosis, services, and coping strategies, with mixed opinions.

Whilst participants were able to identify some specific questions during the care for their son or daughter, many believed that they ‘didn’t even know what questions to ask’ (Participant 4). Many parents felt they needed more information about what to expect with treatments, especially when it came to medication and side effects. Most parents agreed that at some time throughout their family member’s illness they ‘didn’t have a clue what to do’ and were ‘just sort of walking in a blind state…sort of feeling my way’ (Participant 3). Parents agreed this was compounded by the fact they ‘definitely didn’t feel that we got enough information’ (Participant 4).

**Processing information.** Another barrier explored was whether families were ready and able to absorb information on admission. Participants had mixed impressions about the role of written information in overcoming this obstacle. One participant felt that ‘you get a lot of information in writing…but you don’t always take all that in’ (Participant 7). Another participant found that written information had seemed to have ‘gone in one ear and out the other’ (Participant 4). One participant concluded that because the information given cannot always be absorbed all at once, written information that can be regularly revisited was important and that pamphlets ‘are an important part of the learning process… because you cannot possibly absorb everything’ (Participant 1).

Many believed that admission was not always the ideal time to receive information, ‘I was too emotional, I think’ (Participant 7) and found that when given an opportunity to ask questions at this time it was not utilised, ‘it was like a shock so I had really no questions to ask, like I was blank’ (Participant 2). Many participants found the situation was ‘just all very floundering’ (Participant 4) and that for a long time they ‘were just in such shock’ (Participant 2). Participants concluded that there was a time that they started to need information to cope, but this time varied for each person.

**Searching for information.** Many parents appeared to compensate for their lack of access to information by becoming more assertive and proactive in their search for information and resources. ‘I don’t think I was offered much information from the hospital and I decided well I’m just going to have to learn about it for myself’ (Participant 4). They described the experience of having to ‘search things out’ (Participant 2). Even parents with many years of experience with mental illness found that there were ‘still learning’ (Participant 5) to ‘initiate’, be ‘more vocal’ and ‘stand up for myself’ (Participants 1 and 4).

Parents also saw the need for vigilance when it came to pursuing continual education and advocacy skills to increase their participation in their son or daughters’ recovery. One participant felt that unless consistent access to information and established services is maintained, it is difficult to manage care at times of crisis.

*I have noticed that when your child is well, you are well and when you’re child is unwell, you are unwell…you’re coping with all the changes and information and therefore it’s hard to get a lot of services into action if you don’t have that continuity of assistance.* (Participant 2)

Several participants felt that in hindsight some situations may have been easier if they had been kept better informed throughout their son or daughters’ care. Ultimately, participants agreed that maintaining contact with services and keeping informed is an important way to manage the carer role.

*I think you need to be vigilant, whether our child is well or not, to keep them going, to add more information, to support them, to build them up so they get more support, more government support.* (Participant 3)

Several participants highlighted the need for contact with other families through educational programmes or support groups. Participants identified that talking with parents in similar carer roles was positive because it gave them perspective. One participant stated that even though she had ‘been through hell’, hearing someone else’s story made her realise ‘it’s not as bad’ (Participant 5). Participants agreed that contact with others helped reduce isolation. ‘I think it makes you feel a lot better… when you meet others, you know that you’re not on your own. But otherwise you’re there thinking, I’m the only one that’s got this’ (Participant 5).
Participants believed that other carers and families provide an important support network. ‘You know you all have your ups and downs and you’re all there to give that support’ (Participant 7). Other participants even found it an important social contact to have a night out (Participant 3) or have lunch (Participant 6).

**Other unmet carer needs**

Throughout the interviews it was evident that parents were identifying a range of needs (other than for more information or education) that were seemingly unmet, which limited their satisfaction and affected the care of their son or daughter. These unmet needs included managing stress and emotional needs, recognising and including family members in care, and negotiating the best care for their family member within the health system.

**Stress and emotional needs.** Participants discussed their experiences with dealing with stress, grief and feelings of hopelessness, and the need to manage these emotions for good health. One participant did not know why many parents ‘don’t end up having a breakdown’ (Participant 6), especially after being told by her own GP that he couldn’t ‘do anything until your son gets well’ (Participant 6). Participants readily spoke of their feelings of grief and one parent felt that she was grieving for her son because he ‘wasn’t the person that was there before and you’re grieving for someone that has died’ (Participant 5). It was evident that participants experienced intermittent feelings of hopelessness but that they had an ultimate commitment to the ongoing carer role.

Sometimes you feel you can’t deal with it anymore, I love (my son) so much and I’ve decided that above all I feel we’ll be here for him, I feel I’ve had my life... I could never ever walk away. (Participant 6)

**Recognising and including family members.** The need for recognition and greater involvement was identified by families in almost every aspect of care for their son or daughter. Parents expressed their frustration at the lack of involvement and acknowledgment they received as carers. One participant felt that during treatment ‘we should be having a family discussion about it’ (Participant 1). Others agreed with the usefulness of including family members in treatment, however ‘it was never offered and it didn’t seem something that was too easy to arrange’ (Participant 2).

Whilst the need for recognition and involvement was sometimes unmet, there were occasions where families felt they were being consulted on the treatment and planning.

They’ve been really good talking to us... I used to go to the Doctor’s with him... that’s never a problem, as long as (my son) lets me go, they’ve always let me go in with him. (Participant 4)

One participant highlighted that ‘the best thing I think was being kept informed... even if they say, we can’t divulge anything, it’s still contact, it’s still saying well you are the mum’ (Participant 8). On occasion, participants outlined experiences where involvement and collaboration with health professionals was encouraged. Equally, participants had experiences where there was little to no inclusion of parents in treatment.

Several participants believed that, on occasion, not being involved in their son or daughter’s treatment suited their situation at the time as they had ‘been through enough trauma’ (Participant 6). There was general agreement that there should not only be greater choice as to whether parents are involved in the treatment of their son or daughter, but that opportunities for input are given in appropriate situations.

Many parents found that because their son or daughter was recognised as ‘an adult’ who was ‘over the age’ treatment teams did not have to include family in treatment or decision making processes (Participant 3). Often parents felt this was inadequate as their sons and daughters were often ‘too sick to get the information’ necessary for their best interest. Most participants agreed that in this situation, they, as carers should have been given the information on their son or daughter’s behalf as health professionals are ‘not only dealing with their patients, they’re dealing with the parents or the person who is caring for them’ (Participant 6).

**Frustration with the system**

Participants faced deep frustration when negotiating services and treatments within the mental health system, particularly when describing a need for greater continuity of
services their son or daughter received. Many felt this was important for the quality of care and support received. ‘There isn’t the continuity of the doctor; there isn’t the continuity of the service, there isn’t the continuity of therapy, which I think is a valuable part’ (Participant 2). For the majority of participants, inefficient collaboration between services became a source of frustration ‘I just felt there was no correlation between anything... that was a really big hole... but that was a big problem’ (Participant 8).

Participants felt that the adequate care and treatment of their family member was seriously compromised by both staff and hospital bed shortages. Parents felt that often treatment plans were ‘not followed through by the staff’ perhaps due to lack of time or because there was ‘not enough staff to get to it quick enough’ (Participant 2). Parents stated they believed that services ‘understaffed’ and staff ‘underpaid’, however found that ‘as parents, you can only consider one thing, what’s best for your child’ (Participant 2). Another participant stated that she understood the pressures on health services and staff, ‘I feel for them because I feel that they’ve got too many pressures and not enough staff’ (Participant 5).

Almost all participants had experienced a lack of hospital beds for their loved ones in times of need. ‘We thought we’d have to put him in to hospital he was so bad, but I knew there was no hospital beds’ (Participant 5). One participant told of the regular experience of ‘waiting all night long for him to get admitted only to be told he’s ok or there’s no beds’ (Participant 8).

Participants explained their frustration with the processes for accessing the mental health system, particularly when their son or daughter required involuntary treatment. ‘With a mental illness, it’s very hard for you to say... they need treatment, without them having to go through this long process’ (Participant 7). Participants described negotiating between the hospital, police and courts ‘It was a really difficult procedure... just negotiating the system’ (Participant 8).

**Advocacy**

Participants showed continued concern about the influence of community attitudes on their ability to discuss mental illness openly and identify a problem and access services. One participant found that her granddaughter was unable to communicate with other students at her school about her mother’s illness due to the surrounding stigma. ‘From ten to her age now, she hasn’t been able to talk to her peers because of the sickness’ (Participant 1).

Others felt that whilst they were fearful about discussing mental illness with someone else, opening up about it was easier than anticipated. ‘You go to work and you start talking about things and it’s just all too scary...but I’ve been really open about it... It’s quite amazing now when I start talking about it and they say ‘Oh yeah, I know somebody’. (Participant 4)

It was widely stated that the experience of carers and their families would have been made easier if governments ‘would educate the general public about mental illness’. One participant felt that better awareness would prepare families for the possibility of mental illness and lead to earlier detection and treatment.

**We ignored it more than what we should have done and we should have got him help sooner than what we did. So we need greater community education’. (Participant 5)**

**Discussion**

This study sought to understand the education needs of parents who have an adult son or daughter with a mental illness. The participants in this research spoke of needs concerning the admission phase, psychoeducation programmes and ongoing education and information. Furthermore, participants spoke about their feelings as well as other ongoing unmet needs. It would appear that consideration of some of these unmet needs could be incorporated into a psychoeducation programme.

Information needs at the admission phase appear to be the most problematic. Participants in this study wished for more specific information about the illness and what to expect from mental health services. Previous research has shown that carers are dissatisfied with the amount of knowledge they have and want more information about their family members’ illness and available treatments (Hodgson, King & Leggatt, 2002; Gasque-Carter & Curlee, 1999; Scharer, 2002; Winefield & Harvey, 1994). Participants expressed concern that they were often not
included in the management plans for their person with the mental illness. This is despite the *National Mental Health Plan 2003-2008*, which states that mental health services should become more responsive to the needs of carers and that their role must be recognised and supported (Australian Health Ministers, 2003). Noble and Douglas (2004) found that among other things, parents want more information, greater involvement in decision-making, and clearer management plans. It would be impractical to run a full psychoeducation programme for each new admission, and, as the parents indicated, they are so overwhelmed with emotion that they would have difficulty understanding a large amount of material. On first presentations to hospital, parents indicated they don’t even know where to begin to ask questions.

There may be strategies that could be implemented at the admission phase to help address parents’ concerns. Firstly, it may help to have an appointed person in each ward or hospital whose job is to meet with parents to explain personnel and procedures, and basic information on mental illness and medication. This person might then be available by phone or in person for further questions as they arise. In difficult situations, the person may also need to act as an advocate (as identified by Gasque-Carter & Curlee, 1999). The appointed person might be a staff member, an employed consumer or carer consultant, or a volunteer, perhaps from a non-government organisation.

Despite some participants in this study finding written information unhelpful, others found they were able to refer to it when they were ready. It may also allow clarification or memory prompts at a later date. For these reasons, it may be efficacious to provide written material to parents while their son or daughter is in hospital. It would also appear that ongoing education, and reminders to staff of the parents’ need for consideration and collaboration, would go a long way to alleviate problems encountered by parents.

This study confirmed previous research that found carers perceived a lack of communication and involvement in the treatment and planning with their son or daughter (Hodgson et al., 2002). Solomon et al. (1998) reported that clinicians frequently lack an awareness of families’ needs for information and this meant that families who do not express their needs effectively find them unmet. A number of studies have highlighted the importance of collaborative roles for families and mental health professionals (Doornbos, 2002; Peternelj-Taylor & Hartley, 1993; Saunders & Byrne, 2002; Tweedell et al 2004). It is important that professionals recognise the strengths of families and the tremendous burden that they cope with on a daily basis. Families with a collaborative relationship with professionals suffer less stress (Greenberg, Greenley & Brown, 1997). The work of Milliken and Northcott (2003), which parallels the parental experience of not being consulted or being silenced by professionals, with the plight of other oppressed and marginalised community groups needs to be pointed out to professional caregivers. The work of Mohr and Regan-Kurbinski (2001) also needs to be emphasised to professionals, which posits that families dealing with mental illness need as much empathy and understanding, as families with a long term illness such as cancer. The ongoing education and awareness enhancement of staff would require support at the highest level of management and policy.

The awareness of carers’ needs should not be limited to hospital staff as the lack of collaboration was also experienced when the care was transferred to community health services. To further assist parents to gain the inclusion they seek, teaching assertiveness skills in communicating their needs to health professionals could be included in a psychoeducation programme. Participants had several other suggestions on how psychoeducation programmes could better suit their needs. Having an impartial trained facilitator was seen as being important to ensure that the programme was relevant to all members. It has been reported that some models of family psychoeducation can be hindered by lack of programmatic leadership (Dixon et al., 2001). De Groot et al. (2003) suggested that the lack of training of facilitators and variability in programme content resulted in a limited impact on clinical outcomes and experience of caregiving.

The issue of having the adult offspring attend the programme was discussed but on the whole the
participants did not see that their offspring should be attending. When the son or daughter is not included, it gives family members the opportunity to freely discuss issues of primary concern to them (Solomon, 1996). Peternelj-Taylor and Hartley (1993) stressed that an important aspect of family psychoeducation was assisting families to sort out the feelings caused by the family member’s illness.

The participants established that flexibility and choice is important for the success of family psychoeducation programmes. Doornbos’ (2002) recommendations for the construction of a roster of topics or services for formal psychoeducation programmes that would enable families to choose participation based on their perception of their needs, together with Solomon’s (1996) reported success of open-ended programmes with attendance frequency and duration determined by a family based on their perceived needs, would appear to be a particularly useful model.

In practice this may mean that initially a list of topics would be scheduled, perhaps once weekly over two months, but in the long term other topics could be added as suggested by parents. Over a year or more parents could attend sessions they had missed because of other commitments or lack of relevance to their situation at the time (e.g. dealing with depression or burnout). This model supports the literature that emphasises the importance of ongoing guidance, emotional support and education for families, regardless of the length of time their family member had been ill and particularly during their son or daughter’s treatment (Dixon et al., 2000; Greenberg, Greenley & Kim, 1995; Tweedell et al., 2004).

Some studies have shown that home-based programmes are more accessible for some families, particularly low-income groups (Solomon, 1996). The participants in this study did not like the idea of home-based programmes as they felt it would be an imposition on the person hosting the session. Similar to research by Ascher-Svanum et al. (1997) and Gasque-Carter & Curlee (1999) participants seemed to show a preference for a non-threatening health care setting for family psychoeducation programmes. However, they were concerned about some of the difficulties in accessing programmes, most notably driving or catching public transport after dark. It has previously been reported that the barriers of transportation and distance and the responsibility of caregiving are common limitations for parents wishing to access psychoeducation programmes (Biegel & Song, 1995; Gasque-Carter & Curlee, 1999; Solomon, 1996).

Isolation and loneliness were common themes. Participants expressed the usefulness of family psychoeducation in being able to talk with other parents, giving them a new perspective on the situation. They also found family psychoeducation useful in reducing social isolation by increasing their social networks. Research in this area supports the idea that group family interventions help reduce isolation and loneliness felt by family members (Cazzullo, Bertrando, Clerici et al., 1989). They experience the support and validation of others in similar situations as they share experiences, feelings, problems, and difficulties (Peternelj-Taylor & Hartley, 1993), in addition to exchanging valuable information about the practical aspects of caregiving (Chambers, Ryan & Connor, 2001). Studies show that families do find the social support, interaction and networking with other carers as useful for providing crisis intervention, resource information, coping strategies, feedback, and empathy (Doornbos, 2002; McFarlane, 2001; Saunders & Byrne, 2002).

Overwhelming feelings were expressed by the participants in dealing with the illness and the effect it had on their day-to-day lives. This is a similar finding to other qualitative studies of families’ experiences in which overwhelming feelings were recurring themes (Chambers et al., 2001; Mohr & Regan-Kubinski, 2001; Saunders & Byrne, 2002). Furthermore, Mohr and Regan-Kubinski (2001) and Parker (1993) reported that the bereavement associated with having a family member with a mental illness is devastating as it is punctuated by remissions, which offer moments of hope that can make the loss seem ongoing and chronic. It might help to mitigate some of this pain if information on emotions often experienced by families with a son or daughter with a mental illness were incorporated into the programme, to reinforce that their feelings were shared by others. Coping skills
could also be taught. Importantly, professionals should provide a feeling of hope that recovery is possible. Apart from providing information, Linzen, Dingeman, van der Docs et al. (1996) emphasised the importance of allowing carers the time in the group to deal with their emotions, especially the parents of people with a recent onset psychosis.

Participants spoke about the need to educate the community and reduce stigma. Czuchta and McCay (2001) support the idea that reducing stigma would help reduce the burden that caring for a son and daughter places on parents. It has been suggested that a community that is perceived as rejecting makes life even more difficult for carers, and that steps need to be taken to create more supportive and understanding communities (Struening, Perlick, Link et al., 2001). It may be beyond the scope of a psychoeducation programme to be involved in public education and activism to improve conditions in the mental health system that parents found distressing, such as long admission processes and bed shortages. However, the programme could direct parents to organisations in the community whose brief includes these things, such as the Schizophrenia Fellowship.

Many of the issues and concerns identified in our Australian study are similar to other work exploring parents’ experiences of the mental health system. It is of concern that despite guidelines that support carer participation, it appears that in many instances these are not followed. The National Practice Standards for the Mental Health Workforce explicitly states that ‘mental health professionals [should] engage consumers, family members and/or carers as full collaborators in treatment, service planning, development, implementation and evaluation’ (Commonwealth Department of Health and Ageing, 2002:11). Furthermore, it is stated that mental health professionals should ‘develop a comprehensive care plan collaboratively with the consumer and other people nominated by the consumer’ (Commonwealth Department of Health and Ageing, 2002:25). This study has provided an important contribution to the literature concerning the perceived needs of carers around admission, especially first admission.

Limitations and further research

There are a number of limitations associated with this study. All participants were from one geographic area and had been involved in the same local mental health service. Participants were all members of the SFSQ support group and as such may differ in significant ways from the larger population of carers, in that they may be more proactive and have greater expectations of the mental health system. Despite these limitations, the findings of this research are presented in sufficient detail to enable readers to evaluate the relevance to their situations (Krefting, 1991).

Further research in this area is needed to better understand what parents with a son or daughter with a mental illness need, not only from psychoeducation interventions but from the health system as a whole. Whilst there is an emerging body of research on carer needs, greater investigation particularly of the subjective experiences of families, would give better insight into the positive and negative experiences of carers. Research with families shortly after they have participated in psychoeducation programmes would highlight which aspects of an intervention are most helpful at that time. Further investigation of the barriers and supports to accessing information or services could help shape future service development and delivery. Most importantly, further research needs to evaluate current or potential strategies that increase the level of carer participation in their relatives’ treatment planning and service delivery.

Conclusion

This study has explored the experiences and needs of parents who are caring for a son or daughter with a severe mental illness. Whilst the initial scope of this study was to target only the psychoeducation needs of families, it became evident that parents had many other, seemingly unmet needs. The participants of this study have raised many important and widely recognised issues for parental carers of people with a mental illness.

Whilst it is evident that parents are clearly able to articulate their needs, this does not imply that parents should have to become more responsible for the care of their son or daughter. Identifying
and addressing the needs of families should instead be about structuring services and supports so that meaningful participation by consumers and their carers can become a reality. This study adds to an increasing body of knowledge, which advocates for the greater inclusion and involvement of families in the care and treatment of their relatives. The emotive responses in this study highlighted not only the complex and sometimes distressing nature of caregiving, but also how this distress was intensified by structural barriers that prevented the fulfillment of family needs.

Acknowledgements

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persons with serious mental illness. Research in Community and Mental Health, 8, 181-204.


Appendix 1. Interview Schedule

Introduction and rapport building
Gender
Age
Suburb
Cultural background
Age of son/daughter
Date of diagnosis

1. Tell me about your experience with treatments for your son/daughter:

Admission
Has your child had experiences with:
- Involuntary admission
- Police involvement
- Seclusion

Were you involved in your son/daughter’s admission?
What sort of questions did you want to ask at admission? Were they answered?
What sort of initial information were you offered?
Could the information have been offered in a better way?

Treatment
Has your child ever received:
- Acute inpatient care?
- Counselling (for you or your son/daughter)?
- Group therapy?

Have you ever received:
- Counselling (for you or your son/daughter)?
- Group therapy?
- Family therapy?
- Psychoeducation?
  - When? For how long?
  - Where?
  - Was it individual or a group programme?
  - Did your son/daughter attend the programme?

Did you receive information about:
- Mental Health Act?
- Hospital procedures and admission?
- Crisis intervention and where to go for help?
- Diagnosis and what it means?
- Symptoms of the illness?
- Medication and side effects?
- Community resources?
- Communication and problem-solving?
- Coping skills?

Discharge
Have you or your son/daughter ever been consulted about or involved in:
- Treatment planning?
- Discharge planning?
- Goal setting?

Follow-up
Has your son/daughter ever received or attended the following?
- Case management?
- Psychiatric appointments?
- Rehabilitation referral?

2. How did you feel when your son/daughter first became ill? What sort of things would you have found helpful at that time?

3. Have you or your son/daughter ever sought assistance or information or help because you:
   - Could not find it from a health service or professional
   - Weren’t offered it
   - Were unsatisfied with the information already given
   - Needed further clarification

4. At what time did you have the most questions and concerns regarding your son/daughter’s well being? What time have you felt most prepared for answers or resources?

5. In what way would you find the information best presented?
   - Information packs?
   - Leaflets?
   - Individual counselling sessions?
   - Family psychoeducation?

6. If you were to attend a family psychoeducation programme, what times would suit you best to attend?
   - Evenings? Mornings? Afternoons?
   - Weekdays? Weekends?

7. How often and for how long would you find this programme useful?
   - Weekly? Monthly?
   - One session? Regular sessions for a week? Two weeks? Several months?
   - Ongoing?

8. Where would a session best be held?
   - At home?
   - At a hospital?
   - In the community?

9. Would you find a group session with other families useful, or would you prefer to attend sessions individually?

10. Is there anything you would prefer to have in common with other families?
    - Your son/daughter’s diagnosis or the times since their diagnosis?
    - Ethnicity?
    - Experience with health services

11. Are there any other comments you would like to add?
Children of a parent with a mental illness: perspectives on need
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Abstract
Being a child of a parent who has a mental illness involves considerable risk to the child’s secure attachment and long-term mental health. Parental mental health concerns place children at a significantly greater risk of lower social, psychological and physical health than children in families not affected by mental illness. In this paper, previous research is extended by examining the needs of these children from the perspectives of children, parents and mental health and welfare professionals. The study involved qualitative and quantitative data collection from focus groups with children and parents, and a comparison of quantitative findings with mental health professionals. Similar responses from the children and parents included problems with major episodes (e.g. parent hospitalisation), issues regarding coping and the importance of sibling support. Parents also identified a number of different issues (e.g. external support) compared with children (e.g. the importance of friendships). A final component of the research undertook a quantitative comparison of seven core ‘things that might help’ children in the circumstance of their parent being hospitalised. The findings showed differences between parents and mental professionals but most significantly with children. The findings overall are discussed in relation to the needs of children whose parent has a mental illness and recommendations are made regarding policy and service provision.

Keywords
attachment, mental illness, children whose parents have a mental illness, connectedness, focus groups, resilience

Introduction
In Australia, it is estimated that during their lifetime one in five people will experience serious disruption to their mental well being (Commonwealth Department of Health & Aged Care, 1999) and more than one million people will have a psychiatric disorder (Commonwealth Department of Health & Aged Care, 2000). In any 12-month period, up to 4.7 million Australians are thought to be affected by at least one mental disorder (Commonwealth Department of Health & Aged Care, 1999), with 12.6% of the population suffering an anxiety disorder, 9.5% an affective disorder, 9.5% substance abuse and 0.5% schizophrenia (Stedman, Yellowlees, Mellsop et al., 1997).

People with a mental illness and their families are among the most vulnerable in our community. Such families are more likely to experience social isolation, financial hardship...
and marital discord, which, together with the direct impact of the parent’s emotional illness (such as emotional blunting or delusional behaviour), involves increased risk to the child of a parent with a mental illness (COPMI), genetically, psychologically and environmentally (Rutter, 1986). Current research consistently shows a higher rate of behavioural, developmental and emotional problems in such children compared with those in the general community (Beardslee, Versage & Gladstone, 1998; Brotman Band & Weisz, 1988; Cicchetti, Rogosch & Toth, 1998; Compas, 1987; Klimes-Dougan, Free, Ronsaville, et al., 1999; Lazarus & Folkman, 1984). In addition, it is thought that between 25-50% of these children will experience some level of psychiatric disorder compared with 10-20% of children whose parents are not affected by mental illness (Worland, Weeks & Janes, 1987).

Furthermore, the core attachment needs of love, security, physical and emotional nurturing that are essential to the emotional and physical development and appropriate socialisation of children (Bowby, 1969, 1980; Karen, 1998) may be at risk within families where there is a parental mental illness. Bowby (1980) described attachment behaviours as actions engaged in by all humans to attain or maintain closeness to another. Attachment theory is based on the premise that an infant’s first attachment experience (usually with his or her mother) profoundly shapes the child’s cognitive and emotional development (Bowby, 1969) and later relationships (Ainsworth & Marvin, 1995; Karen, 1998). A parent, who responds sensitively and consistently to a child’s needs, sends messages that build an ultimate sense of security and self identity (Chase-Lansdale & Wakschlag, 1995; Howes, 1999; van Ijzendoorn, Sagi & Lambermon, 1992).

Sometimes, however, because of a parent’s mental illness (or for other reasons, including addiction or death), instead of sensitive, responsive nurturing an infant may face inconsistency and/or neglect. Such parental cues often lead to what has been referred to as avoidant, anxious or insecure/disorganised attachment, which in turn, have been linked to a variety of adverse outcomes (Erwin, 1998; Rutter, 1986). In addition, children whose parents have a mental illness may experience the trauma of family disruption and out-of-home placement due to the parent’s hospitalisation or inability to care for them on a day-to-day basis. As parental mental health problems are thought to impact negatively on parent-child attachment (Erwin, 1998; Rutter, 1986) it is, therefore, extremely important to examine the needs of children in such circumstances in order to enhance ongoing parent-child connectedness for the long term normal development of the child.

While there are considerable psychological risks associated with being a child of a parent with a mental illness, this group has frequently been referred to as ‘hidden children’ (Fudge & Mason, 2004) because adult mental health services and other professionals are often unaware that their clients are parents. In addition, there has been very little research in Australia that has examined the needs of children who have a parent with a mental illness (Fudge & Mason, 2004).

A focus group study with parents, undertaken by Cowling (1999), highlighted various issues for children whose parents have a mental illness, including continuity of care when the parent goes to hospital, educating children about their parent’s illness, a need for a support person for the children to talk to, as well as programs where children can meet other children in a similar situation. Aiming to develop Australia wide service guidelines for COPMI, Fudge and Mason (2004) undertook several focus groups with children and adolescents whose parent has a mental illness and found similar results, by highlighting the issues of parent hospitalisation, support, respite, communication and an ongoing need for community education to reduce stigma. Together, both studies (Cowling, 1999; Fudge & Mason, 2004) highlight important issues for COPMI in Australia.

An initial aim of the current research was to replicate the findings of Cowling (1999) and Fudge and Mason (2004). Another aim was to extend current research by examining different viewpoints regarding issues facing children whose parents have a mental illness. While it is important to understand a phenomenon from the consumers’ perspective (Rapp, Kisthardt, Gowdy & Hanson, 1994) a parent’s mental illness affects many members of a family and
consequently, there exist several different consumers, including children. Previous research has shown that need may vary according to the perspective from which it is viewed (Jorm, Korten, Jacomb, Christensen & Henderson, 1999; Jorm, Korten, Jacomb, Rodgers et al., 1999). Consequently, this study sought to determine differences in perspective on the issues facing children whose parents have a mental illness, by undertaking separate child and parent focus group interviews.

In addition, and with reference to the specific issue of parental hospitalisation (Cowling, 1999; Fudge & Mason, 2004), a final quantitative research component of this study sought to quantify and compare child, parent and professional perspectives of the activities that would best alleviate needs of children at such times (i.e. ‘things that might help’). While previous research has outlined a number of activities and supports that might help children when their parent is sick (or hospitalised) (i.e. Cowling, 1999; Fudge & Mason, 2004), this study sought to establish and highlight similarity and disparity of perceptions from the various key stakeholders. Comparing the perspectives of the various consumers, including children, with mental health practitioners is important as practitioners may assess and support families through their own cultural and class filters (Azar, Lauretti & Loding, 1998; Watzlawick, 1976). When identifying the needs of children whose parents have a mental illness there are multiple perceptions, interests, motivations and interpretations which might be highlighted. Identifying these various perspectives is seen as important in highlighting possible intervention and supports for those affected by parental mental illness.

Method

There were two components to this study. The first involved focus groups with parents and children from families where one parent had a mental illness. This aspect of the study was undertaken within the interpretative research paradigm and sought to describe events and situations within a specific context. The second component involved a brief questionnaire to quantify the impact of various strategies which might be helpful for children when their parent was hospitalised (e.g. how helpful is it to have other children who are in a similar situation to talk to?). The questionnaire was completed by the parents and children at the end of their focus group sessions and by mental health professionals as described below. Ethics approval was granted for this project by La Trobe University Human Research Ethics committee (A020/02).

Parent and child focus group participants

Participants were recruited from North East Victoria. The 12 parents included ten with a mental health diagnosis and two partners of a parent with a mental illness. Using self report, five parents had a mood disorder, three an anxiety disorder, three a personality disorder and one had a psychotic disorder (there was a high level of dual diagnosis). Fifty five per cent were single parents and their ages ranged from 29 to 46 years, with a mean age of 39 years. Initially, there were 17 participants in the children’s group, but after approximately 10 minutes, five of the younger participants indicated that they were bored and withdrew. The remaining 12 children ranged in age from six to 16 years; unfortunately more detailed information about the children (e.g. gender, age, mental health status) was not collected. However, it was estimated that the mean age was approximately eight years of age with a modal age of ten years.

Procedure

The focus group questions were prepared by the authors of this paper and the Steering Committee members (see acknowledgements), and guided by the results of Cowling’s (1999) previous study. Focus group questions are presented in Appendix 1. Initial questions were designed to facilitate a discussion of positive information as it has been found that recall of positive information can be hindered if negative information is presented first (Maybery, Maybery, Bresnan et al., 2001). As an overarching aim of this study was to establish and distinguish the issues for children whose parents have a mental illness from different perspectives, focus questions aimed to avoid leading participants to identify specific issues. The questions were developed to allow open responses according to participant experience. Questions were structured to suit the developmental age of the children.
The focus group facilitators were recruited from the Steering Committee and were selected on the basis of their experience in mental health and research. Two clinicians from the local child and adolescent mental health services facilitated the children’s group. The parent focus group was facilitated by the Supporting Kids project worker and an experienced adult mental health clinician. The focus groups ran concurrently for approximately 45 minutes. The questions for each group were in the same order to allow a comparison of child and parent perceptions of need. Participant responses were recorded on audiocassette tapes and subsequently transcribed.

The items on the quantitative questionnaire (‘things that might help’, see Table 2) were developed from the literature (e.g. Cowling, 1999) and from consultation with the Supporting Kids Steering Committee. The seven questions focused on key issues of support for children when a parent is hospitalised and required participants to rate how helpful such strategies were, on a zero (not helpful) to four (very helpful) Likert scale.

Mental health professionals

The mental health professionals’ responses to the seven ‘things that might help’ questions were taken from a larger ‘mental health worker’ study (reported in Maybery, Ling & Szacaks, 2002). The 62 participants were from the North East of Victoria and worked in community health centres, mental health services and from one inpatient facility (from Albury, NSW). The 16 males and 46 females included 12 mental health nurses, 12 general practitioners, 11 social workers, six psychologists, four occupational therapists, two youth workers, one psychiatrist, one support worker and 13 with unspecified mental health or welfare occupations. The length of experience working in mental health varied from no direct experience to forty years. The professionals completed questionnaires that had been distributed by Supporting Kids Steering Committee members or by mail with a reply paid envelope.

Results

Major themes for families experiencing parental mental illness were identified from audiotapes and hand written notes using frequency of mention and importance to participants. The seven core parent group themes and the five themes from the child group are presented in Table 1.

Parent focus groups

Issues around major mental health episodes or hospitalisation. Participants spoke of the difficulties associated with hospitalisation and major episodes. One parent suggested that a strategic plan be developed for each family for when a parent is hospitalised as this would help alleviate some of the difficulties associated with this process. Another commented that police need to be more sensitive to the needs of children when they are involved in the involuntary admission of the parent. A number of parents felt that children need to be debriefed following hospital admission of their parent by a mental health professional.

Importance of siblings. The majority of parents saw siblings as being a great support to one another and particularly as someone to rely on when the parent is unwell. One mother commented that it doesn’t matter how much her two children are arguing or disagreeing - when she is sick they put their differences aside. She indicated ‘mum’s sick and we have got to get in there and help’.

Table 1. Issues for children of parents with a mental illness (COPMI): Parent and child focus group themes

<table>
<thead>
<tr>
<th>Parent focus group</th>
<th>Child focus group</th>
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<tr>
<td>Major episodes (e.g. parent hospitalisation)</td>
<td>Major episodes (e.g. parent hospitalisation)</td>
</tr>
<tr>
<td>Importance of siblings</td>
<td>Importance of siblings</td>
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<tr>
<td>Coping strategies employed by COPMI</td>
<td>Coping strategies employed by COPMI</td>
</tr>
<tr>
<td>External support for COPMI</td>
<td>Importance of friendships</td>
</tr>
<tr>
<td>Education for COPMI</td>
<td>Extra roles assumed when parent unwell</td>
</tr>
<tr>
<td>Community education</td>
<td></td>
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<tr>
<td>Respite for parents and COPMI</td>
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</table>
**Children’s coping mechanisms.** In terms of coping strategies that children employ when the family is experiencing difficult times, some parents spoke of how their children would withdraw or not leave the house. There was talk of children taking extra roles, for example one parent stated that her child took on the mother role, while another parent said that their children ‘try and normalise, they make order out of chaos’.

**External support for children with a parent that has a mental illness.** When asked what would improve things for their children the majority of parent participants commented on the need for more support for the children, particularly from professionals. Statements like ‘someone to talk things through with’, ‘a qualified person to vent to’, ‘someone to ask the children what’s happening to you when mum or dad’s like this’ reflect the notion that parents felt it was important for the children to have more support.

**Education for children who have a parent with a mental illness.** When asked how much their children know about their illness most parents commented that while their children knew something about mental illness, they could benefit from more education. There was an agreement that the age of the child played a big part in education, influencing both what and how much to tell the child. Some parents commented that their children didn’t want to know what was wrong with them or didn’t believe anything was wrong with them. One parent wanted to know who should explain to children about mental illness; they made the comment that ‘workers don’t’. Other parents were curious as to how they should educate not only their children about the mental illness, but also their partners.

**Community education.** Parents thought that the community in general required more education around mental illness and issues involved for children who have a parent with a mental illness. A number of parents commented that within the community there was a lack of awareness regarding children with a parent that has a mental illness, in particular in schools. One parent made the comment ‘AIDS gets more publicity than we do.’

**Respite.** Participants considered respite to be important and helpful both for children and themselves. They also suggested that respite was necessary on a regular basis and should be both in and out of home.

**Child focus groups**

**Issues around major mental health episodes of the parent’s illness.** The majority of children said that the most difficult time for them was when their parent went into hospital, with the exception of one boy who made the comment that ‘it’s no different because mum doesn’t do anything anyway’. He went on to talk about how when his mother is in hospital it just puts more pressure on his father. Another participant said when her parent is in hospital she gets lethargic and depressed and finds it difficult to go to school. While some of the children in the focus group had a well parent or another relative to look after them while their parent was in hospital, some children (in the older age bracket) were required to find their own accommodation, which often resulted in a separation from their sibling/s. These children spoke of the difficulty in accessing transport when visiting their parent in hospital, having limited finances and feeling guilty if they continually asked friends to take them to visit their parent. The children also felt that a more family friendly environment within a hospital setting would be appropriate. Children also spoke of issues around the effects of medication on their parents. One boy described his parent as being unavailable because she was ‘doped up to the hilt’.

**Importance of siblings.** Participants frequently identified sibling relationships as a positive experience in their life. Several children said they felt their brother and/or sister were very supportive and that they could rely on them when things were not going well. The two facilitators of the child focus group commented on the closeness of the siblings that were in the group.

**Children’s coping strategies.** Some children described behaviours or coping mechanisms that might put them at risk for later maladjustment. For example, a few children spoke of withdrawing when the parent was unwell, including not going to school when their parent was in hospital. One child spoke
of not coping when her mother was unwell saying ‘my dog is the closest thing I have to human contact for days when mum is in hospital’.

**Importance of friendships.** Friendships were of great importance to the child participants. Most of the children said that their relationships with friends were positive and supportive. Some children also said that they went to a friend’s house as a way of coping when their parent is unwell.

**Taking on extra roles when the parent is unwell.** Some of the children identified taking on extra roles or jobs to help out when the parent is unwell. One child reported having to look after his parent. Other children spoke of the need to be quiet when their parent was unwell. Cooking and cleaning were other jobs that children mentioned they did when mum or dad was unwell.

**Comparing parent, child and professional ratings for ‘things that might help’**

In addition to the focus group interviews, children and parents completed a five point Likert scale (from zero: not helpful, to four: very helpful) to identify how helpful they felt various activities would be for children whose parent was hospitalised due to their mental illness. Results are shown in Table 2 along with data from the mental health professionals.

The table shows that the mental health professionals scored many items higher than did the parents. Also, apart from item number four (having a friend at school that you can talk to), the children scored all items considerably lower (over 1 point) than parents or mental health professionals. The children scored six of the items between 1.33 to 1.84 points lower than parents or mental health professionals. One way analyses of variance were undertaken to examine if there were differences in group scores for each of these items. Table 2 shows the summary statistics from those analyses including Student-Newman-Keuls post hoc analyses to determine specific group differences.

The statistical analyses showed that the children scored significantly lower on items 2, 3, 5, 6 and 7 compared to the workers and that both the children and parents scored significantly lower than the workers on item 1.

Table 2. Comparison of children’s, parents’ and mental health professionals’ (workers’) scores on ‘things that might help’ items.

<table>
<thead>
<tr>
<th>‘Things that might help’ children whose parent has a mental illness when the parent is hospitalised</th>
<th>Parents (n=12)</th>
<th>Children (n=12)</th>
<th>Workers (n=62)</th>
<th>df</th>
<th>F-ratio</th>
<th>p</th>
<th>Post hoc test</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Having more support from another person in your family who lives at your house? (^a)</td>
<td>2.25 (1.54)</td>
<td>1.64 (1.12)</td>
<td>3.48 (0.79)</td>
<td>2.81</td>
<td>21.68</td>
<td>&lt;0.001</td>
<td>Child and parent group lower</td>
</tr>
<tr>
<td>2. Being able to see/get together more often with someone from your family who does not live at your house?</td>
<td>3.42 (0.79)</td>
<td>2.00 (1.41)</td>
<td>3.36 (0.66)</td>
<td>2.82</td>
<td>14.44</td>
<td>&lt;0.001</td>
<td>Child group lower</td>
</tr>
<tr>
<td>3. Being able to see/get together more often with another adult who is not from your family?</td>
<td>3.45 (0.82)</td>
<td>2.09 (1.30)</td>
<td>3.15 (0.84)</td>
<td>2.79</td>
<td>7.57</td>
<td>&lt;0.01</td>
<td>Child group lower</td>
</tr>
<tr>
<td>4. Having a friend at school that you can talk to?</td>
<td>3.08 (1.24)</td>
<td>3.00 (1.28)</td>
<td>3.41 (0.78)</td>
<td>2.84</td>
<td>1.36</td>
<td>n.s.</td>
<td>No difference</td>
</tr>
<tr>
<td>5. Having other children who are in a similar situation to you to talk to?</td>
<td>3.33 (1.56)</td>
<td>1.75 (1.29)</td>
<td>3.37 (0.73)</td>
<td>2.83</td>
<td>14.45</td>
<td>&lt;0.001</td>
<td>Child group lower</td>
</tr>
<tr>
<td>6. Having time out from your situation?</td>
<td>3.00 (1.65)</td>
<td>2.13 (1.68)</td>
<td>3.46 (0.70)</td>
<td>2.82</td>
<td>8.38</td>
<td>&lt;0.01</td>
<td>Child group lower</td>
</tr>
<tr>
<td>7. Learning more about what’s wrong with your mum or dad?</td>
<td>3.50 (1.24)</td>
<td>2.25 (1.66)</td>
<td>3.66 (0.57)</td>
<td>2.83</td>
<td>12.41</td>
<td>&lt;0.001</td>
<td>Child group lower</td>
</tr>
</tbody>
</table>

\(^a\) In response to the importance of siblings from the focus groups, this question was specifically targeted as such in the worker questionnaire. It read ‘Having support from their brother or sister?’ in the mental health professional study.
Also of note, there were no differences between groups on the question, ‘Having a friend at school that you can talk to’. However, statistical analyses are problematic where there are large differences in the size of samples (see Tabachnick & Fidell, 2001, for details). The sample size from which the worker data emanated was much larger (n=62) than the parent (n=12) and child (n=12) groups. Consequently, some caution should be taken with the interpretation of this finding.

Discussion

In the discussion, an overview of the issues for children whose parents have a mental illness, from the perspectives of parents and children is outlined, followed by the various ‘things that might help’ such children (when a parent is hospitalised), according to children, parents, and mental health practitioners. Seven core themes for families experiencing parental mental illness were identified by parents in the focus group, and five themes were identified by children. Most of these core issues are generally consistent with previous research (i.e. Cowling, 1999, Fudge & Mason, 2004). The three themes that were common to the parent and child groups were: the problems associated with the parent having a major mental health episode (e.g. hospitalisations); the importance of other siblings as supports in times of crisis; and the development of various (often inadequate) coping mechanisms.

The findings confirm that a major time of risk for children is when their parent has a major mental illness episode (Cowling, 1999, Fudge & Mason, 2004). This suggests that the disruption to the family unit when a major mental health episode occurs has considerable ramifications for children. Responses indicate that such times put considerable added pressure on the whole family and may lead to mental health concerns for the children themselves. Consequently, future programs and services need to focus on assisting families to better manage at such times.

A second finding, from both parents and children, was that the way children coped with their parent having a mental illness might be a potential risk factor for the child’s future mental wellbeing. Withdrawing, avoiding and distancing were identified (by both parents and the children themselves) as coping strategies employed by children whose parents have a mental illness. In the coping literature, these strategies are commonly referred to as emotion-focused (Folkman & Lazarus, 1988) and are regularly labeled as ‘unhealthy’ if maintained as long term strategies (McCrae & Costa, 1986).

From a useful coping perspective, both groups identified the support of other children within the family as especially important. The children’s focus group identified the relationship with their brother/sister as positive generally and both parents and children highlighted the importance of sibling support when things were not going well in the family. Others have suggested that taking care of siblings leads to ‘…self confidence and a healthy sense of power’ (Brenner, 1997:160) leading to resilience in the face of difficult situations (Werner & Smith, 1982; Widmer & Weiss, 2000). The importance of sibling support is also consonant with Fudge and Mason’s (2004) study, which highlighted the family as an important source of support. Consequently, sibling support should be encouraged and not underestimated for its value as a coping mechanism that may encourage adaptive behaviour. While Cowling (1999) clearly identifies support from outside the family as important (e.g. meeting other children in similar circumstances, someone for children to learn to trust) the findings in the present study indicate that sibling support is considered essential for children when a parent has a mental illness and opportunities to encourage this needs to be incorporated in future programs.

Overall, parents and children identified two different sources of support. The parent group identified external support, education regarding the illness, and respite as being important. While parents considered it important for children to have someone professional to talk to, the children themselves identified friends as being very important in their lives generally and as people upon whom they could rely for support. Similar to previous research findings (Cowling, 1999; Fudge & Mason, 2004), the children also identified having to undertake extra roles when the parent was sick as being an important issue. Together these are important concerns for children and should be considered in future
programs aiming to address the needs of children whose parents have a mental illness.

The quantitative findings regarding the ‘things that might help’ children whose parents have a mental illness (when their parent is hospitalised) also highlight similarities and differences between the perspectives of parents, children and mental health professionals. While interpretative caution should be observed due to the statistical analyses employed, the most startling finding was that the children scored all but one of the seven items significantly lower than the mental health professionals and all but two items lower than their parents. Professionals might have identified supports as more helpful than other key stakeholders, because of their role in having to identify and employ appropriate supports for numerous families. Another interpretation might be that mental health professionals have a vested interest in being able to provide various services, such as the providing respite and educating others about mental illness (items six and seven). Parents on the other hand might have inflated and overemphasised their scores to encourage more resources and actions to be made available to their children. Equally, the children may not realise the gravity of their circumstance and have underestimated their need for assistance at such times. Regardless of these explanations the surprising finding is that the group of children scored significantly lower than the other groups on almost all items – this suggests that the view of the problem may be quite different depending on the perspective taken. Policy makers and program deliverers should heed the variety of points of view in their decision making regarding children whose parents have a mental illness. In addition, future research should be undertaken with equal size respondent groups to verify the current response differences.

A statistically non-significant between groups difference was noteworthy. The children rated ‘having a friend at school that you can talk to’ when their ill parent was being hospitalised at an equivalent level to parents and mental health professionals (i.e. between helpful and very helpful). This was notable because the child rating was one point more helpful than their ratings for the other strategies. Erwin (1998) also highlighted the importance of maintaining friendships in times of stress: ‘Unfortunately, many stressful situations may simultaneously disrupt friendships and hence remove them as a potential source of support’ (Erwin, 1998:9). This finding lends further support to the differences highlighted in the focus group data and indicates that maintaining and developing friendships for children whose parents have a mental illness is very important. Overall however, the remaining six strategies were not considered to be particularly helpful for children at the time of parental hospitalisation.

Given that the parent-child connection is at risk in families where a parent has a mental illness, it is important for such children to have the opportunity to develop other social connections, both within and outside of the family. Social connectedness emphasises the independent self in relation to others (Lee, Draper & Lee, 2001) and it is thought that family and peer connectedness are important for promoting resilience in young people generally (Fuller, McGraw & Goodyear, 1999; Resnick, Harris & Blum, 1993). Consequently, even if the parent-child attachment is broken or dysfunctional, a child’s resilience may be fostered through connectedness to another source. The children involved in the present study suggest their current sibling and friend relationships as important sources of connectedness. While future policy and programs should continue to develop external supports for these children, programs should also encourage and develop children’s existing support networks. Improving and developing such family and friendship connections may buffer some of the adverse effects that the parental mental illness has on adult-child attachment (Erwin, 1998).

Summary and conclusions

Although this study is limited in its generalisability due to the small sample size and need for replication across different samples (e.g. according to location, type of illness), three general areas of recommendations can be drawn from the findings. In conjunction with previous research findings (Cowling, 1999; Fudge & Mason, 2004), a central issue is the welfare of the children when the parent suffers a major mental illness episode and/or is hospitalised. The findings suggest that this is a key crisis period for the family that needs to be better managed. In addition, intervention for such children should
also focus on developing and improving support and coping mechanisms (e.g. problem focused coping, developing adaptive cognitive styles, fostering social skills with peers and siblings, encouraging the use of other support during times of crisis) and on education (e.g. about their parents mental illness and support services in their community such as respite, mental health services).

Finally, according to the children themselves, rather than emphasise external support, intervention needs to focus on enhancing and supporting existing sibling and friendship groups for children whose parents have a mental illness. Although this research was from a relatively small sample, the findings highlight the different perspectives on what might be helpful for children whose parents have a mental illness. Future research might consider the needs of different children, for example, across gender, ages and socio-economic groups. In general however, program developers, funding bodies and researchers should be cognisant of ‘whose perspective on the problem’ is underpinning decision making for COPMI families. In particular, the child or adolescent’s point of view should be regularly sought so that young people are empowered in their own lives, rather than being made reliant on supports outside themselves, which may not always be accessible or available. We need to ensure that programs do not exacerbate or reinforce young people’s needs, based on someone else’s perception, without making an effort to uncover the young person’s perception of their own needs and potential supports.

Note
Parts of this paper are adapted from a more extensive report by Maybery, Ling and Szakacs (2002) that was published privately for limited distribution, and from a paper presented at the VICSERV Conference 2002.

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**Appendix 1: Focus Group Questions**

**Focus group questions for children**

1. What are the good things about your family?
   - What are the fun, enjoyable things that happen in your family?
   - Who do you have the most fun with?
   - What sort of things makes it fun?
   - Who can you rely on the most in your family?
   - When you think back over the last few years what have been the three (get them to write these things down) most enjoyable things that you have done?
   - Do you sometimes think about or daydream about things that you have done in your family that make you happy? What are they (get them to write these things down)?
   - What are the things about your family that make it better than anyone else’s?

2. What are the not so good things about your family?
   - What sort of things makes it not so enjoyable?
   - Who do you have the least fun with?
   - Who are you not able to rely on the most in your family?

3. Does the fact that someone in your family is not well have an effect on you and your family?

4. Do you think that people treat your family different to other families?

5. How do you cope and what works well for you when there are problems in the family?
   - What things do you do?
   - Do you rely on someone outside of the family at such times?

6. What would help you most when you are not able to cope very well?

7. When do you feel like you need help the most?

8. When there are problems in your family do you receive help from people outside the family? What sort of things do these people do? Who are they? Are there factors that might stop you from seeking outside help?

9. Do you have any suggestions as to how we might be able to help you and your family?

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**Focus group questions for parents**

1. What are the good things about your family?
   - What activities do your children do that are the most fun for your family?
   - Do your children rely on other individuals/groups?
   - When you think back over the last few years what have been the three (get them to write these things down) most enjoyable things that you have done?
   - Do you sometimes think about or daydream about things that you have done in your family that make you happy? What are they (get them to write these things down)?
   - What are the things about your family that make it better than anyone else’s?

2. What are the not so good things about your family?
   - What sorts of things make it not so enjoyable?
   - Who do you have the least fun with?
   - Who are you not able to rely on the most in your family?

3. Does the fact that you or someone in your family suffers from a mental illness have an effect on your family?

4. Do you feel that your family is treated differently to other families?

5. How do you cope and what works well for you when there are problems in the family?

6. What would help you the most when you are not able to cope very well?

7. When do you feel that you need help the most?

8. When there are problems in your family do you receive help from people outside the family? What sort of things do these people do? Who are they? Are there factors that might stop you from seeking outside help?

9. Do you have any suggestions as to how we might be able to help you and your family?
Mental illness recovery and place

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Abstract

This paper explores fifteen residents’ perspectives on a supported housing program for people recovering from low prevalence mental health disorders in rural Gippsland, Victoria, Australia. It moves beyond the often unproductive institutional versus community care dichotomy to present a more complex consideration of the residents’ perceptions of supported housing as a site for recovery. This paper contributes to the literature on consumers’ experiences of mental health care in particular places. The residents’ narratives highlight the importance of supported accommodation as an integral part of a recovery focused service system delivered predominantly, but not exclusively, in the community.

Keywords

recovery, rural mental health, place, mental health promotion, community care

Introduction

Place, care and recovery

Reading Australian mental health policy gives the impression that governments and their health services have a clear understanding of the relationship between place and recovery. Policy and service provision have been shaped by the deinstitutionalisation debates of the 1960s to 1990s when the ‘healthy place’, the place of recovery, or the most ‘therapeutic environment’ moved from the asylum or mental hospital on the hill to the ‘community’ (Barham, 1992). Mental health system insiders - practitioners, consumers, patients or clients and their friends and families - while as committed as governments to the new cultural norm of care in the ‘community’, express a more complex and nuanced understanding of the relationship between place and mental health. These insiders reported difficulty gaining appropriate care in the era of large stand alone asylums and now say they find similar problems in getting effective treatment and care, beyond medication, in the community (AIHW, 2004; Deegan, 1996; HREOC, 2005; Prior, 1993).

Australian poet Sandy Jeffs (1993:22) has written in The Revolving Door about the problems associated with care and recovery in both the community and the institution:

It will be hard when she goes 
out to the hostile world.
It will be hard to survive dead-end boarding houses
or the half-way communities of suffering sufferers.

When the haunting delusions return,
and the way becomes unclear,
sadly it is back to the asylum with
the jangle of the keys and the closing of the doors.

In Jeffs’ poem both the community and the institution are seen as problematic. Jeffs doesn’t really need to work hard on her image of the
asylum as we are ideologically prepared by the deinstitutionalisation debates to shudder at ‘the jangle of the keys and the closing of the doors’. But why does she represent life in the community in the way that she does? Where are the pleasant images of country homes or inner metropolitan houses or apartments shared with family and friends? She represents it that way, we believe, because many people recovering from low prevalence disorders (usually associated with psychosis) find recovery difficult because they have problems accessing stable community standard housing and supportive relationships (Burdekin, 1993; Harvey, Evert, Herrman et al., 2002; Robinson, 2003).

While the location of care is important so is the nature and quality of care. An important element of asylum care was the ‘hotel services’ such as beds, food, physical health care and recreation (Rogers & Pilgrim, 2001). Community care, we argue, must also include these key care elements. Services can’t be adequately delivered or the recovery process commenced unless basic needs are met. Harvey et al. (2002:54) concluded that ‘even the best clinical services will fail to meet the needs of those with the most complex problems unless there is close co-operation with housing, welfare and disability support’. On the other hand we contend that housing, welfare and disability support services will fail this low prevalence disorder group unless access to effective clinical services is facilitated.

There is significant homelessness and loneliness among people with mental illness (for examples see Burdekin, 1993; Harvey et al., 2002; HREOC, 2005; MHCA, 2003). However, service users, consumers, patients or residents’ perspectives on these key issues are rarely published, although the work of Robinson (2003) is a welcome exception.

This paper offers some positive stories of residents of a psychiatric disability housing and support program in Gippsland, a region in south-eastern Victoria. We report briefly that our fifteen respondents reflect the well documented statistical profile of this population as presented in the literature. We then re-integrate nine key themes that emerged from our in-depth interviews into two key meta-themes, firstly the importance of a place to base recovery and secondly the lack of supportive, meaningful relationships for this group. Housing and support programs provide stable, affordable housing. However, despite the support of workers and other consumers, the all important meaningful relationships prove more difficult to provide.

**Affording care and recovery in the community**

In a fourteen country study ‘active psychosis’ ranked higher than paraplegia and blindness as the third most disabling health condition (World Health Organization, 2001:x,33). Research in Australia indicates that 85% of the low prevalence disorder population receive a government pension or benefit (Harvey et al., 2002). A study by Lambert, Ricci, Harris and Deane (2000:5) found that the income levels of 87% of their respondents with a psychiatric disability were in the two lowest income quintiles compared with 36% of the rest of the Australian population. This study also showed that people with a psychiatric disability were much less likely to own or be buying their own home (27% as compared with over 70% of the Australian population as a whole). Significantly Harvey et al. (2002:xi) report on late 1990s survey data showing 42% of survey respondents ‘living with psychotic disorders in marginal accommodation in Melbourne’, compared with 21% of a similar cohort of respondents in a study in 1989.

In addition to low incomes and poor access to stable, affordable community standard housing many people recovering from low prevalence disorders are socially isolated (Harvey et al., 2002). As relationships such as marriage, partnerships and friendships are closely linked to housing affordability, especially home ownership, relative poverty in addition to social isolation is likely to result in dependence on parents, government support or residence in marginal commercial accommodation such as boarding houses and caravan parks. Marginal accommodation is often associated with increased use of alcohol and other drugs and increased exposure to violence and stress (Harvey et al., 2002; Robinson, 2003). Residing with parents, while often a cost effective alternative, is stressful for adolescents and older people as well as for parents acting as carers (Siegloff & Aroni, 2003).
Developing the principles of supported housing in the community

The debates around deinstitutionalisation have resulted in a powerful ideological commitment to community based services and living and have assisted the formation of a stronger consumer or service user movement as well as the development of a theoretical basis for supported community living (AIHW, 2004; Deegan, 1996; Howie the Harp, 1990; HREOC, 2005). When asked, consumers have shown a preference for independent living and ordinary housing in the community. As Howie the Harp (1990:85) reports, if you ask mental health clients or consumers where and how they want to live the overwhelming answer will be ‘in my own place’, or ‘in a place shared with someone of my own choosing’. This strong and unequivocal commitment to western cultural norms of independence and independent living, tempered by the reality of service users need for support, encouraged Hogan and Carling (1992: 220-223) among others to try to define a new paradigm of ‘supported housing’. The key supported housing parameters include the requirements that:

- Housing must be chosen by consumers
- Neighbourhoods should be chosen based on their likely ability to assimilate and support consumers
- The number of labelled or stigmatised residents in relation to the total number of residents in the overall housing unit is critical and should be limited and consistent with community norms
- The appearance of housing should be consistent with neighbourhood norms

They added that the distinctive nature of psychiatric disability ‘dictates’ three extra guidelines:

- Housing which keeps levels of stress manageable should be selected
- Housing should enhance stability, not be time limited
- Housing should enhance opportunities for control over the environment.

These classic ‘supported housing’ guidelines are underpinned by a theory of staff behaviour that recognises that it is the client, or resident who should control entry and day to day life style decisions (Ridgway & Zipple, 1990:19). These highly idealistic principles reflect ideologies of normalisation, human rights and disability rights and continue to theoretically underpin the current provision of supported accommodation and government housing in Victoria in the 21st century.

Supported housing policy implementation in Victoria

In 1992/93 two sections of the Department of Human Services (DHS) in Victoria set up a coordinated Housing and Support Program (Robson, 1995). The Mental Health Branch and the Office of Housing worked with the newly emerging psychiatric disability rehabilitation and support services sector (PDRSS) to deliver housing and support programs (McKenzie, 1998; VICSERV web site). To date in Victoria, a state with a population of approximately 4.5 million, there are approximately 1,202 public housing properties in this program in regional and metropolitan areas (DHS Office of Housing, 2004:20). The support for residents in this program is provided by PDRSS’s funded by DHS. The residents are (in most services) tenants of the Office of Housing and enter into semi-formal to informal negotiated support relationships with their designated PDRSS support service. Robson (1995:1-3) evaluated the program and found that the resident turnover was low, that residents enjoyed ‘increased wellness, characterised by such measures as reduced hospital stays’. Harvey et al. (2002:x) reported that ‘residents of supported accommodation seem to be doing better than [people living in marginal or institutionalised accommodation]’.

SNAP - a housing and support provider

In this study we focused on interviewing residents receiving services from one agency; SNAP Gippsland Inc. SNAP is a non-government organisation in regional Victoria that provides a range of services for people recovering from serious mental illness, principally low prevalence disorders and associated psychiatric disability. SNAP became involved in the state government’s housing program in 1993 and is now responsible for 23 properties in Sale and Bairnsdale, and the nearby holiday and fishing town of Lakes Entrance. SNAP, DHS and the Office of Housing work closely together to run the local supported
housing program. The Office of Housing first identifies suitable properties that can be spot purchased (that is, they are stand alone properties, not part of public housing estates) and then SNAP workers and the Committee of Management, which includes past and present consumer representatives, inspect the properties. The aim is to find convenient properties in good residential streets, close to facilities and services.

The units SNAP has allocation rights over are all two bedroom modern brick single storeyed units. A lack of one bedroom units in these rural locations resulted in roomier and more comfortable properties being bought, and although the units have two bedrooms, SNAP made the decision to offer the entire unit to one person or one family group and received approval from the Office of Housing to do this. Having had experience with a group home, management and workers were convinced that single person or single family occupancy was more in tune with clients’ wishes and housing needs, a conclusion supported by Robinson’s research (2003:24). Residents have security of tenure and can continue to occupy the property irrespective of their support needs. Rental payments are based on a percentage of income and if residents need to go into hospital the rent is reduced to a nominal sum and the property remains for them to return home to when they are well.

Researching residents’ experiences

Participants

In this Monash University-funded and ethics approved study, we were keen to hear how residents recovering from low prevalence disorders and coping with psychiatric disability managed in their supported housing. All twenty-one current and one immediate past client of SNAP’s housing and support program were asked to participate in interviews. Four people declined to be interviewed, two were hospitalised and unable to participate and one could not be contacted. The fifteen service users who participated - eleven women and four men - were renamed Sheila, Jackie, Bill, Deanne (who had recently left a SNAP unit and bought her own house), Joanne, Cathy, Barb, Heather, Deborah, Anne, Helen, Paul, Maureen, Mick and Jacko. The ages of the residents ranged from the late thirties to the mid fifties, except for Jackie who was twenty-six. All of the residents were of Anglo-European descent except Mick, who is an Aboriginal Australian. Three staff members were also interviewed. The residents lived alone, except for Jackie, Cathy and Deanne who live with their children, and Anne who has recently begun to share her house with another SNAP service user, Joanne.

Service users were referred to SNAP by the area clinical mental health service or by local general practitioners. While disability support services are not preoccupied with diagnosis, all respondents had a diagnosis of a low prevalence disorder such as schizophrenia, bipolar disorder or a personality disorder. No respondents had been long term residents of asylums or mental hospitals, but they were all ‘known’ to the mental health system and have made intermittent use of in-patient services, usually acute in-patient units that have been relocated from stand alone psychiatric hospitals to general hospitals. All fifteen participants reflected the statistical profile of mental health service consumers, that is they were all living on low incomes, usually disability pensions, and were either unemployed or underemployed. Before moving into their houses residents had either moved between caravan parks, hotels or boarding houses, or lived at home with parents, or with violent or uncongenial partners.

Interviews

In-depth, semi-structured interviews were arranged and conducted by RJ with the assistance of a male volunteer and mental illness service consumer advocate who conducted two interviews. RJ had no previous connection with the residents and she made her separation from the agency clear at all times. Interviewees could choose the time and location of the interview. In the interviews we asked a series of open-ended thematic questions and encouraged participants to speak about their houses/homes and the support they received from SNAP. Residents were asked to describe their house, or place (both physically and emotionally); what they liked and did not like about their house; if the house felt like home and why or why not; how their experiences of their houses changed over time; and their ideal house. They were also asked to give their opinions of the support
services they received from SNAP. The interviews, which took between forty-five and ninety minutes, were tape-recorded and deidentified before being transcribed (Denzin & Lincoln, 2003:74-77).

The interviews would fall largely into an ‘emotionalist’ framework (Silverman, 2001): they aimed to elicit subjective experience, and gauge personal attitudes, perspectives and lived experiences. The interviews produced highly subjective data about residents’ feelings, thoughts, experiences and desires about living in a housing and support program house. We do not see subjectivity as ‘bias’ from the ‘truth’ but as important knowledge in its own right (as per Crabtree & Miller, 1991:146; Silverman, 2001:90-94).

Analysis

The interviews were analysed using Strauss and Corbin’s (1998) description of open coding, Silverman’s (2001) description of the development of themes and a modified version of Colaizzi’s (1978) seven steps of phenomenological analysis (the seventh step was omitted). Nine key themes emerged from the interviews: identity, privacy and autonomy, stability, physical comfort, domesticity, support, homeownership and love and loneliness. These themes were identified, separated, introduced and briefly discussed in a previous article (Jones, Chesters & Fletcher, 2003). In this paper we want to focus on two key meta-themes that emerged from our analysis of the interviews: the importance of a place to base recovery; and the issue of loneliness and the lack of supportive meaningful relationships for this group. We have done this by re-integrating the themes and focusing on stories that represent the experiences of all fifteen residents.

Results

The importance of a place to base recovery

Fourteen of the residents reported that they were happy with their units and all felt supported by SNAP support staff. Like most people they daydreamed about living in different and more luxurious homes, some also dreamt of owning their own home. They also spoke about their hopes of finding that ‘someone special’ to live with in their house and make it more of a home. Most residents felt an increase in control of their lives and stability since moving into their unit. They were able to decide who came in to their home and who didn’t and were keen to make their mark on their house. Two male residents didn’t decorate and one found the two-bedroom unit model too small, too sterile and too restrictive, and yearned for room for children to play, wood to cut and animals to feed.

Nine of the women residents had experienced either physical or emotional violence that had resulted in homelessness. The women reported that they had moved in with people to escape homelessness and loneliness but then had to deal with physical or emotional violence. Sheila was asked about the sort of places in which she had lived in the past:

Mainly caravan parks. I lived in a house up in the mountains... for a year. That was a horrendous time in my life. I met this fella... He was just bad news. I've stayed in heaps of caravan parks 'til I got the SNAP flat.

Sheila continued to be threatened by her ex-boyfriend and was offered the choice of moving to a unit in another town to help her break the cycle of violence. Housing ‘swaps’ can be used to aid recovery and also to enable neighbourhood conflict to be resolved, one of the few advantages that public housing has over home ownership.

Before moving into her home, Heather had been living with her parents. Despite her generally positive experiences with her SNAP home she had some anxiety about the security of her housing. Heather chanted a mantra to remind herself of what she felt she needed to do to keep her unit:

You know it belongs to somebody else. But you keep the place clean and tidy, keep yourself clean and tidy, showers... vacuuming, just do your washing and clean up. Human Services they come round and make sure everything is clean and tidy. That you’ve dusted and vacuumed. Garden’s looking good and the front’s been swept up. Everything that you do at home. If you had your own little home you’d keep it nice and clean and tidy.

Significantly Heather said ‘you know it belongs to somebody else’, and ‘if you had your own little home’. SNAP workers say they need to repeatedly reassure some residents that the unit
is theirs and that they will have security of tenure as long as they abide by the public housing regulations. However in a culture that understands security of tenure most clearly in the context of home ownership, it is not surprising that people who have struggled with the uncertainty of recovery would be fearful of letting their guard slip and inadvertently doing ‘something wrong’.

Sheila expressed the same anxiety in different terms:

*It’s my home, they can’t take it away from me unless I do something drastic, which I have no intention of doing... I get scared sometimes that I’m not going to be able to keep this place but I don’t know what it is that scares me about losing it. I’m doing nothing wrong. I just get scared that they’re going to take it away from me because I’m so happy: I mean I’m happy I’ve got it, but I’m unhappy most of the time. It has got nothing to do with where I live. It would kill me if I had to leave. I love this place.*

Sheila made it clear that she was happy to have her unit but that she was not happy in herself. She said that it was a friend’s support that gave her the will to keep living.

Most residents connected a discussion of their housing and support experiences to periods of hospitalisation. They concluded that just as access to supported housing programs helped recovery so did timely access to acute in-patient care. Jackie was ‘hospitalised’ not long after she moved into her SNAP unit. When she returned home she found her unit needed a major clean up and a cleaning team was sent in. Jackie said she ‘didn’t know how it got into that state’, but recognised that she ‘was that ill’ she didn’t ‘realise how bad it was getting’. Deanne also moved in and out of hospital and was pleased that her support worker could organise someone to clear the letterbox and feed the animals.

Heather, like most of the residents, wanted to avoid being sent to hospital and for her, she believed that means taking medication and not upsetting her doctor. But, like most of the residents, she said that if you are unwell then hospital might well be the best place to be:

*I see the doctor now and again; I haven’t seen him for a while because I haven’t had any problems. I think the doctor’s pretty happy with me. ...if you are sick you shouldn’t be too afraid to go to hospital over it - get treated. I know it’s hard. Once they get some medication into you and the nurses and doctors talk to you. You really do feel a lot better.*

**Loneliness and lack of supportive meaningful relationships**

All of the residents had experienced the kinds of homelessness that is common for people dealing with psychiatric disability. Jacko’s story was typical of the male residents. He moved from his parents’ house to an inner city pub where he said the publican helped him manage his money. Jacko had also lived in a city boarding house where most of the other residents had ‘psychiatric histories’:

*That’s the trouble - half these people that get out of psychiatric hospitals end up in these boarding houses and most of them will stay there unless someone comes along and does something for them, helps them out.*

Jacko came home to live with his parents in Bairnsdale on the promise of a SNAP unit of his own. However, the first unit he moved into was shared with a succession of other men who drank, took illicit drugs and, in his terms, ‘played up something shocking’.

Jacko finally got a place of his own and has succeeded in making a stable home that provides him with a sense of identity, a private space over which he could exercise control. However, for him there seemed to be a significant aspect missing from his idea of what a home should be. Segal and Baumohl (1988:249) theorise home as a place with ‘a matrix of desirable and highly valued attachments’. In similar vein Somerville (1992) identifies seven key signifiers of home: shelter, hearth, heart, privacy, roots, abode and paradise (Jones et al., 2003). Jacko’s home provides shelter, hearth, heart, privacy, roots and abode but it does not provide heart or paradise as he has no one with whom to share his home. His lack of a relationship or intimate attachment clearly affects his recovery. For Jacko, place, space and attachment make a home. However, he said he was ‘a very lonely person’ who ‘didn’t know how to join in conversations’. Jacko moved the interview along at this point and clearly didn’t want to dwell on what he saw as an important gap in his life.
Having a place of your own can relieve pressure on families and friends. A home of your own might be more costly, involve more work and perhaps increase feelings of loneliness but it can improve relationships between family members. Deborah, like most of the residents, had some unhappy experiences of living at home as an adult. Deborah lived with her mother before moving into her SNAP unit. As she said:

[I] wouldn’t move back with my mother unless I had no other choice because I found it very stressful. We’ve both got our own ideas of the way we want things done and sometimes they clashed. One thing that used to annoy me was that my mother would keep talking while I was trying to watch telly... she just wouldn’t be quiet... Also she used to nag me about the way I spent my money. It wasn’t really helpful to have someone telling you that you are doing the wrong thing all the time. I know she was right, that I wasn’t spending my money wisely... On the whole I get on with her better [now].

All fifteen residents expressed varying degrees of social isolation and reported relying on SNAP support workers for both friendship and links to community as well as the more conventional support associated with housing and support programs. For example, Cathy said she hated her birthdays, but she was pleased when a party was organised and her support workers came along with their children. She said ‘they could have left work at work and gone home to their kids, but no they bring their kids along and they came to my birthday party’. In Robinson’s (2003: 15) terms all of the residents in this study had experienced ‘relational exclusion’, ‘inadequate social participation’ and a ‘lack of social integration’.

Moving on from housing and support

The residents are physically located in their community. However, their main sense of community connection comes through networks of other residents and SNAP workers. These disability and health-mediated networks are reminiscent of the asylum and hospital. The community of residents and other non-residential SNAP members is so strong that often judgements about wellness and recovery are associated with moving out of the SNAP community to engage with mainstream community groups, either in work, housing, recreation or friendships. For example, service users might say to other participants or to staff that they haven’t seen someone for a long time, and generally the response from staff is that the service user in question has resumed school, got a job or has a new partner and is no longer in need of SNAP support and the community of fellow residents and service users.

Deanne is an example of someone moving away from the specialist services offered by SNAP. She is recovering and has moved out of her SNAP unit and bought her own home. She described her recovery process as:

Outgrowing SNAP in stages... it [SNAP] served a really valuable purpose in my life and does for many people. I guess I’m really lucky that I was able to find a way of buying a place. The irony is that the SNAP housing - I could have stayed there the rest of my life if I wanted - it was affordable, better condition and twice the size of the place I’m living in but there is something about - it was cleaner and more modern and had more storage and central and all of that – but you know what, buying my house is the most wonderful experience. It’s mine. Now I’m extremely pleased that we are closing my file at SNAP for support.

Deanne is a young mother who had recently separated from her partner when she first came to SNAP. She needed the security of stable, clean accommodation in order to continue to have access to her young son. She described the unit as a ‘catchment’ that brought her and her son together in a supportive environment. In those early days in the unit, Deanne was still far from well. In her first twelve months she had five admissions to hospital for periods of from one to six weeks. Deanne felt that the only thing missing in the mix of services provided by SNAP was a really intensive home based service that could help people who ‘were still not really well’ avoid hospitalisation and remain in their homes. Deanne, like the majority of residents, appreciated the leisure and drop-in programs that were offered. She recalled that one aspect of that program she really valued was a creative writing course that ended up with a number of participants publishing a book of poetry. Deanne summed up:

So I guess SNAP is about not just safe and affordable housing, it’s about support to meet people’s changing needs, to help them to live independently, to reintegrate back into the
community, to keep – I guess the biggest thing was having a support worker that never stopped believing in your ability – I don’t think there’s anyone else, not even my mum, that really believed that I could do it.

Deanne sees recovery as a return to normal life in the community. Hogan and Carling (1992: 219) argue that the concept of normalisation ‘remains an excellent tool for operationalising community integration’, but suggest that it has not been used effectively in the mental health field. ‘Normal’ desires and needs for homes, interesting work, relationships and friendships, as well as appropriate medical care when necessary, are the very basis of mental health and wellbeing for everyone. There is no reason why people recovering from mental illness and coping with psychiatric disability shouldn’t maximise their mental health in the same way.

Gaining equity in her own home enabled Deanne to take advantage of increases in land and house prices in the growing coastal town into which she had bought. When prices increased she sold her home and moved to a smaller and cheaper inland location. The price differential enabled her to gain more equity in her new home and buy a better car to deal with the increased distances she needed to travel. However, if she needs to access clinical services she will find this very difficult in the quite remote inland location into which she has moved.

Some residents stay in their units but find they can manage alone without the support component. Helen commented that she wasn’t receiving much support ‘because I’m giving them the flick’, quickly going on to say that she was ‘well enough not to need them now’. She then added ‘if you want to know what support I did get – heaps and heaps and heaps’. Helen strongly believed that if she needed help in the future, the service would not let her down.

Conclusion

Because of the socioeconomic status, stigmatised position and relational exclusion of people recovering from low prevalence disorders and dealing with psychiatric disability, many will find a lot of truth in Sandy Jeffs’ poem *The Revolving Door*. It is often hard in the ‘hostile world’ and sometimes it will be ‘back to the hospital with the jangle of keys and the closing of the doors’. But for these residents in this study there is a home and even if they need to go to hospital for a time, there will be a place to return to when things are better.

SNAP’s housing and support program meets all of the supported housing principles and the residents certainly ‘control the keys’. These residents have homes and they can stay there for life. They have all the ‘normal’ benefits of public housing – security of tenure, affordable rents, maintenance plans and the possibility of relocation if neighbour relations deteriorate. As well, residents have well situated, appropriate properties and the benefit of a support program that they regulate. Their home provides a sound base for survival and for recovery. But there are limitations. Housing and support programs are not always available, some communities and neighbourhoods are not always welcoming; and vital elements of home like love, friendship and relationships are not as easy to provide as a housing unit and a support package.

It is less than helpful to continue to talk about deinstitutionalisation as if the asylum and the community were dualities with little in common. Both of these treatment and living places are venues for attempts to put together the right ingredients to help facilitate recovery. A place to live, support to live there and social engagement are essential to recovery. These elements were an important ingredient of asylum care and they must be an important ingredient of community care if it is to succeed.

References


VICSERV [www.VICSERV.org.au](http://www.VICSERV.org.au) Peak body for the Victorian psychiatric disability rehabilitation and support services sector.

A Healthy Start: Mental health promotion in early childhood settings

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Abstract

Childcare services are an important part of life for many families. Childcare workers have a vital role in the development of a child’s mental health, and yet are often under-trained in this area. This paper describes the implementation, evaluation and sustainability of the Healthy Start program in regional Western Australia, with particular attention to outcomes for childcare workers. Healthy Start aimed to build the capacity of the childcare workforce to promote the mental health of children attending childcare, their families and those working in the childcare sector. A range of strategies was developed and implemented, including mental health literacy training and communication skills training which were delivered to over thirty-five childcare workers. Pre and post-training questionnaires showed that awareness of risk factors, protective factors and referral sources, as well as levels of confidence in discussing mental health issues with parents, increased immediately after training. Baseline and follow-up telephone surveys showed however that the childcare workers’ awareness of risk and protective factors was not sustained over a twelve month period. The findings suggested that messages need to be reinforced post-training to retain new knowledge and confidence. As a result, agency partnerships have grown to include a range of early childhood professionals and provide annual training.

Keywords

child care, settings approach, mental health literacy, mental health promotion, evaluation

Introduction

The early years are recognised as a significant period for prevention programs to change the course of early mental health problems and to minimise the effect of risk factors in a child’s life (Commonwealth Department of Health and Aged Care, 2000a). Childcare services are an important part of life for many families with young children. Children attending childcare services are a ‘captive’ group whose mental and social development is affected by the environment, and the interaction and nurturing they receive whilst in care. Of significance are children who attend childcare full time (i.e. regularly attend for eight or more hours per day, for four or more days per week) as they rely on the childcare service for a large part of their mental and social development. Some children may spend up to 12,500 hours in childcare before starting school (50 weeks x 50 hours x 5 years). This is only 500 hours less than a child spends in class during thirteen years of primary and secondary education (40 weeks x 25 hours x
As well as being significant figures in the lives of the children in their care, childcare workers provide advice, support and interaction to families.

**Settings approaches to health promotion**

Settings approaches to health promotion identify ways to increase the extent to which the particular setting, be it school, workplace or childcare centre, can enhance health. By forming partnerships and building the capacity of community groups and services who are undertaking incidental, yet significant, health promoting roles, key health agencies can encourage a systems based approach to the promotion of mental health and wellbeing (Baum, 1998).

The childcare setting has been used to promote nutrition messages and organisational change has seen the adoption of healthy menus for children attending long day care (Lewis & Pollard, 1999). There has been a call for national action to provide quality childcare which promotes social and emotional wellbeing and to develop mental health promoting learning environments in early childhood settings in order to prevent later mental health problems (Commonwealth Department of Health and Aged Care, 2000a).

**Mental health problems in early childhood**

The need to prevent or intervene early in mental health problems was highlighted in the Western Australian Child Health Survey (Zubrick, Silburn, Garton et al., 1995). Approximately one in five children were identified as having a mental health problem in the six months prior to the survey and only 22% of children identified as having a mental health problem have a single mental health syndrome. Up to 10% of children were reported as having thought problems, 6% attentional problems, and 6% social problems. There were increased rates of mental health morbidity among those children whose parents were considered to use coercive or inconsistent disciplinary styles (29% and 24% respectively).

Mental health difficulties in childhood also have been linked to more severe mental health problems later in life (Marshall & Watt, 1999; World Health Organization, 2003). Younger children, aged under seven years, are less likely to exhibit measurable signs of mental illness, however their level of exposure to risk factors, such as harsh, punishment-driven discipline and high levels of family stress can be easily identified (Commonwealth Department of Health and Aged Care, 2000a).

Prevention programs that develop protective factors have greater likelihood for long-term success. Effective, evidence-based early childhood programs have targeted: the childcare environment (e.g. the High/Scope Perry Preschool curriculum comparison program, Schweinhart & Weikart, 1988); group education of parents (e.g. the Positive Parenting Program, Sanders & Markie-Dadds 1995); and home visiting programs (e.g. the Community Mothers Program and Best Beginnings: Office of Mental Health, 2002).

These programs included strategies such as enhancing social competence and cognitive development in children, providing a variety of support and educational services, and teaching caregivers skills in effective behaviour management (Commonwealth Department of Health and Aged Care, 2000b). The effects of high quality early childhood settings have been shown to continue into adulthood (Schweinhart & Weikart, 1988).

In responding to the need for quality childcare that promotes social and emotional wellbeing, and to develop mental health promoting learning environments in early childhood settings, it is important to look at the childcare environment as a whole, as well as identifying evidence-based interventions such as those listed above.

**Capacity building in childcare settings**

Using a capacity building model (Hawe, King, Noort et al., 2000), an initial step may be through workforce development to increase the mental health literacy of childcare workers, and organisational development to review workplace practice and plan for mental health promotion activity. Further steps may be the building of partnerships with a range of mental health and human service agencies and the allocation of specific resources for mental health promotion interventions.

Techniques developed for other settings may be adapted for use in childcare services. Of particular relevance is the Health Promoting...
Schools model, which encourages achievement of health through an integrated holistic approach. A ‘Health Promoting Childcare Service’ might aim to:

- actively promote the self-esteem of children by demonstrating that everyone can make a contribution to the life of the childcare service;
- develop staff/children and staff/staff relations in the daily life of the childcare service;
- make clear to staff, parents and children, the social aims of the service;
- provide stimulating challenges for children through a wide range of activities;
- develop childcare service/home/community links;
- promote staff wellbeing; and
- utilise the potential of specialist services in the community for advice and support (adapted from Kickbusch, 1992).

It is potentially easier for childcare services to promote mental health than it is for schools. Children’s services (such as childcare centres, child health clinics, playgroups) focus on human development, education for life, learning how to learn and catering for individual differences. Children’s services are not restricted by curriculum and can enhance community development (Cummings, 1991).

Childcare workers can promote or enhance the mental health of at least three different groups: children, parents and guardians, and colleagues. Opportunities for mental health promotion exist in the physical and social care environment of infants and children, interactions with children, parents and guardians and relationships between colleagues. The organisational environment of the childcare service, including accreditation requirements, policy and governance, formal communication with stakeholders and relationships with other agencies also provide opportunities for mental health promotion.

**The Healthy Start program**

Australian childcare service providers (long day care centres, occasional day care centres and family day care) have previously received no specific training in mental health promotion or early intervention yet many have contact with children with emerging mental health problems or families in distress. At a local level, childcare service providers in the Lower Great Southern region of Western Australia had recognised a need for professional development and support in the area of mental health through their regional childcare network (Cannon, 2000).

*Healthy Start* aimed to build the capacity of the childcare workforce to promote the mental health of children attending childcare, their families and those working in the childcare sector. It began as a pilot project, funded by Healthway, Western Australia’s health promotion foundation, and developed by the Great Southern Public Health Service. The pilot sought to equip childcare service providers with the knowledge and skills to promote positive mental health and an awareness of early intervention to families who use their services and reside in the local government areas of Albany, Plantagenet (Mt Barker) and Denmark. There were ten childcare service providers in the region at the time, offering up to 960 childcare places.

The objectives of Healthy Start were:

- To measure and increase levels of awareness of mental health risk and protective factors in children among childcare workers and parents.
- To measure and increase levels of awareness of the signs of postnatal depression and conduct disorder among childcare workers.
- To measure and increase levels of confidence in dealing with parents presenting with mental health issues among childcare workers, including the ability to refer to appropriate agencies.

The *Healthy Start* program used two types of health promotion action. The personal skills of childcare workers were developed and mechanisms for creating supportive childcare environments for children, parents and childcare workers were produced. This paper describes the implementation, evaluation and sustainability of the *Healthy Start* program, with particular attention to outcomes for childcare workers.

**Method**

**Telephone survey**

A literature review identified specific knowledge and skills for mental health literacy in issues
applicable for early childhood, as shown in Table 1. These components were used to generate questions for the structured telephone interviews. Childcare workers gave passive consent for their details to be sourced from childcare service databases and were contacted at work to complete the 20-25 minute interview. Eighty childcare workers were interviewed. Results from the telephone survey informed the content and activities of the subsequent information training and communication skills training and formed a baseline comparison for a follow-up survey.

The structured telephone interviews were repeated twelve months after the commencement of the program with 35 of the 80 childcare workers. Reasons for attrition included: had moved into other types of work, had left the area, or did not want to participate in the follow-up survey.

<table>
<thead>
<tr>
<th>Table 1. Mental health literacy components applicable for early childhood</th>
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<tr>
<td><strong>Knowledge of mental illness risk factors</strong></td>
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<tr>
<td>(0-5 year olds) Lack of warm relationship with caregivers; low birth weight; genetic makeup; harsh or inconsistent punishment.</td>
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<tr>
<td>(Adults) Relationship difficulties, lack of a personal support network.</td>
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<tr>
<td><strong>Mental health protective factors</strong></td>
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<tr>
<td>(0-5 year olds) Warm, secure attachment with caregivers; skills/resources to stimulate intellectual and emotional development; good infant health; genetic makeup; quality care in safe environments; consistent, fair behaviour management practices; low family stress; social and language skills.</td>
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<tr>
<td>(Adults) Social support, positive coping styles to deal with challenges and alleviate stress, family resilience; flexible, supportive workplaces.</td>
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<tr>
<td><strong>Awareness of signs and signals of mental health problems</strong></td>
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<tr>
<td>Awareness of the spectrum of mental health, of symptoms of conduct disorder and postnatal depression (as per DSM IV), personal and professional limitations and the need for professional diagnosis.</td>
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<tr>
<td><strong>Self efficacy: Confidence in dealing with parents presenting with mental health issues</strong></td>
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<tr>
<td>Active listening skills, clear understanding of personal and professional limitations, duty of care.</td>
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<tr>
<td><strong>Referral to appropriate agencies</strong></td>
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<td>Ability to list three or more avenues for referral.</td>
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**Focus groups**

Five groups of five childcare workers participated in focus groups. Questions related to concerning behaviours, methods of dealing with problem behaviour, interactions with parents and use of agencies. Results of the focus groups informed the content and activities in the training sessions. Focus group themes:

- Workers identified a range of sources for more information and referral, but expressed a need for information about behaviour management for children with specific health issues and about approaching parents and dealing with emotional parents.
- Parents approached childcare workers for advice on behaviour management or developmental issues and some turned to workers in times of crisis. Many workers would encourage discussion, but were not able to respond effectively due to work demands or lack of knowledge.
- Attitudes towards parents were varied: some workers felt that children’s behaviour was related solely to parenting and that parents alone were responsible for behaviour change. Workers felt that family factors and a mother’s emotional state could impact negatively on the child. Some workers had felt used by ‘emotionally demanding parents’.

**Mental health information training**

Two sessions, each of two hours duration, were developed for childcare workers and dealt with risk and protective factors that impact on the mental health of children, conduct disorder, postnatal depression and referral options. The project officer and a social worker delivered the mental health information training to 35 childcare workers in four series. All had participated in the baseline telephone survey. Pre and post-training questionnaires were completed by 35 and 26 childcare workers respectively.

**Communication skills training**

Six sessions, each of ninety minutes duration, were developed for workers and dealt with communication principles, active listening, recognising and responding to emotional crisis, discussing sensitive issues with parents, referral services and self care. The project officer and a mental health nurse delivered the series once to
22 childcare workers. Pre and post-training questionnaires were completed by 22 and 18 childcare workers respectively.

**Evaluation**
An extensive evaluation of the Healthy Start program was conducted in collaboration with the Survey Research Centre at the University of Western Australia. Evaluations assessed the effect of individual strategies, as well as the effect of the overall program over a twelve-month period. This paper focuses on the results applicable to the childcare worker training strategies. (Resources for parents and a mental health promotion action plan were also developed and evaluated, but are not explored in this paper. 1)

### Results

**Mental health information training**
Thirty-five childcare workers completed the pre-training and 26 completed the post-training questionnaire. Workers rated their confidence in their ability to recognise the signs of postnatal depression and conduct disorder (see Table 2). At the conclusion of training, the proportion of workers expressing confidence (fairly confident or very confident) in their ability to recognise the signs of postnatal depression had increased by 43.8%, and confidence in recognising the signs of conduct disorder had increased by 40.7%.

**Communication skills training**
Twenty-two childcare workers completed the pre-training questionnaire and 18 completed the post-training questionnaire. Workers rated their confidence in their ability to discuss the emotional problems of a child in their care, as well as adult emotional problems, with the child’s parents or guardians (see Table 4). By post-training the proportion expressing confidence (fairly confident or very confident) in their ability to discuss a child’s emotional problems with parents had increased by 34.4%. By the end of training, the proportion expressing confidence in their ability to discuss the emotional problems of adults with parents had increased by 40.4%.

| Table 2. Confidence in recognising postnatal depression and conduct disorder |
|-------------------|-------------------|-------------------|
| Rating of confidence | Postnatal depression | Conduct disorder |
|                    | Pre % | Post % | Pre % | Post % |
| Very               | 8.6   | 46.2   | 8.7   | 30.8   |
| Fairly             | 40.0  | 46.2   | 42.9  | 61.5   |
| Not very           | 31.4  | 7.7    | 25.7  | 7.7    |
| Not at all         | 8.6   | 0.0    | 11.4  | 0.0    |
| Not sure           | 11.4  | 0.0    | 11.4  | 0.0    |

| Table 3. Number of risk and protective factors listed for children’s mental health problems, and number of risk factors and referral options listed for postnatal depression. |
|-------------------|-------------------|-------------------|
| n listed | Children’s mental health problems | Postnatal depression |
|          | Risk factors | Pre % | Post% | Risk factors | Pre % | Post % |
| 1        | 25.7 | 0.0 | 34.3 | 0.0 |
| 2        | 42.9 | 23.1 | 34.3 | 11.5 |
| 3        | 25.7 | 38.4 | 25.7 | 26.9 |
| 4        | 2.9  | 7.7 | 5.7  | 34.6 |
| 5+       | 2.8  | 30.8 | 0.0  | 26.9 |

|          | Protective factors | Referral options |
|          | Pre % | Post % | Pre % | Post % |
| 0        | 40.0 | 7.7 | 5.7 | 3.9 |
| 1        | 40.0 | 7.7 | 25.7 | 19.2 |
| 2        | 17.1 | 53.9 | 57.1 | 26.9 |
| 3        | 2.9  | 19.2 | 8.6  | 38.5 |
| 4        | 0.0  | 11.5 | 0.0  | 11.5 |
Table 4. Confidence in discussing the emotional problems of the child and the adult

<table>
<thead>
<tr>
<th>Rating of confidence</th>
<th>Child’s emotional problems</th>
<th>Adult’s emotional problems</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pre %</td>
<td>Post %</td>
</tr>
<tr>
<td>Very</td>
<td>13.6</td>
<td>16.7</td>
</tr>
<tr>
<td>Fairly</td>
<td>40.9</td>
<td>72.2</td>
</tr>
<tr>
<td>Not very</td>
<td>27.3</td>
<td>5.6</td>
</tr>
<tr>
<td>Not at all</td>
<td>18.2</td>
<td>0.0</td>
</tr>
<tr>
<td>Not sure</td>
<td>0.0</td>
<td>5.6</td>
</tr>
</tbody>
</table>

Telephone survey follow-up

The childcare workers recalled risk factors for mental health problems in children. The comparison between baseline and 12 month follow-up survey (see Table 5) shows that childcare workers increased their ability to recall only one of four specific risk factors for mental health problems in children (‘lack of warm relationship with caregivers’). The ability to recall specific risk factors for postnatal depression had generally decreased between the baseline and follow-up surveys, except for ‘genetic makeup’. The proportion of workers recalling recognised protective factors for mental health problems had generally decreased at follow-up (however recall of ‘warm relationships’ and ‘positive parenting’ remained high).

Table 5: Recalled factors for children’s mental health problems and postnatal depression

<table>
<thead>
<tr>
<th>Factors</th>
<th>Base line %</th>
<th>Follow up %</th>
<th>Diff %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Risk factors for children’s mental health problems</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of warm relationship with caregivers</td>
<td>56.2</td>
<td>84.6</td>
<td>+28.4</td>
</tr>
<tr>
<td>Low birthweight</td>
<td>29.9</td>
<td>5.1</td>
<td>-24.8</td>
</tr>
<tr>
<td>Genetic makeup</td>
<td>26.3</td>
<td>21.5</td>
<td>-4.8</td>
</tr>
<tr>
<td>Harsh or inconsistent punishment</td>
<td>21.2</td>
<td>23.0</td>
<td>+1.8</td>
</tr>
<tr>
<td>Risk factors for postnatal depression</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationship difficulties</td>
<td>31.2</td>
<td>21.0</td>
<td>-10.2</td>
</tr>
<tr>
<td>Lack of a personal support network</td>
<td>67.5</td>
<td>56.4</td>
<td>-11.1</td>
</tr>
<tr>
<td>Genetic makeup</td>
<td>8.7</td>
<td>12.8</td>
<td>+4.1</td>
</tr>
<tr>
<td>Existing mental health problem</td>
<td>44.9</td>
<td>10.2</td>
<td>-34.7</td>
</tr>
<tr>
<td>Protective factors for children’s mental health problems</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Warm relationship with caregivers</td>
<td>100</td>
<td>92.3</td>
<td>-7.7</td>
</tr>
<tr>
<td>Good infant health</td>
<td>32.3</td>
<td>15.4</td>
<td>-16.9</td>
</tr>
<tr>
<td>Genetic makeup</td>
<td>1.2</td>
<td>2.5</td>
<td>+1.3</td>
</tr>
<tr>
<td>Positive parenting practices</td>
<td>100</td>
<td>92.3</td>
<td>-7.7</td>
</tr>
</tbody>
</table>

Childcare workers rated their level of confidence in identifying and discussing the signs of postnatal depression and conduct disorder, and in recognising the need for referral (see Table 6). At follow-up, the proportion expressing confidence in their ability to recognise the signs of postnatal depression increased by over 12%, while the proportion expressing confidence in their ability to recognise the signs of conduct disorder decreased slightly.

The proportion of workers who were confident of their ability to discuss postnatal depression with parents increased slightly at follow-up. However, they were less confident in their ability to discuss conduct disorder with parents at follow-up. A smaller proportion were confident of their ability to recognise when a child or family should be referred to a specialist at follow-up than at baseline.

Table 6. Confidence in identifying and discussing postnatal depression and conduct disorder, and in recognising need for referral

<table>
<thead>
<tr>
<th>Confidence level</th>
<th>Base line</th>
<th>Follow up</th>
<th>Diff</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identifying signs of postnatal depression</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very confident</td>
<td>13.8</td>
<td>20.5</td>
<td>+6.7</td>
</tr>
<tr>
<td>Fairly confident</td>
<td>53.0</td>
<td>59.0</td>
<td>+6.0</td>
</tr>
<tr>
<td>Total</td>
<td>66.8</td>
<td>79.5</td>
<td>+12.7</td>
</tr>
<tr>
<td>Identifying signs of conduct disorder</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very confident</td>
<td>21.3</td>
<td>20.5</td>
<td>-0.8</td>
</tr>
<tr>
<td>Fairly confident</td>
<td>65.0</td>
<td>64.1</td>
<td>-0.9</td>
</tr>
<tr>
<td>Total</td>
<td>86.3</td>
<td>84.6</td>
<td>-1.7</td>
</tr>
<tr>
<td>Discussing postnatal depression</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very confident</td>
<td>12.5</td>
<td>12.8</td>
<td>+0.3</td>
</tr>
<tr>
<td>Fairly confident</td>
<td>43.8</td>
<td>48.7</td>
<td>+4.9</td>
</tr>
<tr>
<td>Total</td>
<td>56.3</td>
<td>61.5</td>
<td>+5.2</td>
</tr>
<tr>
<td>Discussing conduct disorder</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very confident</td>
<td>23.8</td>
<td>12.8</td>
<td>-11.0</td>
</tr>
<tr>
<td>Fairly confident</td>
<td>42.5</td>
<td>51.3</td>
<td>+8.8</td>
</tr>
<tr>
<td>Total</td>
<td>66.3</td>
<td>64.1</td>
<td>-2.2</td>
</tr>
<tr>
<td>Ability to recognise need for referral</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very confident</td>
<td>13.8</td>
<td>12.8</td>
<td>-1.0</td>
</tr>
<tr>
<td>Fairly confident</td>
<td>70.0</td>
<td>61.5</td>
<td>-8.5</td>
</tr>
<tr>
<td>Total</td>
<td>83.8</td>
<td>74.3</td>
<td>-9.5</td>
</tr>
</tbody>
</table>

The childcare workers listed which services they would refer families to for emotional or mental health problems. At follow-up, they were more likely to refer postnatal depression issues to a general practitioner or child health nurse and more likely to refer conduct disorder issues to a child health nurse (see Table 7). The average
number of referral sources recalled decreased between the baseline and follow-up survey for postnatal depression (from 2.5 to 1.7 options) and for conduct disorder (from 2.5 to 1.5 options).

Table 7. Referral services for postnatal depression and conduct disorder

<table>
<thead>
<tr>
<th>Specialist</th>
<th>Postnatal depression</th>
<th>Conduct disorder</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Base line</td>
<td>Follow up</td>
</tr>
<tr>
<td>General practitioner</td>
<td>61.2</td>
<td>74.3</td>
</tr>
<tr>
<td>Child health nurse</td>
<td>27.5</td>
<td>56.4</td>
</tr>
<tr>
<td>Childcare supervisor</td>
<td>18.7</td>
<td>-</td>
</tr>
<tr>
<td>Family &amp; Children’s Services</td>
<td>20.0</td>
<td>12.8</td>
</tr>
</tbody>
</table>

Discussion

In the short term, the training strategies were successful in awareness raising and developing confidence amongst workers. Childcare workers reported greater confidence in discussing mental health issues with parents. The mental health literacy of childcare workers was enhanced, as they were better able to answer questions about postnatal depression, conduct disorder and mental health in general. Knowledge of local services and programs for families with children under five increased, as workers could list a greater number of alternatives for families needing specialist assistance.

Overall, the telephone interview results showed decreases in recall of mental health risk and protective factors over a twelve month period. For postnatal depression, but not conduct disorder, confidence in identifying signs and discussing with parents increased. Confidence in ability to recognise the need for referral actually decreased over the 12 month period.

There are a number of issues that should be considered when interpreting the results. During the baseline telephone interviews, respondents were encouraged to offer as many responses as possible. At follow-up, the number of responses was limited to three. The coding of these open-ended responses was potentially inconsistent between baseline and follow-up analysis as no inter-rater reliability tests had been undertaken.

In assessing knowledge of risk and protective factors, workers were asked to recall factors without prompting. Another technique would have been to identify factors from a list.

The small sample size of the follow-up survey may also have an impact on the ability to make comparisons between baseline and follow-up results. Feedback indicated that the baseline survey was too long to be completed during work hours (20-25 minutes), and that workers did not want to be contacted out of hours for telephone surveys.

At the time of the pilot, there was a lack of standardised evaluation tools for assessing changes in mental health literacy (particularly knowledge and skills) as a result of small group education strategies (as explained by Francis, Pirkis, Dunt et al.’s 2002 review). As attitudinal information was collected during the focus groups, it would have been useful to revisit the attitudes of workers post-training.

The data assessing knowledge of referral agencies could be interpreted in a number of ways. Child health nurses in the region delivered the Triple P program, and referrals to child and adolescent mental health services were only accepted from general practitioners. General practitioners also made referrals to the postnatal depression intervention program. The data could reflect a better understanding of how the mental health system in the region operated, and a more targeted referral process by childcare workers. Application of this knowledge would only be effective if general practitioners and child health nurses were aware of the likelihood for more contact from childcare workers, so that requests for information or referrals would be handled appropriately.

It is difficult to assess how increased mental health literacy would change workplace practice. There is a need to follow up the implementation of other program strategies, and to identify how training sessions could have explored the use of these.

There was much interest in mental health amongst childcare workers; however, it was necessary to explain mental health promotion carefully and to move early discussions away from behaviour management. Anecdotally, skill development enabled workers to enhance their role, decrease work related stress and feel more comfortable discussing issues with parents.
Conclusions
This paper described the outcomes of two strategies of a mental health promotion program for the childcare setting. Education and skills training sessions were effective in the short term in increasing knowledge of mental health risk and protective factors and individual confidence in recognising and discussing mental health and emotional issues. Gains in skill and confidence generally were not retained at twelve-month follow-up and it is unclear what impact the training had on changing workplace practice. The training strategies appear to be a useful first step in building workforce capacity for mental health promotion. Further intervention would be necessary to ensure that the issues remained on the agenda for childcare service providers. Follow up of other program strategies would be useful to assess how much support childcare centre coordinators require to become advocates for mental health promotion in the workplace.

Lessons learnt
At the end of the pilot, the Steering Committee recommended that the health, welfare and education sectors raise awareness of mental health promotion amongst early childhood professionals to maintain a level of information and support for families from birth into the school system (0-6 years). Other settings and workforces for mental health promotion for young families were identified including maternity wards, child health clinics, child development centres, general practitioner clinics, parent information centres, kindergartens and preschools, playgroups, toy libraries, local libraries, neighbourhood centres, privately owned child recreation centres, and pharmacies.

The Steering Committee found that developing rapport with childcare services was dependent on linking training clearly to the early childhood role to improve work practices. Organisational change could be encouraged by centre based visits, specific action plans, resources and information in a range of formats. Elements that could hinder rapport with childcare services included:

Assuming sector-wide and workforce-wide motivations. At the time, family day care workers were more likely to attend training for networking and professional development. Long day care workers were more likely to attend for accreditation purposes. Occasional care workers were more difficult to attract, as they did not have as rigorous an accreditation process at the time. Specialised in-house training was more likely to appeal to this group.

Lack of understanding of service priorities. Incentives must be offered for childcare services to undertake health promotion activities, such as meeting accreditation requirements, state or national certification, grants, sponsorship for equipment or maintenance, or promotion of the service.

Sustainability
Since the completion of the pilot in July 2001, the program has been recognised in the Western Australian Mental Health Promotion and Illness Prevention Policy (2002) as a best practice program. The audience for training now includes child health nurses, physiotherapists, occupational therapists, childcare students, and preschool and kindergarten staff. The training has been condensed into a comprehensive four-session package, which combines communication skills development and mental health information. This package has been delivered to over 70 professionals. The Coordinator of Mental Health Promotion, Great Southern Public Health Service, oversees coordination of training delivery, which is co-facilitated by Great Southern Child and Adolescent Mental Health Service staff.

The Steering Committee has disbanded, however members are represented on interagency committees and help to sustain the concepts and strategies of the program. The Coordinator of Mental Health Promotion liaises with the Lower Great Southern Childcare Network and the Albany and Narrogin Mental Health Promotion in Schools committees, to ensure coordinated annual delivery of training. In particular, the Lower Great Southern Childcare Network provides an opportunity to build capacity of childcare administrators and to link mental health promotion strategies to Australian childcare accreditation requirements.

Negotiations are underway to deliver the training package in the Central and Upper Great Southern Health regions of Western Australia. There has also been interest from interstate health services in adapting the package to suit their needs.
Note

1. Other strategies which formed part of the Healthy Start program include:

A parent information module. A one-hour information module and facilitator’s guide, which dealt with mental health issues affecting families with young children, risk and protective factors and agencies for support, was delivered eight times to thirty parents.

A parent resource kit. A resource kit for parents included seven fact sheets that could be tailored to the ages of children in each family. The fact sheets dealt with risk and protective factors, prevalence of postnatal depression and conduct disorder, as well as referral options. Eight hundred copies of the kit were disseminated through childcare services.

Mental Health Promotion Action Plan. A twelve-month mental health promotion action plan template was developed with reference to the quality areas of the Quality Improvement and Accreditation System (QIAS) for Long Day Care Centres (NCAC, 2001). The action plan was trialed by five childcare service providers and was distributed to all ten services.

Acknowledgements

The Healthy Start Steering Committee members, the Lower Great Southern Child Care Network, WA Country Health Services - Great Southern Public Health Service, Marcelle Cannon, Tony Evers, Brett Kipling, Maree Dawes and Healthway.

References


Suicidality, interpersonal trauma and cultural diversity: a review of the literature

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Abstract

There are substantial bodies of literature focusing on suicide and interpersonal trauma, and on suicide across cultures. There is also a growing body of knowledge relating to interpersonal trauma across cultures. However, there is a marked gap in the literature that brings these three areas together. Studies that specifically investigate the prevalence of suicidality in relation to experiences of domestic violence, sexual assault and childhood abuse in a cross-cultural context are indeed scant. Moreover, inconsistencies in data collection and reporting and considerable variability in results among the few existing studies highlight substantial methodological limitations and definitional differences in the research. The identification of at-risk groups is thus hampered, as is an examination of possible risk and protective factors. What is clear is that interpersonal trauma and suicide are linked in significant and complex ways. What is less evident is how culture mediates this inter-relationship. It is suggested that gender and cultural biases in suicide research may well account for our limited understandings in this area. Implications for practice include the need for alternative research perspectives and more inclusive frameworks that promote greater cross-discipline dialogue and intersectoral collaboration. There is thus ample scope for further research in this area so as to elucidate the implications for suicide prevention, intervention and postvention work with culturally and linguistically diverse communities.

Keywords

suicide, suicidality, culture, interpersonal trauma, domestic violence, sexual assault, childhood abuse, mental health

Objective

To conduct a critical review of the literature published in Australia and overseas on suicide and parasuicide related to interpersonal trauma within culturally and linguistically diverse communities.

Method

CIAP was used to perform a literature search across four medical/nursing databases (Medline, PsycINFO, Cinahl, Journals@OvidFullText). An additional search of two social science/humanities databases (Sociological Abstracts, Academic Research Library) was performed using ProQuest. Fifteen search terms were used in various combinations to search for all articles that appeared to be relevant, that is, those that related to suicidality and domestic violence (family violence/intimate partner violence/gender-based violence), sexual assault (rape/child sexual abuse) and physical and emotional abuse and neglect of children (child abuse/maltreatment) within culturally and linguistically diverse, immigrant and refugee communities. Initially, the search was limited to only those articles published between 1994 and 2004. Additional references from earlier dates that were deemed important were sourced through a manual identification process using the reference lists of the selected articles.
An initial search combining the three areas of interest (suicide and interpersonal trauma and cultural diversity) yielded fewer than 20 citations. The search was then broadened to identify all those articles relating just to suicide in the context of interpersonal trauma. This yielded over 1,000 results. A second search combining the terms ‘suicide’ and variations of the term ‘cross-cultural’ yielded a similar number of results, as did a third search combining the terms ‘interpersonal trauma’ and ‘cross-cultural’ (and their variations). The abstracts were then scanned for relevance to the specific issue under investigation. Eventually, approximately 175 articles were identified as relevant to the project. The literature reviewed includes prevalence studies, cross-cultural and cross-national comparisons, theoretical analyses and international literature reviews.

**Purpose and scope**

The primary purpose of the literature review was to investigate the extent to which:
- the suicide and interpersonal trauma literature canvasses issues of culture in the assessment and management of suicidal clients who have histories of abuse
- the multicultural mental health/cross-cultural suicide prevention literature considers the links between interpersonal trauma and risks for suicidality
- the cross-cultural literature on interpersonal trauma considers suicidality as a possible outcome of abuse.

It was anticipated that this process would expose the gaps in the literature, thereby pointing to directions for future research. A secondary purpose of the review was to highlight the implications of the findings for suicide prevention and intervention work in a culturally and linguistically diverse society such as Australia.

**Limitations and exclusions**

The review is not exhaustive; key studies were selected for review and analysis. In order to limit the parameters of the project, the review excludes the following:

*Suicide within Aboriginal and Torres Strait Islander (ATSI) communities.* The alarmingly high rate of suicides within ATSI communities, and indeed among other indigenous populations that have a colonial history, is documented in a number of sources. The present review does not address itself in any detail to issues for Aboriginal communities. The rationale for this is that a separate project is required in order to do justice to the complexity of the issues.

*Suicide in the context of non-domestic interpersonal violence.* The prevalence and impact of trauma resulting from state-sanctioned violence (such as rape in war and the abuse of children within the context of armed conflict) is acknowledged, as are experiences of interpersonal violence between strangers (such as assault with robbery). The present review, however, focuses specifically on domestic/family violence, sexual assault and child abuse perpetrated within an intimate or family setting.

*Suicide of perpetrators of interpersonal violence.* There is a growing body of literature that documents the occurrence of suicide by perpetrators of abuse, particularly Child Sexual Assault (CSA) offenders, usually after exposure and/or sentencing, and also in cases of domestic homicide/suicide. The focus of this investigation is on the experiences of victims.

**Terminology**

A number of related terms are used in the literature. For the purposes of clarification, the following terms are defined as they are used in this review:

*Interpersonal trauma* is trauma that is sustained as a result of violence/abuse perpetrated within the context of an intimate or family setting; inclusive of the terms:
- Domestic violence
- Intimate partner violence
- Gender-based violence
- Family violence
- Sexual assault/abuse
- Rape
- Child sexual assault
- Physical abuse and neglect of children
- Childhood abuse/maltreatment (inclusive of emotional abuse).

*Suicidality* is used to include both deaths resulting from suicide (fatal suicide) and the range of non-fatal suicidal behaviours that do not result in death (also referred to as ‘parasuicide’). These include verbalised threats and thoughts of suicide (ideation/cognition), without necessarily
the intention to die. Non-habitual self-harming acts are included in this definition, but repetitive self-mutilating behaviour is not, as a different intention motivates this sort of self-harm. While it is acknowledged that some habitual self-harmers may also become suicidal, self-injury per se is not generally considered to be on the continuum of suicidality.

**Cultural diversity** is used as an inclusive term that reflects the reality of a multicultural society such as Australia. It connotes the variety and richness of communities with diverse norms, beliefs, practices and values and may be based on culture, language, ethnicity or a combination of these, in addition to a range of other dimensions of difference (such as gender, class, age, sexual orientation etc.). The term ‘cross-cultural’ is used to mean dealing with or comparing two or more cultures, while the term ‘transcultural’ may be interpreted more broadly to mean extending across all human cultures.

**Findings**

**Prevalence of suicide**

Inconsistencies in data collection and reporting, definitional issues and methodological limitations and biases lead to some inconsistencies in findings, making it difficult to assess prevalence of suicide with any accuracy. Moreover, given the range of sample types and sizes and the variety of research methodologies (cross-sectional population-based, longitudinal prospective follow-up, retrospective self-reports, retrospective casenote analysis, ‘psychological autopsy’

6), cross-cultural comparisons of results is fraught with difficulty and complexity.

**The global picture**

The World Health Organisation (WHO) estimates that at least one death by suicide occurs every minute, representing an annual global mortality rate of about 14.5 per 100,000 people. These figures make suicide the thirteenth leading cause of death worldwide (Krug, Dahlberg, Mercy et al., 2002). In addition to those who die, many more people engage in non-fatal suicidal behaviour and still more people think about killing themselves. Evidence suggests that only about 25% of those who take suicidal action make contact with support services or health facilities, such as hospitals (Diekstra & Garnefski, 1995; Kjoller & Helweg-Larsen, 2000; Sayer, Stewart & Chipps, 1996). Although suicidal ideation is undoubtedly more common than suicidal action, its extent is even less clear (Kessler, Borges & Walter, 1999). Data in relation to these categories of suicidal behaviour that do not have fatal outcomes are therefore likely to be even more limited than those regarding suicide deaths (which do not include ‘accidental deaths’, many of which may in reality be disguised/unsubstantiated suicides). It is therefore reasonable to assume that any estimates of the global prevalence of suicide and parasuicide are under-estimates.

National suicide rates vary substantially (possibly due as much to inconsistencies in data collection as to sociocultural differences in attitudes towards suicide), with the highest recorded rates being found in Eastern European countries and low rates generally in Latin America and some Asian countries (e.g. Philippines and Thailand). The suicide rates in other parts of Europe, North America and parts of Asia and the Pacific (including Australasia), fall somewhere between these extremes. There is little data available from African countries and from other developing nations (Krug et al., 2002).

Important demographic markers of suicide risk are known to be gender, age and ethnicity. Globally, suicide deaths are higher among men than women and parasuicide rates are consistently higher among women than men (Weissman, Bland, Canino et al., 1999). Exceptions to this suicide mortality trend are found in the People’s Republic of China and in India where higher rates of suicide deaths are reported for young married women (Brockington, 2001; Khan, 2002; Pritchard, 1996). There is little explanation in the literature of the possible reasons for this anomaly. It is reasonable to speculate that it is a function of a number of compounding factors, including lethality of methods, lack of access to health facilities and gendered meanings of suicide (an aspect that will be explored later in this paper).

Worldwide, suicide rates tend to increase with age, with rates among those over 75 years of age being approximately three times higher than those of young people aged 15-24 years (Krug et al., 2002). However, the absolute number of
cases recorded is actually higher among those under 45 years than among those over 45 years and many countries have indicated an alarming rise in youth suicide over the past few decades. However, Gould, Greenberg, Velting and Schaffer (2003) report that in the past decade there has been a marked decline in the youth suicide rate in Western developed nations. They posit the increase in the prescription of anti-depressants for adolescents as one of the most plausible reasons for this recent decrease (Gould et al., 2003:386).

Epidemiological studies indicate that the prevalence of suicide among ‘Caucasians’ is approximately twice that observed in other ‘races’, with generally lower rates observed among African Americans, although rates are reportedly increasing among this group (Moscicki, 1999). A significant exception to this, however, is the disproportionately high suicide rates among indigenous peoples with histories of colonisation. This is documented among Australian Aboriginal people (Hunter & Harvey, 2002; Tatz, 1999), the Maori of Aotearoa / New Zealand (Langford Ritchie & Ritchie, 1998), the Canadian Inuit (MacMillan, MacMillan, Offord & Dingle, 1996), the native American Indian peoples (Robin, Chester & Rasmussen, 1998) and Hawaiian peoples (Yuen, Nahulu, Hishinuma & Miyamoto, 2000).

The Australian context

In Australia, suicide is ranked as the 7th leading cause of death (14.6 per 100,000 population – Australian Bureau of Statistics, 2002). Australia’s rate of youth suicide is counted among the highest in the world with an estimated ten young people each week killing themselves and a further 1,000 acting on suicidal thoughts (Cantor, Neulinger, Roth & Spinks, 1998; Loff & Cordner, 1998). Young men and young people in rural and regional areas are considered to be most at risk, with Aboriginal youths 40% more likely to die by suicide than anyone else in the community (Hunter & Harvey, 2002). In the last fifty years, the male youth suicide rate has almost trebled and the rate among young women has doubled (Loff & Cordner, 1998), with young gays and lesbians experiencing heightened risk for suicidal behaviour (Fergusson, Horwood & Beautrais, 1999; Millard, 1995; Schaffer, Fisher, Parides & Gould, 1995).

Despite the fact that approximately 21% of deaths due to suicide occur in persons who were born overseas (Steenkamp & Harrison, 2000), most suicide research in Australia has omitted to address issues for people of non-English speaking backgrounds. The research that has been conducted amongst immigrant groups in Australia indicates great diversity in suicide rates among the various ethnic and cultural groups and that rates among some groups may be higher than native rates especially amongst women (McDonald & Steel, 1997).

A recent report by VicHealth on the health costs of intimate partner violence found that domestic violence was the single greatest risk factor associated with death for women aged 15-44 years, accounting for 10% of deaths, more than half of which were attributed to suicide (VicHealth, 2004).

As is the case elsewhere, non-fatal suicides are generally under-reported and therefore reliable data are lacking. It has been suggested, however, that in Australia the number of non-fatal suicides could be as high as 67% more than reported rates (Bevan in Bashir & Bennett, 2000). Consistent with global trends, the documented rate of attempted suicide among women in Australia is substantially higher than among men (Australian Bureau of Statistics, 2002). While hospitalised self-harm should not be seen as equivalent to ‘attempted suicide’, it is significant to note that rates for women in this category are markedly higher than among men for all age groups, with an overall ratio of male to female of 0:74 (Steenkamp & Harrison, 2000). In NSW in 1996-97, the ratio of ‘attempted suicide’ that resulted in hospitalisation to suicide death was 23.5:1 in females as compared to 4.4:1 in males. The rate of non-fatal suicide resulting in hospitalisation is even higher among young women, with approximately 40 attempts for every ‘completed suicide’, as compared to approximately 6 attempts for every death among young men (Ansari, Chipps & Stewart, 2001).

Suicide related to interpersonal trauma

Childhood abuse

The association between childhood trauma and suicidal behaviour has been well-documented over the last two decades. Physical abuse and neglect emerge as strong and independent risk
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factors (Brent, Baugher, Bridge et al., 1999; Briere, 1992; Brown & Anderson, 1991; Browne & Finkelhor, 1986; Kaplan, Pelcovitz, Salzinger et al., 1997; Osvath, Voros & Fekete, 2004; Richie & Johnson, 1996; Santa Mina & Gallop, 1998; Silverman, Reinhzer & Giaconia, 1996; Windle, Windle, Scheidt & Miller, 1995). Fewer studies have focused on emotional abuse as a possible precursor of suicidality (Nilsen & Conner, 2002). Researchers have typically focused on the assessment of risk among adolescents and adults (Fergusson, Woodward & Horwood, 2000; Gex, Narring, Ferron & Michaud, 1998; Gould et al., 2003), with relatively few studies looking at the risks among children (Hukkanen, Sourander & Bergroth, 2003; Kovacs, Goldston & Gatsons, 1993). Some researchers have examined the links between growing up in a family characterised by domestic violence and later suicidal behaviour (Baldry & Winkel, 2003; Botsis, Plutchik, Kotler & van Praag, 1995). A Norwegian study by Ystgaard, Hestetun, Loeb & Mehlum (2004) concluded that both physical and sexual abuse in childhood are significantly and independently associated with chronic suicidal behaviour. Dube, Anda, Felitti et al.’s (2003) retrospective cohort study of over 17,000 adult primary care clinic attenders found a powerful graded relationship between multiple experiences of trauma (in any category) and lifespan risk of attempted suicide.

Sexual assault

A solid research base also exists correlating histories of sexual assault with suicidal behaviour. Much of this literature focuses on child sexual assault (CSA) (Bagley, Bolitho & Bertrand, 1997; Boudewyn & Liem, 1995; Bryant & Range, 1997; Dinwiddie, Heath, Dunne et al., 2000; Ernst, Angst & Foldenyi, 1993; Gladstone, Parker, Mitchell et al., 2004; Jarvis & Copeland, 1997; Mullen, Martin, Anderson et al., 1993; Neumann, Houskamp, Pollock et al.,1996; Peters & Range, 1995; Sullivan, Bulik, Carter & Joyce, 1995; Yellowlees & Kaushik, 1994). Longitudinal studies are believed to be the most methodologically rigorous design to examine the connection between CSA and subsequent suicidality ‘due to the serious problems of retrospective recall in this area’ (Gould et al., 2003:395). Several such studies have found self-reported CSA to be significantly correlated with increased risk of suicidal behaviour (Fergusson, Horwood & Lynskey, 1996; Silverman et al., 1996; Kaslow, Thompson, Brooks & Twomey, 2000; Plunkett, O’Toole, Swanston & Oates, 2001). Plunkett et al. (2001) found that in a sample of 183 young people who had experienced CSA, 32% had attempted suicide and 43% had thought about suicide since they were sexually abused. In New Zealand, Lynskey and Fergusson (1997) found that in a sample of 1,025 young people, 22.2% of CSA survivors had made suicide attempts. Beckinsale, Martin and Clark’s (1999) investigation of the relationship of CSA, depression and suicidal thinking from a cohort of 3,144 young Australians visiting GPs confirms these findings. In addition, they found that young men had a significantly higher suicide index than young women (40% had made serious suicide plans compared to 20% of young women). Another large Australian study by Martin, Bergen and Richardson (2004) found that 55% of sexually abused boys had attempted suicide as compared to 29% of girls. These findings are consistent with a study by Garnefski and Arends (1998) involving a large representative community sample of adolescents in the Netherlands. They found that 26.5% of abused boys reported a former suicide attempt, a rate that is thirteen times higher than that for non-abused boys. These gender differences clearly have implications for assessment of CSA in boys and young men.

A number of studies address suicidal behaviours as potential sequelae of adult sexual assault and rape (Bang, 1991; Davidson, Hughes, George & Blazer, 1996; Petrak & Campbell, 1999; Stepakoff, 1998). Some studies look at the impact of sexual assault in both childhood and adulthood (Cloitre, Scarvalone & Difede, 1997; Ullman & Brecklin, 2002; Van Egmond, Garnefski, Jonker & Kerkhof, 1993). Ullman and Brecklin (2002) examined demographic and psychosocial correlates of suicidal ideation and suicide attempts and found that in a national sample of American women those with histories of sexual assault in both childhood and adulthood reported significantly greater odds of lifetime suicide attempts. Another American study of 1,025 college students found that 15%
of adolescent women who had experienced frequent unwanted sexual touching had ‘often’ made suicidal gestures or attempts in the previous six months, compared with 2% of those who had no experience of sexual assault (Bagley et al., 1997). A number of researchers have studied populations of women prisoners and found significant correlations between previous experiences of sexual violence, harmful drinking and/or drug use and suicidal behaviour. Borrill, Burnett, Atkins et al. (2003) found that 46% of their sample reported making at least one lifetime suicide attempt. The high rate of attempted suicide in these samples prompts questions regarding the effects of incarceration as a variable in suicide risk assessments of sexual assault survivors.

Domestic violence

Almost a decade ago, Stark and Flitcraft (1995) identified domestic violence as possibly the single most important precipitant of female suicide, finding that in a sample of women who had attempted suicide and who attended the emergency department at Yale-New Haven hospital over a one-year period, 29.5% were ‘battered’. They also note that ‘studies with shelter, convenience, or volunteer samples of battered women have indicated that a substantial number, 35 to 40 percent, attempt suicide’ (Stark & Flitcraft, 1995:44), a proportion far higher than in the general population. Taft notes that ‘thirteen studies of suicidality demonstrated that abused women were three and a half times more likely to report past suicide action than non-abused women’ (Taft, 2003:7). Several other studies confirm this connection (Abbott, Johnson, Koziol-McLain & Lowenstein, 1995; Bergman & Brismar, 1991; Kaslow et al., 2000; McCauley, Kern & Kolodner, 1995; Olson, Huyler, Lynch et al., 1999; Wiederman, Sansone & Sansone, 1998). Two studies found that abused women and those who reported significant levels of ‘marital discord’ were three times more likely to report past suicide action than were non-abused women (Abbott et al., 1995; Kaslow et al., 2000). In homes where there is a firearm, the risk is up to five times greater (Wiebe, 2003). In a large population-based study of suicides among women in North Carolina two data sources were used, medical examiner files and interviews with law enforcement officials. Of the 882 women who died by suicide between 1989-1993, 34.4% had taken previous action or had a known history of suicidal ideation. Significantly, while only 3.5% of the medical examiner files noted a history of domestic violence, 37.8% of the law enforcement officers noted ‘interpersonal conflict’ between the victim and her current or former intimate partner as a common precursor (Runyan, Moracco, Dulli & Butts, 2003). A hospital-based study of 500 women presenting to emergency rooms in Utah, the first in the US to link domestic abuse with suicidal ideation in adults, found that 40% of the women who disclosed that they were abuse victims had considered suicide (Allen, 2004). A cross-sectional self-report survey of 1,207 women attending thirteen doctors’ surgeries in London showed domestic violence had strong associations with most measures of psychiatric morbidity including suicidality (Coid, Petruckevitch, Chung et al., 2003).

The influence of ‘culture’

Very little of the literature documenting the links between suicide and interpersonal trauma comments on sociocultural variables. Some studies compare national suicide rates, but such comparisons are fraught due to differences in data collection and reporting and the methodological limitations of studies, sample sizes and biases already noted.

The most significant finding seems to be the gender anomaly of higher rates of fatal suicides by women in rural China and on the Indian subcontinent (Brockington, 2001; Khan, 2002; Pritchard, 1996). While there is some suggestion that domestic violence plays a role in this finding, a close analysis of possible explanations is lacking.
Suicide across cultures

Many questions remain unanswered in relation to differences in suicide risk across ethnic and cultural groups and the information that is available concerning ‘minorities’ is particularly limited and often contradictory.

The cross cultural suicide literature that does exist tends to focus on the notion of different ‘cultural idioms of distress’, that result in differing manifestations of mental illness and different methods of suicide (Dusevic, Baume & Malak, 2002).

Most studies also emphasise the impact of sociocultural variables, with some researchers focusing on specific cultural groups (e.g. Kok & Tseng’s 1992 study of suicidal behaviour in the Asia-Pacific region) or ethnic minorities (eg Eshun’s 2003 comparison of suicidal behaviour in American and Ghanaian college students). In Australia, McDonald and Steel (1997) studied suicide prevalence rates among immigrant and refugee groups, identifying both cultural differences and similarities in risk factors.

The impact of migration and refugee experiences is also a dominant theme in this body of literature. Research among immigrant populations indicates that in general, patterns of suicide tend to be more like those in country of origin initially, becoming more like the host country over time and with ‘acculturation’ (Dusevic et al., 2002). A number of researchers also note that migration appears to have differential impacts on men and women, although the findings differ, adding to what Falicov calls ‘the ambiguities of migration’ (Falicov, 2003:382). McDonald and Steel (1997) and Klierwer and Ward (1988) note a marked increase in the relative rate of female suicides with immigration. They suggest that a possible explanation for more negative impacts on women is that the decision to migrate is often made by the man. Dusevic and her colleagues note that in this case, ‘the woman is less aware of, and less prepared for, the difficulties that may be encountered in the country of resettlement’ (Dusevic et al., 2002:10). Other research indicates a reversed gender dynamic, with many immigrant women gaining more personal freedoms with migration, which in turn makes them less vulnerable to depression and suicidality (Hondagneu-Sotelo, 1994). Falicov makes the observation that the key issue here ‘probably rests in whether immigrant women become part of the labour force or whether men maintain their privilege by continuing to be the sole family breadwinner’ (Falicov, 2003: 382).

Bayard-Burfield and her colleagues also note that the effects of migration are likely to be mediated by a climate of xenophobia thereby heightening risk for suicidality among foreign-born nationals in countries of resettlement where racism and discrimination are rife (Bayard-Burfield, Sundquist, Johanssen et al., 1999).

The impact of ‘cultural conflict’ compounded by intergenerational differences is noted particularly for young people of immigrant parents. One study reported that 76% of a sample of Asian American youths indicated that conflict with parents was a contributor and a ‘disciplinary crisis’ was the most common precipitant of a suicide attempt (Lau, Jernewall, Zane & Myers, 2002).

A diagnosis of post-traumatic stress disorder (PTSD) in refugees who are torture and trauma survivors is also linked with suicidality in the literature (Ferrada-Noli, Asberg, Ormstad et al., 1998; Gong-Guy, Cravens & Patterson, 1991).

Childhood abuse, domestic violence and sexual assault as risk factors

Very few of the cross-cultural suicide studies make direct links with interpersonal trauma as a risk factor. Generally, there is some reference to ‘negative/adverse life events’ and/or ‘spousal or family conflict’, but these are not highlighted and ‘cultural factors’ tend to assume priority in importance.

Some of the transcultural suicide literature takes account of gender in discussion of sociocultural variables and begins to link this with a noting of interpersonal trauma among possible antecedents of suicidality (Andriolo, 1998; Canetto, 1992; Falicov, 2003; Khan, 2002; Marecek, 1998; Pritchard, 1996;)

There is a tendency in the cross-cultural suicide literature to frame particular variables such as ‘collectivism’ and ‘religiosity’ as potentially protective factors for suicide, an assumption that requires some interrogation in relation to experiences of interpersonal trauma. This will be explored in a later section of this paper.
Interpersonal trauma across cultures

The prevalence and manifestations of intimate gender-based violence is a growing field of cross-cultural research. An international review of the literature conducted by Krantz (2002) indicates that some forty population-based quantitative studies conducted in 24 countries on four continents revealed that between 20-50% of the women interviewed reported that they had experienced violence from their male partner (Heise, Pitanguy & Germain, 1994).

Some of these studies focus on specific cultural manifestations, such as ‘bride-burning’ (Jutla & Heimbach, 2004; Martin, Moracco, Garro et al., 2002) and ‘honour killings’ (Ahmad, 2000; Kandela, 2000; Pervizat, 2002). Other research has focused on the somatisation of emotional/mental distress that is more common among women where ‘mental illness’ is highly stigmatised (Lown & Vega, 2001; Weingourt, Maruyama, Sawada & Yoshino, 2001). A few articles make reference to issues specific to refugee women in abusive relationships (Burnett & Peel, 2001; Lamb, 1999; Friedman, 1992; Pittaway, 1999).

There is also a gradually expanding body of international literature regarding child abuse and protection issues from a cross cultural perspective (Baylis & Downie, 1997; Farmer & Owen, 1996; Korbin, 1991; Levinson, 1989; Phillips, 1995). Many studies highlight the role of cultural norms in relation to perceptions of child abuse and some studies have found notable cross-cultural differences in relation to both child sexual assault and physical and emotional abuse of children. Several Chinese studies, for example, found that the traditional concept of ‘filial piety’ (xiao) may be conducive to the acceptance of child abuse and certainly act as an inhibitor to disclosure (Rhind, Leung & Choi, 1999; Tang, 1996, 2002). However it must also be noted that cultural values in relation to familialism, for example, may also act as protective factors. A number of studies focus specifically on the experiences of refugee children (Berman 1999; McCloskey & Southwick, 1996; Savin, Sack, Clarke et al., 1996). A particularly valuable area of cross-cultural research looks at the experiences of abused children from non-dominant cultural groups, particularly black children, within the context of societal racism (Bernard, 2002; Hill & Sprague, 1999; Jackson, 1996).

Cohen, Deblinger, Mannarino and de Areliano (2001) contend that the influence of cultural factors on mental health outcomes, help-seeking patterns, referral pathways and preferred service responses among abused and neglected children and their non-offending caregivers is generally poorly understood by clinicians.

Suicide as a possible outcome of childhood abuse, domestic violence or sexual assault

Given the extent of the research in relation to interpersonal trauma and suicide and the growing interest in cross-cultural suicide prevention, there are remarkably few cross-cultural studies that investigate the links between suicide and interpersonal trauma. However, those that do may provide the basis for a new field of cross-cultural research.

As previously noted, disproportionately high rates of fatal suicide have been found among women in rural China (Meng, 2002; Pritchard, 1996) and in Indian women (Banerjee, Nandi, Nandi et al., 1990; Patel & Gaw, 1996). Similarly high rates have also been found among ethnic South Asian women living in Pakistan (Khan & Reza, 2000), Sri Lanka (Miller & Kearney, 1988), South Africa (Wassenaar, Marchiene, Van der Veen & Pillay, 1998), Malaysia (Morris & Maniam, 2001), Singapore (Mehta, 1990) and in the UK (Chantler, Burneer, Batsleer & Bashir, 2002; Hicks & Bhugra, 2003; Patel & Gaw, 1996). Canetto and Lester (1995) found consistently higher rates for Asian women, arguing that the combination of the concurrent stressors of sociocultural transition and ‘marital conflict’ contribute to a higher than average mortality rate. Khan and Reza (1998) also studied gender differences in non-fatal suicidal behaviour and found that while ‘domestic troubles’ was a precipitating factor among both women and men, ‘negligence by husband’ was the reason most commonly given by women (35%).

Loue and Faust (1999) refer to one South African study that estimated that violence occurs in 50-60% of marriages and that approximately 25% of women in these marriages take suicidal action. Stark and Flitcraft (1995) report that studies in Greece and Denmark have reported
abuse as a factor in as many as 44% of non-fatal suicides among women (Arcel, Mantonakis, Petersson et al., 1992). Several studies of South Asian women in the UK note that the factors endorsed most frequently and strongly as probable precursors of suicidal behaviour are physical and sexual violence by the husband (Chantler et al., 2002; Hicks & Bhugra 2003). Chantler and her colleagues note the interlocking effect of uncertain immigration status, domestic violence and shame (Chantler et al., 2002). Similar findings are reflected in Australian research conducted by Echavarria and Johar (1996) by the Centre for Refugee Research at the University of NSW (2004).

Liu Meng (2002) raises the issue of women’s (lack of) autonomy over their lives in a highly patriarchal society. She frames the meaning of suicide for Chinese women as an act of revenge and ‘one of the ways for women to rebel against their oppressive status in the society and a real denouncement of the unequal relationship between genders in China’ (Meng, 2002:308). Similarly, a study of sexual abuse trauma among Chinese survivors concluded that ‘the patriarchal fetish for female chastity in the Chinese cultural construction of sexual victimization’ (Tsun-Yin, Echo, Luo, 1998:1013) may increase the traumagenic effects of sexual assault. The extreme stigmatization experienced by survivors may, it is argued, increase the likelihood of suicide.

Case studies collected by Dorothy Counts from a range of Oceanic, African and South American societies similarly suggest that ‘suicide may be a culturally constructed way in which a powerless person may avenge herself on her tormentor’ (Counts, 1987: 198). She argues that, in the absence of support, ‘an abused woman may, by following the rules that govern a meaningful suicide, require her survivors to demand compensation from or take revenge on her abusive husband’ (Counts, 1987: 198).

Fischbach and Herbert’s (1997) analysis of gender-based violence across cultures draws attention to reports of suicide in the aftermath of rape and other displays of violence against women, ‘particularly in cultures where virginity is highly prized’ (Fischbach & Herbert, 1997:1170). The dishonour and shame associated with sexual assault is also noted by previous researchers (Fauveau & Blanchett, 1989; Heise, 1993). Indeed the claim is made that ‘in some societies, female suicide is regarded as a socially sanctioned behaviour that enables the politically powerless or entrapped to avenge those who have made their lives intolerable’ (Heise, 1993:1171).

The suggestion that suicide may be a ‘culturally acceptable way out’ of an abusive marriage for many women in India and indeed ‘the only viable alternative to eventual murder by the husband or his family’ is similarly made by Loue and Faust (1999:533). Despite the introduction of anti-dowry legislation, the occurrence of ‘dowry suicides’ is still relatively widespread (Banerjee et al., 1990; Patel & Gaw, 1996). Indeed, Banerjee et al. (1999) found that ‘spousal conflict’ was a factor in 46% of female suicides in West Bengal. Sitaraman (1999) however frames these deaths more as ‘forced suicides’ or ‘disguised homicides’.

A high prevalence of non-fatal suicides is also noted in studies among women in Turkey (Baral, Kora, Yuksel & Sezgin, 1998; Tutken, 1996; Zoroglu, Tuzun, Sar et al., 2003). Baral and his colleagues note that in Turkey histories of domestic violence and/or childhood abuse are not often recorded, as these issues are ‘rarely addressed directly by mental health professionals’ (Baral et al., 1998:427). Nevertheless, Tutken (1996) reports that a suicide attempt rate of 64% was observed in those with a dissociative disorder and a recorded history of CSA. Zoroglu et al. (2003) surveyed 862 high school students and similarly found that those who had a history of abuse or neglect had a 7.6 fold higher rate of suicide attempts than those who did not.

Despite the paucity of suicide research from Africa and other developing countries, one large cross-sectional study of 10,468 adults in Ethiopia found that 63% of those who reported a lifetime suicide attempt were women between 15 and 24 years and that ‘marital or family conflict’ was the most frequently cited precipitant (Alem, Kebede, Jacobsson & Kullgren, 1999).

Research linking suicide with interpersonal trauma among immigrant communities in Australia is limited, but work by Dusevic et al. (2002) and Fry (2000) give some indication of
the prevalence of attempted suicide and suicidal ideation among women in abusive relationships and those with histories of childhood abuse. Dusevic et al. (2002) found that domestic violence was seen to be the dominant risk factor (14%) among the immigrant women they surveyed, followed by ‘relationship problems’ (14%) with sexual assault accounting for 5% of responses. Abuse was also noted as a suicide risk factor by 14% of the non-English speaking background young people surveyed.

Ann Fry’s work with young migrant women in Blacktown (NSW) locates predisposing factors to suicidal behaviour within ‘cultural and intergenerational conflicts embedded in gender roles’ with sexual abuse and domestic violence perpetrated by males being precipitants for 17% (Fry, 2000:156).

**Emerging questions**

Interpersonal violence and suicide are two forms of violence that are clearly related in significant and complex ways. However, the gaps in our understandings of how culture mediates this inter-relationship begs the question of why there is still so little research in this area.

**Gender and cultural biases in research?**

While suicidologists have tended to focus on suicide mortality, which is typically male and epidemiologically quite rare, non-fatal suicidal behaviour, which is typically engaged in by more women, is actually more common. Indeed, Canetto and Lester (1995) suggest that when rates of fatal and non-fatal actions are combined, women are in fact found to be at greater risk of suicide-related events. Why then is there so little research in relation to women’s suicidality?

Range and Leach (1998:24) note the ‘inherent bias against women and non-majority cultures’. in suicide research. They assert that the relative lack of alternative worldviews is reflected in the methodologies adopted and that more feminist research is called for. They characterise feminist research as being based on a collaborative, egalitarian relationship between researcher and participant and addressing context and issues of power, rather than the detached, reductionist approach employed in the scientific empiricist tradition.

A tendency among mental health professionals to pathologise culture has been noted by Burr (2002). Her study of mental health professionals’ explanations for the relatively high suicide rates (and low rates of treated depression) among women from South Asian communities living in the UK highlights how the construction of such cultural stereotypes forms the bedrock of a potentially racist mental health discourse. Falicov (2003) highlights the importance of recognising that our systems, process and diagnostic categories are culturally bound and that there is a need to ‘start anew by incorporating unheard voices, untold worldviews, local knowledge and native psychologies’ (Falicov, 2003:385).

Canetto (1992) also questions much of the epidemiological analysis and research methodology and highlights the role of language in directing research. For example, the terminology commonly used in the suicide literature refers to ‘attempted’ and ‘completed’ suicide, implying a ‘failure’ in the case of the former and ‘success’ in the latter. She argues that such language has constructed a continuum of suicidality, on which ‘less serious’ behaviour becomes conceptualised as ‘more feminine’ and ‘more serious’ behaviour logically is seen as ‘more masculine’. Similarly, the term ‘parasuicide’ is open to critique as it has implications of ‘pretence’ or ‘faking’. As non-fatal suicidal behaviour obviously signals intense distress and ‘attempted suicide’ is one of the strongest predictors of ‘completed’ suicide (Gunnell & Frankel, 1994; Mosicki, 1999), there is a strong case for seizing opportunities for effective intervention with identified subgroups of ‘attempters’.

There is generally less research in the area of parasuicide probably because of difficulties with reporting and data collection, but because non-fatal suicide is more characteristic of women’s suicidal behaviour than of men’s, this means that women are less ‘visible’ in the suicide research. This means that domestic violence (in which women are overwhelmingly the victims worldwide) also tends to be less visible as a risk factor for suicidality. Hicks and Bhugra (2003) note that the significance of marital violence as a specific factor in women’s suicidality is often obscured within the general and often vague
categories of ‘family conflict’ and ‘marriage difficulties’. In this context, Canetto’s point that ‘what researchers ‘find’ depends on what researchers look for and are willing to see’ is especially salient (Canetto, 1992:13).

**A need for new paradigms and frameworks for understanding?**

The lingering influence of outmoded theories of suicide may also be partly responsible for the gaps in the research. For example, Durkheim’s (1897) theory that both marriage and religion act as protective factors for suicide still has considerable currency among suicidologists. While marriage may well act as a protective factor for men, the same cannot always be said in relation to women. Viewing risk from a ‘gender-neutral’ perspective in this context has the net effect of rendering domestic violence as invisible in suicide risk assessment, especially in cultural groups perceived to be particularly ‘religious’.

Lester and Abe’s (1998) study of suicide in Japan also questions the applicability of Durkheim’s theory to non-European nations, finding that the strong levels of social integration and regulation that characterise Japanese society do not necessarily protect against suicide. Analysis of suicide in Taiwan also found results in conflict with predictions from Durkheim’s theory (Lester, 1995).

While ‘religiosity’ and prohibitions against suicide are frequently referred to as protective factors (Kok, 1998; Neelie, Wessley & Lewis, 1998; Stack & Wasserman, 1992), there is little attention paid to the influence of these on the prevalence of non-fatal suicidal behaviour. A study by Eskin (1999) comparing rates of suicidal thoughts and attempts in Swedish and Turkish adolescents found that despite strong sociocultural and religious prohibitions against suicide in Turkey, the Turkish students reported greater current suicidal ideation and significantly more suicide attempts than their Swedish peers. While living in a highly religious ‘culture of relatedness’, such as the Turkish culture, may have an effect on the rates of suicide deaths, it does not in and of itself ‘protect’ against suicidality.

In the context of higher rates of depression and non-fatal suicidal outcomes among women, Stack’s (1998) argument that suicide is more ‘acceptable’ among men is worth interrogating. If women die by suicide less often than men because it is less ‘acceptable’ for them to kill themselves, does this mean that those women who do die from suicidal acts are transgressing gender roles in the only way they deem is possible? Stark and Flitcraft’s (1995) reframing of female suicidality as the exercising of ‘control in the context of no control’ shifts the theoretical framework to one that highlights social context. Liu Meng’s (2002) construction of rural Chinese women’s suicides as acts of ‘rebellion’ supports this reframing. By extension then, are women who have transgressed their gender-roles being omitted by researchers because they don’t ‘fit’ the expected gendered patterns of suicide?

Similarly, beliefs about the protective effects of ‘collectivist’/sociocentric cultures may serve to hide the context of suicidal experiences of many people. Idealised images of extended family groups and ‘communal living’ may well have the effect of hiding the occurrence of child abuse and domestic violence, making it more difficult for victims to disclose and seek help. When the family is the source of the problem, or is unable to solve the problem and discourages the seeking of outside help, the negative effects of a ‘close community’ may be compounded. In this context, Anne Fry raises the possibility that ‘when taken to extremes, protective factors transmute into risk factors’ (Fry, 2000:158).

Accounting for such complex interactions between gender, culture, age, immigration and acculturation processes is thus bound to raise more questions than answers. The links between interpersonal trauma and suicidality become even more complex when regarded through a multi-focus lens.

**Implications for policy and practice**

**Who is most at risk?**

Given that the aetiology of suicidal behaviour is complex and multifaceted and that risk appears to accrue the greater the number of factors that interact, it is difficult to state categorically who is most at risk. The answer to this question depends on what sort of risk is being assessed and what data are being used. As noted, published suicide statistics indicate that young men and the elderly are the groups most likely to
die from suicide. Assessing risk for suicide attempts and suicidal ideation, however, results in a different picture as statistically more women, particularly young women, engage in non-fatal suicidal behaviour. If this risk is overlaid with other factors related to culturally-based gender roles and the effects of immigration, resettlement and pre-arrival experiences, then perhaps the answer to the question of who is most at risk may be a different one to that which is generally suggested.

**What needs to be done?**

**Prevention**

A range of prevention strategies is discussed in the literature, although rigorous evaluation of prevention efforts is sorely lacking (Krug et al., 2002) and very few have shown a significant effect on reducing suicidal behaviour or producing longterm sustainable results (Goldney, 2000). Prevention programs specifically targeting culturally and linguistically diverse communities are rare (Dusevic et al., 2002). While the suicide literature is replete with discussion of risk factors, much less is written about protective factors and potentially moderating co-variables (De Leo, 2002). Social support and connectedness, however, consistently emerge as key protectors (Nisbet, 1996; Wichstrom, 2000). It may well be that focusing on factors such as emotional wellbeing and support from family and friends may be as effective or more effective than trying to reduce risk in the prevention of suicide. In the context of reducing risk related to interpersonal trauma, it may be reasonable to assume that initiatives designed to raise awareness of domestic and family violence within diverse communities will contribute towards a reduction in suicidality in these communities.

**Intervention**

A number of pathways to care are suggested in the literature, the most common being appropriate risk assessment and management. Training initiatives targeting general practitioners and other allied health professionals are strongly advocated (Michel, Runeson, Valach & Wasserman, 1997; Rotheram-Borus & Bradley, 1991). The issue of cultural competence of service providers, however, does not appear to be adequately addressed in the literature. Dusevic et al. (2002) note the potential for assessing the role and ability of bilingual general practitioners in immigrant suicide prevention. Most importantly, our cross-cultural suicide assessment frameworks need to incorporate a dimension that assesses for history of interpersonal trauma and abuse.

**Postvention**

Those bereaved by suicide may have limited opportunity to share their grief and hence there is clearly a need for support to surviving relatives and friends. Dusevic et al. (2002) note that the effectiveness of postvention initiatives however has not been demonstrated due to methodological limitations in studies exploring this issue (Patton & Burns, 2000). Young and Papadatou (1997) also note that the stigma related to suicide can act as a barrier to accessing bereavement services. This is likely to be an issue particularly for some immigrant and religious groups and thus has implications for cross-cultural practice also in the area of grief and loss counselling.

**Policy considerations and concluding thoughts**

Australia prides itself on being one of the first countries to develop a comprehensive national strategic approach to suicide prevention. But could it be more comprehensive?

Current policy, as articulated in the Commonwealth Department of Health and Aged Care’s (2000) LiFe (Living is For everyone) framework, outlines a number of key areas for action, including progressing the evidence base for suicide prevention and good practice. Physical and sexual abuse, particularly in childhood, are noted in the document as risk factors for later suicidality, but little mention is made of domestic violence and its effects on women. Not surprisingly then, the framework omits to suggest that thorough suicide risk assessment ought to incorporate assessment of current risk of harm from others, as well as risk of harm to self (and to others). Much is made of the need to develop and foster partnerships across agencies, sectors and communities, but there is little acknowledgement that such collaborations may involve working with and
negotiating a way through the tensions created by sometimes clashing paradigms.

While people from culturally and linguistically diverse backgrounds are named as a specific population group in the LiFe framework, there is scant recognition of gendered differences in suicidal behaviour among immigrants and resettled refugees. The Framework for the Implementation of the National Mental Health Plan 2003-2008 in Multicultural Australia (Commonwealth Department of Health and Ageing, 2004) is a timely document that presents a number of challenges to mainstream mental health service provision. It complements not only the National Mental Health Plan, but also suicide prevention policy.

There is thus ample scope within the existing policy context to act on some of the issues raised by this literature review. A thorough analysis of the policy landscape is beyond the scope of this paper, but it is likely that such an undertaking would reveal a number of policy vacuums and opportunities to cross-reference policies. Linking suicide risk assessment and management protocols to domestic violence routine screening and safety planning, for example, is one way of dovetailing policies and facilitating cross-discipline communication.

Based on what we know about the global prevalence of interpersonal violence perpetrated within intimate and family contexts, it seems reasonable to suggest that there is a need for further research into these experiences as they are lived within immigrant and refugee communities in Australia.

Focused research into the experiences of young people of diverse backgrounds, particularly second generation immigrant and refugee young people, will enable valuable exploration of the intersecting effects of intergenerational and intercultural conflict.

Perhaps the research light also needs to be shone more intensely on the role of protective factors in suicide prevention. It seems probable that efforts to reduce domestic and family violence must inevitably have a protective effect against suicidality for those sub-groups most affected by this kind of interpersonal trauma (i.e. women, children and young people).

However, in advocating for more culturally-inclusive research a caveat applies. Cross-cultural research is a delicate balancing act requiring careful avoidance of the pitfalls of an ‘all or nothing’ approach to cultural diversity. Too much focus on difference perpetuates an ‘us and them’ way of thinking; too little universalises individuals’ experiences, obscuring important culturally specific detail that can make a crucial difference to an intervention.

Finally, there is an urgent need to develop an inclusive framework for practice that reflects the diversity of our potential client base. An ‘intersectional’ approach, embedded within an ecological or integrative framework may emerge as a useful way for practitioners in a range of professional contexts to understand and respond to the issues in a cross-cultural setting. Indeed, such an enterprise opens up rich possibilities for the valuable cross-fertilisation of divergent discourses and perspectives.

Notes

1. ‘Postvention’ is a term used in some of the suicide literature to denote the provision of bereavement care and support to the surviving family and friends of the person who has died.

2. For an exploration of suicide within Aboriginal and Torres Strait Islander communities, see Bird (2002), Durie (2003), Hunter and Harvey (2002). For a discussion of suicide among Canada’s native people see MacMillan et al. (1996); for Maori people see Langford et al. (1998); for native American peoples, see Robin et al. (1998); for native Hawaiian people, see Yuen, et al. (2000).


5. ‘Psychological autopsy’ is a term used by some suicidologists to describe the process of determining the state of mind of the person and events occurring in the weeks and months before
death. This is generally done by interviewing surviving family members and close friends.

6. The ingestion of poisonous organophosphate insecticides is the most common method of suicide in China; self-immolation is still relatively common in India.

7. According to Counts, among the Kaliai women of Papua New Guinea the ‘rules for a person who intends to kill herself’ include warning others of her intent, dressing herself in her finest clothing, killing herself in the presence of others (or where they will be certain to find her body) and communicating to others the identity of the individual who is responsible for her death (Counts, 1987:195).

References


The employment of people with mental illness

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Abstract

People with a mental illness are among the most socially and economically marginalised members of the community. They experience high levels of unemployment and non-participation in the labour force. Unemployment has a number of negative effects including the loss of purpose, structure, roles and status and a sense of identity which employment brings. Employment enables social inclusion in the wider community and is an important way that people with a mental illness can meaningfully participate in the wider community. Australia has a mental health strategy, which guides the ongoing reform of mental health services. However, specific strategies to address the social and economic marginalisation of people with a mental illness have not been addressed. A recovery-oriented approach is recommended, which integrates the key sectors involved. To date there has been little inter-sectoral collaboration between the various sectors such as mental health services, housing, and vocational services. People require more role-specific assistance to enable them to participate in socially valued roles implicit with citizenship. There is a need to formulate improved pathways to assistance and more evidence-based forms of assistance to re-establish career pathways. This report aims to: 1) collect relevant overseas and Australian evidence about the employment of people with mental illness; 2) identify the potential benefits of employment; 3) describe patterns of labour force participation in Australia among people with mental illness; 4) identify how mental illness can cause barriers to employment; 5) outline the type of employment restrictions reported by people with mental illness; 6) identify the evidence-based ingredients of employment assistance; 7) identify relevant policy implications; and 8) suggest strategies to improve employment outcomes and career prospects for people with mental illness.

Keywords

mental illness, work, policy development, vocational interventions, supported employment, evidence-based components

Note: Figure 1 on page 10 requires colour printing.
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1. Introduction

1.1 Background

There is substantial evidence that the vocational rehabilitation needs of people with mental illness are not being adequately addressed. High levels of unemployment and non-participation in the labour force prevail among people with mental illness in Australia and in other countries with developed market economies. Labour force non-participation and unemployment levels of 75-90% are found in the United States [1], 61-73% in the United Kingdom, and reach 75-78% among people with psychotic disorders in Australia [2-3]. In a recent Australian survey of 134 disability employment service providers assisting 3025 jobseekers [4], psychiatric or psychological disabilities represented the largest category (30%) and fared worse than any other disability category in terms of both securing and retaining employment. Following 16 months of disability employment assistance, 44% of job seekers with psychiatric disabilities remained unemployed, while only 23% attained durable employment, defined as accumulating 6 months or more of employment of 8 or more hours per week. These statistics indicate that despite the availability of assistance in Australia, the majority of people with mental illness appear excluded from employment opportunities. To counter this disadvantage, more effective assistance appears needed to help people with mental illness establish and re-establish career pathways, to reduce exclusion from mainstream society, and to increase prospects for equitable social and economic participation.

In countries with developed market economies, people with mental illness experience difficulties in achieving the basic right to work [5]. They are also sensitive to the negative effects of unemployment and the loss of purpose, structure, roles, status, and sense of identity which employment provides [6]. Employment enables social inclusion in the wider community and represents an important way people with mental illness can meaningfully participate in society. People with mental illness need the same opportunities to participate in life activities and their local communities as people with good mental health [7].

Australia has a national mental health strategy [8-14] which guides ongoing reform of mental health services. This strategy recognises the challenge of inter-sectoral difficulties in terms of disability support, education, housing, and employment. However, the intersectoral collaborations called for by the strategy have not been adequately evaluated [8,11]. This is probably because no such collaborations appear to have materialised, even though these are recognised as essential to address the social and economic marginalisation of people with mental illness [13-14]. More specific strategies appear needed to restore the career disruption caused by mental illness and to restore functioning in socially-valued roles. Such roles in education, employment, parenting and caring for others, are not automatically restored with clinical improvement and may remain impaired throughout the lifespan, even when full remission of clinical symptoms is achieved.

This policy and service delivery failure was recently highlighted by the Queensland Public Advocate who observed that people with mental illness would be better served if public mental health services adopted recovery-oriented practices beyond a strict bio-medical approach. A broader recovery oriented approach was recommended [15, pp. 29-30] which "...integrates peer support, housing, community infrastructure, vocational rehabilitation and training, and other key sectors."

The lack of inter-sectoral collaboration in Australia exacerbates the structural division of public mental health services from other key sectors such as housing and employment. This in turn obstructs inter-sectoral policy development as well as the coordination and delivery of mental health and vocational services [16]. Mental health expertise and specialised vocational rehabilitation expertise remain insulated within their respective sectors with little knowledge transfer across sectors. Consequently, Australian clinicians may not be aware of developments in the emerging science of psychiatric vocational rehabilitation, and may not understand how employment is feasible even when more severe psychiatric symptoms and disabilities are present.
Through similar structural isolation from clinicians, vocational professionals can lose touch with the latest developments in mental health treatment. Subsequently, they may not be aware of current treatment goals and methods, may fail to recognise ineffective or sub-optimal treatment, and may miss opportunities for identifying alternative or enhanced treatments likely to reduce employment restrictions, and improve health outcomes as well as employment prospects. In addition, when uncoordinated, both treatment and vocational plans are at risk of mutual interference, which at any time can obstruct progress in both domains and negatively impact on mental health consumers, their families and carers.

1.2 Aims and scope of this report
This report aimed to: (1) collect relevant overseas and Australian evidence about the employment of people with a mental illness; (2) identify the potential benefits of employment; (3) describe patterns of labour force participation in Australia among people with mental illness; (4) identify how mental illness can cause barriers to employment; (5) outline the type of employment restrictions reported by people with mental illness; (6) identify the evidence-based ingredients of employment assistance; and (7) identify policy implications and (8) suggest strategies to improve the career prospects of people with mental illness.

1.3 Terminology
The term mental illness refers to clinically diagnosed mental disorders such as the anxiety, affective, and psychotic disorders as defined by DSM-IV and ICD-10 classification systems [17-18]. The term mental illness represents more than mental health problems, a term used to refer to short-term adverse mental health states which can occur in response to life stressors and challenging life events. Psychotic disorders typically refer to schizophrenia spectrum disorders, bipolar disorders (when psychosis is present), depression (with psychosis) and other mental disorders involving disturbances of thought and perception.

In the USA, the term supported employment refers to an approach to vocational rehabilitation emphasising ‘place and train’ in competitive employment opportunities, as opposed to 'train and place' the approach associated with traditional vocational rehabilitation. On-going assessment is conducted in real work contexts, and lengthy pre-employment assessments and gradual stepwise approaches to vocational rehabilitation are avoided whenever possible. In Australia, the nearest equivalent term is open employment as defined in the Australian Government's Disability Services Act, 1986. Similarly defined in this Act, the term supported employment refers to group-based assistance provided by business services, offering sheltered work in modified (not fully competitive) work settings. One or more disability categories may be accommodated by business services (previously known as sheltered workshops) more often for intellectual and physical than for psychiatric disability. In this report the USA meaning of the term supported employment is used.

Whereas work can refer to any structured non-recreational activity, employment is defined by the Australian Bureau of Statistics (ABS) as paid work of one hour or more per week in accordance with industrial awards, unpaid work in a family business, or unpaid work on a family farm. Competitive employment is a widely agreed priority for psychiatric vocational rehabilitation [19-22] and is defined as: part-time or full-time work in the competitive labour market at award wages with supervision provided by personnel regularly employed by the business. The nearest equivalent official term in Australia is open employment. In competitive employment the work is to be performed alongside non-disabled people in integrated settings and the job can be filled by people without disabilities. Although the job design may be modified, it is not designated exclusively for a person with a disability. Competitive employment is distinguished from sheltered work, voluntary work, or pre-vocational training. Sheltered work is characterised by one or more of: additional supervision by mental health staff or by other staff external to the workplace; pay at less than the minimum award wage; use of a supported wage award; segregated work settings; or jobs reserved exclusively for people with disabilities.
**Vocational rehabilitation** is another term which can cause confusion. In a general sense it refers to a form of psychosocial rehabilitation where the focus is on restoring (rehabilitating) career pathways, often in conjunction with other forms of psychosocial treatment and rehabilitation. In Australia, the term also refers to the type of vocational assistance typically provided by CRS Australia, as the Government owned sole public provider, where a rehabilitation partnership is developed and intensive efforts can be made to prepare a person for employment, secure employment, and provide support to achieve continuous employment for three months, or until the rehabilitation consultant is confident the position is stable. At its best, the Australian version appears more intensive than the form provided in the U.S.A., where case loads may be higher and less intense assistance appears to be provided.

1.4 **Education and employment opportunities as human rights**

Although Australia does not have a Constitutional Bill of Rights, individual responsibilities and rights are implicit in Australian citizenship. All people in our community have the right to suitable employment in conditions which reflect equity, security, human dignity and respect. Work is important to the mental health and wellbeing of individuals. It is a central aspect of life for most people and provides economic security, valued personal roles, social identity, and an opportunity to make a meaningful contribution to the community. Suitable employment enables social and economic participation in society. Opportunities for social and democratic participation are critical elements to the mental health and wellbeing of individuals, organizations, communities, and nations [23].

According to Australia's *National Mental Health Plan 2003-2008* [9, p. 5], Australians, including people with mental illness, have a fundamental right to both education and employment:

*The human rights of all people in Australia should be respected. Individuals should not be discriminated against in housing, law, employment, or education. Mental health problems and mental illness should not be stigmatised in the media, by the general community or by mental health services themselves.*

Despite a 65% increase in Government spending on mental health throughout 1993-2002 [8], people with mental illness continue to be socially and economically marginalised from mainstream Australian society. More role-specific assistance appears needed to enable people with mental illness to participate in the socially-valued roles implicit with citizenship, such as worker, student, rehabilitation participant, carer, or homemaker. These roles enable people with mental illness to outgrow the roles of mental health patient and welfare recipient, which attract additional stigma and unfair discrimination.

1.5 **The disease burden of mental illness**

Mental illnesses are the third leading cause of overall disease burden in Australia (14% of total) following cardiovascular diseases (20%) and cancers (19%), as measured by disability adjusted life years, a scale of disease burden combining the influences of mortality and morbidity. In terms of morbidity, as measured by life years lost to disability, mental illnesses are the leading cause of disease burden in Australia [24]. Participation in employment and other socially-valued roles can reduce the high burden of mental illness by reducing the secondary effects of social and economic marginalisation on individuals. Employment may also reduce the burden on families and carers, although to date there is no evidence to support this expectation. The financial burden on the community may also reduce with greater participation in employment and other socially-valued roles, through reduced welfare dependence, reduced use of public mental health services, and greater involvement in local communities.

1.6 **The challenge of ageing populations**

Reducing the impact of mental illness on labour force participation and employment can contribute to meeting the challenge of ageing populations. The Organisation for Economic Co-operation and Development (OECD) advise member countries [25-27] to implement policies reducing the dependence ratio of older people (aged 65 years or older) to those of working age (15-64 years). The OECD warns that failure to heed this advice will lead to falling living standards as the dependence ratio increases from 22%
to 46% by the year 2050. To help achieve this, the impact of mental disorders on labour force participation and career pathways needs to be reduced. This may require a coordinated Government approach via health treatment services, income support and taxation systems, as well as through improved Job Network, disability employment services, and vocational rehabilitation services.

People with mental illness over 55 years of age face additional disadvantage as members of the ageing community. Through reduced employment opportunities throughout the working life they may be more poverty prone in retirement and may have left the workforce years earlier than people without mental illness (see Figure 1). For those continuing employment or voluntary work in the community, additional barriers can emerge with ageing, such as transport problems, the onset of age-related physical limitations and disabilities, difficulty accessing health and mental health services, and difficulty accessing vocational service providers willing to provide appropriate assistance. The combination of mental illness and ageing highlights the need for disability and lifestyle support for people with mental illness throughout the life span, independently of role specific assistance in education or employment.

1.7 Implications for policy development

Equitable access to career opportunities throughout the working life is an implicit right of Australian citizenship which are not restored by the provision of mental health services alone. Governments have a social justice obligation to prevent mental illness becoming a life-sentence of social and economic marginalisation. Evidence-based forms of disability-specific education and employment assistance appear needed to address the lifelong social and economic marginalisation caused by mental illness. Employment and education assistance are not intended to displace disability and independent living support provided by the psychiatric disability services sector. National strategies to combat the challenge of ageing populations can include specific strategies to encourage labour force participation by people with mental illness throughout the working life. Additional disability support strategies will be needed to accommodate the increasing assistance needs of ageing people with mental illness.

2. The impact of mental illness on employment

2.1 Reduced labour force participation and unemployment

Recent Australian population surveys provide evidence of career disadvantage among people with mental illness. For example, from the Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers, 1998 [3,28-31] found that 75% of people with psychotic disorders and 47.1% of people with anxiety disorders did not participate in the labour force. These levels represent 3.8 times, and 2.4 times respectively, the 19.9% non-participation by healthy Australians aged 15-64 years.

2.2 The impact of anxiety disorders on employment

Anxiety and depression are prevalent in the community and together are found in approximately 5-10% of the population [32-36] at any time. Although anxiety disorders are among the most treatable mental disorders, in a recent national survey [26] 40.9% of people with anxiety disorders reported not receiving mental health treatment. Of those that receive treatment, not all received optimal treatment [37,38]. Anxiety disorders are associated with increased non-participation in the labour force, deflated employment trajectories (see Figure 1) and impaired work performance compared to healthy people [30,31,39]. People with anxiety disorders are also unlikely to receive appropriately intense employment assistance, because in the ABS survey mentioned, only 2.5% of persons with anxiety disorders reported receiving job placement assistance [31].

People with more severe forms of anxiety disorders such as obsessive compulsive disorder (OCD), panic disorder (PD), generalised anxiety disorder (GAD), and posttraumatic stress disorder (PTSD), may be particularly disadvantaged. These anxiety disorders commonly produce severe to profound employment restrictions. Treatment of these disorders can require specialised therapies (e.g. cognitive behaviour therapy, graduated exposure therapies, narrative therapy, motivational interviewing) in addition to usual
psychiatric treatment [38]. However, the limited public funding and partial medical insurance coverage for specialised psychological treatments in Australia, means that these treatments may be too expensive for most people.

2.3 The impact of depression on employment
Depression, like anxiety, often remains untreated, and not all people treated for depression receive optimal treatment. In the SDAC 1998 [29], 56% of people with clinical depression received any form of professional treatment. Depression is known to cause absenteeism from work [39-42] and impair work performance when at work [40, 43-45]. People with depression also have reduced labour force participation, reduced working hours and may earn less than healthy workers [46]. In U.S.A. studies, more sick days were found lost from depression than any other health condition [41-42]. Furthermore, depression is associated with five times more work days impaired through presenteeism (present at work but not functioning as efficiently) than lost to absenteeism [39,44].

People with depression may have impaired motivation, impaired decision making, and a reduced capacity to initiate a particular course of action. Depression can be misunderstood by employers and vocational service providers as poor motivation for work generally, or when employed, as low motivation for working productively. Like those with psychotic disorders or severe anxiety disorders, people with dysthymia and major depression may need specialised treatment to reduce employment restrictions, and may need a relatively intensive and continuous form of vocational rehabilitation to help restore and maintain career pathways.

2.4 The impact of bipolar affective disorder on employment
Little is known about the impact of bipolar affective disorder on employment. In a recent national mental health survey [47] 61.8% of those with a diagnosis of bipolar affective disorder were not participating in the labour force, 4.5% were looking for work, and 28% were employed. The effect of this disorder on employment approaches the magnitude of the effect caused by psychotic disorders. However, anecdotal evidence indicates that this disorder can fluctuate more than most other mental disorders, and may involve a manic phase where productivity and creativity can be high, where time and energy management may be impaired and the person may over-exert themselves until a depression cycle is reached. The danger with this disorder is that a continuing need for assistance may not be recognised due to apparent high functioning during the well or early manic phases. In addition, the person affected by this disorder may correctly judge that assistance is not needed during the manic phase, but may forget the extent of difficulty experienced during the depressive phase. People with bipolar affective disorders may have relatively little difficulty obtaining employment, but unless new strategies are learned to monitor warning signs (e.g. increasing energy, productivity and creativity at work; or increasing social withdrawal at work and difficulty getting to work) job retention is likely to be the major issue. Treatment plans coordinated with vocational plans and interventions, with access to continuing support as needed, can be essential to achieve sustainable employment for people with this disorder.

2.5 The impact of psychotic disorders on employment
The onset of psychotic disorders can permanently disrupt education, employment and career development [2,3]. Although of low point prevalence compared to anxiety and depression at approximately 0.47% of the population [47], psychotic disorders are associated with lifelong career disruption. In 1998 [3] 75.2% of householders with psychosis were non-participants in the labour force, 21.1% were employed, and 3.7% were looking for work (see Table 2). Despite evidence of career disruption, long-term outcome studies [48] and successful vocational programs [19-22,49-50] support the feasibility of employment for a substantial proportion of persons with psychotic disorders.
Table 1. Labour force activity among Australians with anxiety disorders aged 15-64 years compared to persons without disability or long-term health conditions.

<table>
<thead>
<tr>
<th>Persons with ICD-10 anxiety disorders and employment restrictions of which the most restrictive is:</th>
<th>Not in the labour force %&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Looking for work %&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Employed part time or full time %&lt;sup&gt;a&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>profound</td>
<td><strong>100.0</strong></td>
<td><strong>0.0</strong></td>
<td><strong>0.0</strong></td>
</tr>
<tr>
<td>severe</td>
<td><strong>60.1</strong></td>
<td>5.5</td>
<td>34.3</td>
</tr>
<tr>
<td>moderate</td>
<td>32.7</td>
<td>12.9</td>
<td><strong>54.3</strong></td>
</tr>
<tr>
<td>mild</td>
<td>45.3</td>
<td>6.1</td>
<td><strong>48.6</strong></td>
</tr>
<tr>
<td>no employment restrictions&lt;sup&gt;d&lt;/sup&gt;</td>
<td>23.2</td>
<td>9.2</td>
<td>67.6</td>
</tr>
<tr>
<td>Total persons with ICD-10 anxiety disorders</td>
<td>47.1</td>
<td>7.5</td>
<td>45.4</td>
</tr>
<tr>
<td>Persons without disability or long-term health conditions (Controls)</td>
<td>19.9</td>
<td>6.3</td>
<td>73.8</td>
</tr>
</tbody>
</table>

Notes: a. Row percentages shown. b. Standard errors represent 25-50% of the estimate value. c. Standard errors exceed 50% of the estimate value. d. Reference level. ** Statistically significant at the 99.9% confidence level for Z score of difference with respect to within column reference level. * Statistically significant at the 95% confidence level. ns Not significantly different from the reference level of no employment restrictions.

2.6 Employment restrictions among people with mental illness

At a population level [30] the most commonly reported employment restrictions among people with anxiety disorders are: restricted in the type of job (24.0%); need for a support person (23.3%); difficulty changing jobs (18.6%); and restricted in the number of hours (15.4%). A substantial proportion of people with anxiety disorders (23.3%), and 61.3% of people with psychotic disorders [3], report a need for a support person if participating in employment (see Table 3). The high proportions of people with anxiety disorders reporting employment restrictions (from Table 1: severe to profound 26.7%; mild to moderate, 36.9%; no employment restrictions 36.5%) indicate a need for services which can both reduce employment restrictions and help employers to accommodate these restrictions in the workplace.

The psychotic disorders are associated with the greatest proportions of employment restrictions. However, substantial proportions of people with depression and anxiety disorders also report employment restrictions [30]. Figure 1 shows how the impact of depression and anxiety disorders on employment, also depends on age and the severity of employment restrictions [51].

Table 2. Labour force activity by employment restrictions among Australian householders with psychotic disorders aged 15-64 years.

<table>
<thead>
<tr>
<th>Persons with psychosis and employment restrictions, of which the most restrictive are:</th>
<th>Not in the labour force %&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Looking for work %&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Employed part time or full-time %&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Persons %&lt;sup&gt;a&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>profound</td>
<td>100.0</td>
<td>0.0</td>
<td>0.0</td>
<td>100.0</td>
</tr>
<tr>
<td>severe</td>
<td>88.2</td>
<td>0.0</td>
<td>11.8</td>
<td>100.0</td>
</tr>
<tr>
<td>moderate</td>
<td>32.6</td>
<td>0.0</td>
<td>67.4</td>
<td>100.0</td>
</tr>
<tr>
<td>mild or none</td>
<td>77.2</td>
<td>0.0</td>
<td>22.8</td>
<td>100.0</td>
</tr>
<tr>
<td>Persons with psychosis, without activity or employment restrictions</td>
<td>50.0</td>
<td>14.7</td>
<td>35.3</td>
<td>100.0</td>
</tr>
<tr>
<td>Total persons with psychosis aged 15-64 years living in households</td>
<td>75.2</td>
<td>3.7</td>
<td>21.1</td>
<td>100.0</td>
</tr>
<tr>
<td>Control group. Healthy persons aged 15-64 years, without disability or long-term health conditions.</td>
<td>19.9</td>
<td>6.3</td>
<td>73.8</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Notes: a. Percentages shown sum to 100 within rows. b. Standard errors represent 25-50% of the estimate value. c. Standard errors exceed 50% of the estimate value.
Table 3. Employment restrictions among Australians aged 15-64 years with anxiety disorders compared to those with psychotic disorders.

<table>
<thead>
<tr>
<th>Type of employment restriction</th>
<th>Persons with anxiety disorders %&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Persons with psychotic disorders %&lt;sup&gt;b&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Need for a support person</td>
<td>23.3</td>
<td>61.3</td>
</tr>
<tr>
<td>Restricted in type of job</td>
<td>24.0</td>
<td>* 31.2</td>
</tr>
<tr>
<td>Difficulty changing jobs or getting a better job</td>
<td>18.6</td>
<td>* 28.3</td>
</tr>
<tr>
<td>Restricted in number of hours</td>
<td>15.4</td>
<td>* 18.1</td>
</tr>
<tr>
<td>Need for ongoing supervision or assistance</td>
<td>3.2</td>
<td>* 12.7</td>
</tr>
<tr>
<td>Need for time off work</td>
<td>7.7</td>
<td>* 12.5</td>
</tr>
<tr>
<td>Need for special arrangements or equipment</td>
<td>5.5</td>
<td>** 1.0</td>
</tr>
<tr>
<td>No employment restrictions</td>
<td>12.5</td>
<td>** 6.9</td>
</tr>
<tr>
<td>Total persons aged 15-64 years</td>
<td>100.0</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Notes: a. Rows are not mutually exclusive as multiple employment restrictions were frequently reported. b. Column percentages shown. * Standard errors for these estimates represent 25-50% of the estimate value. ** Standard errors for these estimates exceed 50% of the estimate value.

Figure 1. Proportions employed by employment restrictions, diagnostic category and age group, among Australian household residents aged 15-64 years in 1998.

2.7 The impact of mental illness on education and vocational training

The onset of mental illness can truncate primary, secondary or tertiary educational attainment and vocational training, and disrupt normal career development. For psychotic disorders, this may occur because the typical onset age is from 10-30 years, which may coincide with the critical career stages of completing formal education and establishing a career pathway. Through disrupting education, mental illness can indirectly cause long-term unemployment and limit career prospects. Hence, mental illness can displace career paths downwards and limit attainment to less skilled jobs, lowering both work status and income expectations.
Several studies have identified the importance of education to career development. A recent longitudinal study [52] and a secondary analysis of data from the USA National Health Interview Survey on Disability, 1994-95 [53], linked educational attainment to increased employment outcomes and higher employment status in the U.S.A. In Australia, educational attainment is closely associated with employment outcomes. Two national surveys [2,47,54] found positive links between educational attainment and both current employment and durable employment among people with psychotic disorders. Among those not completing secondary school, 11.6% of people with psychotic disorders reported current employment. The employed proportion increased with secondary school completion (22.1%), vocational qualifications (34.3%), and attaining Bachelor degrees or higher (46.7%).

The need to restore educational attainment following disruption by mental illness is recognised by the *National Mental Health Plan 2003-2008* [9, p. 22]. Federal and State Ministers previously endorsed the findings of the 1995 Mental Health Forum on Intersectoral Linkages supporting linking mental health services with other sectors as a priority under both the first and second plans in 1992 and 1997. However, this need was overlooked by Australian welfare and disability employment service reform throughout the 1990s [55]. In the current mental health plan, the key directions (18.1-18.3) refer to fostering non-specific linkages between sectors and levels of Government at a local level. However, evaluations of the plan to date have not reported on progress with respect to establishing inter-sectoral links [8].

**2.8 The need for specialised treatments to reduce employment restrictions**

The public mental health sector in Australia represents an alternative source for specialised psychological and psychiatric treatment for all forms of mental disorders, which can target and ameliorate employment restrictions. However, service priorities and admission criteria vary by State and Territory. In some States, people with severe anxiety disorders can be excluded from the public mental health system because of high demand for services and because psychotic disorders may be considered a higher priority. In other States, people with more severe anxiety disorders can obtain access to good psychiatric care, case management, and specialised therapies. That this is not uniform across Australia is unfortunate because public mental health services have the multidisciplinary teams capable of being trained in providing the full range of specialised treatments required for these disorders.

In some states and territories, people with mental disorders can have difficulty obtaining both optimal treatment and suitable vocational assistance. They may be turned away by vocational professionals who recognise the extensive employment restrictions associated with the severe forms of these disorders. Vocational professionals may be unwilling or unable to provide specialist psychological and psychiatric treatments as part of a comprehensive vocational rehabilitation plan. However, specialised psychological treatments coordinated by a vocational plan may be particularly effective through leveraging treatment motivation with vocational motivation. Providing timely and effective supplementary treatment is therefore likely to reduce employment restrictions and increase the prospect of favourable vocational outcomes. Specialised treatment need not delay vocational plans because these can be provided in parallel with vocational interventions.

**2.9 Implications for policy development**

Lower levels of employment restrictions among people with mental illness are associated with greater labour force participation and employment participation. Those with more severe employment restrictions who have lower educational attainment are the most disadvantaged.

At a population level the evidence indicates that more can be done to assist Australians with a mental illness to participate in formal study, vocational training and employment. It is likely that people with mental illness could benefit from more assistance to access suitable services, and may benefit from more intensive, continuous and individually tailored assistance than is currently provided.

Specific strategies are needed to allocate responsibilities for the funding and delivery of disability-specific education assistance in primary, secondary, vocational, and higher education, over and above the generic assistance available to people with all categories of disability at education institutions.
3. Capacity and desire to work

3.1 Capacity for work

Non-participation in the labour force and high unemployment do not mean that people with mental illness are incapable of working. Studies of the long-term course of illness and health outcomes of people with schizophrenia [53,56-61] have found substantial heterogeneity of course and outcome, with improvement over time in social functioning in 40-70% of people previously classified as having the most severe disabilities.

Controlled studies of the effectiveness of supported employment [20] demonstrate the feasibility of competitive employment, even when no screening criteria other than initial interest, determine program entry. In a recent review, Bond found that 40-60% of consumers receiving evidence-based supported employment assistance obtained competitive employment. Long-term outcome research and controlled studies of supported employment support the feasibility of psychiatric vocational rehabilitation for people with mental illness, including a substantial proportion of persons with the most severe forms of schizophrenia.

3.2 Desire to work

Labour force non-participation and high unemployment do not imply that people with mental illness do not want to work. Low labour force participation may represent discouraged job-seeking or loss of vocational-hope, because a substantial proportion of mental health service consumers with severe mental illness consider employment feasible [62] and a key element to their recovery [63-65]. When specifically prompted, consumers frequently state that they want employment [57,66-68] even when mental health providers rate employment as a low priority [69]. Other qualitative studies [70-75] have found that people with a severe mental illness actively strive to obtain meaningful roles and an appropriate vocational place in the community.

Not every person with a mental illness regards competitive employment a feasible goal, or regards the return to expected roles as necessary for their recovery [62]. For some people, alternative socially-valued roles as students, rehabilitation participants, voluntary workers, partners, homemakers, parents, and carers, can be equally important depending on personal circumstances and the extent each alternative role offers meaning and purpose to life [75], while reducing the stigma associated with roles of low or negative social value [76-77].

3.3 Implications for policy development

A substantial proportion of people with mental illness have the capacity and desire to work but may not be aware of available assistance or may have lost hope of gaining a vocational place in the community. Improved pathways to assistance, and more evidence-based forms of assistance, appear necessary to re-establish career pathways following the onset of a mental illness. The implication for policy makers is that there is a need to educate the community about the feasibility of employment by people with mental illness, and to ensure that suitably intense, evidence-based, and more continuous forms of assistance are provided. In addition, support is needed for socially-valued roles other than employment, which can also help people regain a valued place in society.

4. The value of employment

4.1 Employment as mental health treatment

Extensive claims have been made for the value of work in psychiatry. From these, Rowland and Perkins [68] identified four benefits of work: work as a restorative psychological process; work to improve self-concept; the protective effect of work; and the social dimension of work. Although there is limited Australian evidence, in North America the evidence suggests that for those seeking employment assistance, employment has few negative effects and is more beneficial than voluntary work [20].
Positive and meaningful employment experiences have been linked to improved self-concept and self-efficacy [75], higher ratings of subjective well-being [78], regaining self-esteem [79], improved engagement in work activity with associated symptom reduction [80-81] and increased personal empowerment [82]. Work may also improve clinical insight for those with severe mental illness who have less severe cognitive impairments [83]. In Australia, participation in vocational rehabilitation provided by CRS Australia is associated with reduced clinical symptoms and higher levels of functioning as measured by the Behaviour and Symptom Identification Scale [84].

4.2 Reducing workplace and community stigma

People with psychiatric disabilities experience considerable stigma and discrimination [76,85-86] from both employers and the general community. Vocational professionals can counter the stigma associated with psychiatric disability by strategic disclosure to employers and to other third parties throughout vocational rehabilitation. Vocational professionals have the opportunity to counter community stigma by enabling people with mental illness to demonstrate their work potential. Personal contact with people experiencing mental illness in the workplace, supported by planned education of managers, supervisors and co-workers, may counter stigma both in the workplace and in the wider community.

4.3 The personal value of employment

Reviews of randomised controlled trials [20] reveal that the main benefit of supported employment is on short-term individual employment outcomes. Other benefits associated with work include structuring time and routine, social contact, collective effort and purpose, social identity and status, personal achievement, and regular activity and involvement [5-6].

However, job retention challenges all forms of employment assistance [87-88] indicating that continuing support to retain employment is critical for people with mental illness. Although there is evidence that sustained employment enhances the non-vocational outcomes of improved self-esteem and symptom control, there is no consistent evidence that employment leads to reduced hospitalisations or improves quality of life [89-90]. Despite these evidence gaps, suitable and meaningful employment can be highly valued by individuals. The following account (Scott, personal communication to MIFA, March 2005) illustrates the personal value of employment:

I have found that working part-time has definitely given me the positive edge on a more healthy self-esteem. Working has taken away the dread of socialising and meeting new people as to when I am asked in conversation, what I do for a living. Once upon a time I had the embarrassment of saying nothing or else saying that I was on a disability pension. Then there was the fear that they would inquire more deeply and I would be exposed as explaining I had a mental illness. With a large portion of society ignorant about mental illness and still having stigma, this position would further squash an already low self-esteem. Working has given me the opportunity to flee this scenario as well as giving me structure and routine.

If I have days or weeks where I’m starting to get slightly unwell, work is the best therapy for me. It gets my eyes off myself and focussed on to others’ needs. Being employed as a supervisor of an Activity Drop-In centre for people with a mental illness, I find serving others needs and healing is good for the soul. I have discovered that the best way to help yourself is simply by helping someone else. With mental health issues, loneliness and boredom are a good recipe for becoming unwell and work has structured my time, so even if I feel lazy and unmotivated, I have to get into action and attend and perform in my job. For people who are ready to take the next step of some degree of work I encourage the system to give them every opportunity as it is vital to that road to recovery.

4.4 When employment has a negative effect

Not every person with more severe forms of mental illness such as schizophrenia who attempts employment, experiences reduced clinical symptoms. For those with severe cognitive deficits, vocational rehabilitation may have negative consequences. By re-examining data from a previous study, Lysaker et al. [83] found a subgroup of people with cognitive deficits whose symptoms either increased or remained the same following five months of vocational rehabilitation. Although the reasons were not established,
Lysaker et al. suggested that severe cognitive impairments may interfere with the ability to fully appreciate the purpose of a work activity, thereby rendering work activity unduly stressful for some people. For those with severe cognitive impairments who are not interested in competitive employment, alternative forms of meaningful employment may be feasible, or support for alternative socially-valued roles may be indicated.

4.5 Implications for the psychiatric disability support sector

Providing more specialised, intensive and continuous support for education and employment should not be at the expense of services in the disability support sector which provide independent living, lifestyle and general disability support to people with mental illness, their families and carers. A distinction can be made between (1) assistance for independent living, social-recreation, non-vocational socially-valued roles; and (2) assistance for the vocational roles of formal study, training and employment. Increasing the value of employment for people with mental illness does not imply displacement of other forms of disability and independent living support. However, change will be needed if existing disability support services are unwittingly discouraging competitive employment, or are providing pre-vocational training as a form of psychosocial rehabilitation, without enabling the realisation of competitive employment goals. Section 7 of this report explains how vocational services are best provided, based on evidence of effectiveness.

4.6 Implications for policy development

This evidence indicates that competitive employment opportunities are valued by people with mental illness. However, at any time a proportion of people may need alternatives to competitive employment, or help in transitional steps towards competitive employment that provide opportunities for personal growth and to learn core work skills. Others may have personal circumstances which require their participation in alternative socially-valued and meaningful roles. Those adversely affected by prior stigma experiences may have long-term competitive employment goals yet in the short term may need the benefit of a stigma-safe work environment. The implication for policy development is that while appropriate assistance with formal education and competitive employment is a priority, assistance is also needed with: alternative roles (e.g. as carer, parent, home maker, rehabilitation participant, and student); other personal recovery goals; and with alternative or transitional employment goals. Transitional employment experiences can be used to develop core work skills including work-related social skills, provide vocational training, and facilitate the transition to competitive employment. In this regard, business service forms of employment and Clubhouse transitional employment can play an active part. Social firms and other business services that offer long-term employment can help by providing jobs and career learning experiences in low-stigma work environments.

5. The organisation of Australian services

5.1 Public funded vocational services

Vocational rehabilitation for physical and sensory disabilities in Australia was established in response to the needs of returning World War II veterans. Open employment services were introduced with the Disability Services Act, 1986. Coverage by disability employment services and vocational rehabilitation was extended to people with mental illness and psychiatric disabilities in the early 1990s.

Australian Government departments were reorganised in 2004 to shift responsibility for open employment services and CRS Australia, from the Department of Family and Community Services (FaCS) to the Department of Employment and Workplace Relations (DEWR). Three types of mainstream services are currently available throughout Australia [16] and are in theory accessible by people with mental illness of working age. These are: (1) disability employment services, including open employment services and business services (group based programs providing employment opportunities in sheltered settings); (2) vocational rehabilitation services (via CRS Australia); and (3) Job Network services. Approximately 10%
of open employment services and three CRS Australia outlets specialise in assisting people with mental illness. Applicants are assessed by Centrelink disability officers (the Australian Government's income support agency) and referred to one of the three streams according to the assessed level of employment support needs.

5.2 Other Government programs

People with mental illness can access a range of mainstream programs designed to help people when looking for work. These include: Australian Job Search, a job vacancy database; self-help job search facilities; career information and career planning assistance; Community Development Employment projects for unpaid work and skills development; work for the dole; new apprenticeship access program; self-employment development and new enterprise assistance; and a transition to work program for those who have been out of the workforce for more than two years.

Another Australian Government program titled Australians Working Together offers support services relevant to people with mental illness. These services include: the Personal Support Program (PSP); Voluntary work and community work; Working credits; and Personal Advisors. Further information about these programs and services is available through the FaCS and Centrelink official websites.

Few if any employment services are funded by State Governments in Australia. This is because under the State-Federal Disability Agreement, employment for people with disabilities is an Australian Government responsibility. However, State Governments administer vocational training, which encompasses the new apprenticeship training scheme. This program subsidises training in a range of industry-specific and job-specific skills. People with mental illness can benefit from the new apprenticeship scheme, which provides access to relevant paid work experience and structured industry-based training.

5.3 Vocational rehabilitation

Public funded vocational rehabilitation is available in Australia through CRS Australia (previously the Commonwealth Rehabilitation Service). There are no other authorised providers. However, services from the private rehabilitation sector are routinely contracted by CRS Australia staff. The differences between vocational rehabilitation and open employment services are shown in Table 4. The method of access via Centrelink assessment is the same as for open employment except CRS Australia staff can exclude people from assistance if they consider substantial gain as stated in the Disability Services Act, 1986, is unlikely to be achieved. The additional programs available to open employment services are also available to CRS Australia. The major limitation of vocational rehabilitation provided by CRS Australia is that on-going support is only officially provided for 12-13 weeks, designed to achieve initial stability of the job placement. Anecdotal reports by people with mental illness indicate that CRS Australia services can be effective when the service is accessible. In some cases continuing support can be arranged by transferring the person to an open employment service.

5.4 Open employment services

Open employment services are typically non-government organisations, which are soon to be funded on a 100% per capita basis. People with disabilities are helped to obtain employment in competitive jobs of their choice. Open employment services specialising in psychiatric disability provide five of the seven components (see rows 1-7 of Table 4) identified as evidence-based in the Individual Placement (IPS) and Support approach to supported employment in the U.S.A. [20]. The two major differences are: (1) initial access is based on Centrelink assessment followed by agency assessment of suitability, rather than consumer choice; and (2) there is little collaboration with mental health services, except in some locations where strong inter-agency relationships have developed.

As for IPS services, Australian open employment services offer rapid commencement of career planning, job research, job searching, and job placement with time-unlimited on-going post-placement support
available if needed. Australian open employment services also have access to other supporting Government programs, in particular: (1) the Supported Wage System for accessing productivity based wages and productivity assessments; (2) Wage Subsidies (reimbursement of short-term wage subsidies paid to employers); (3) access to vacancies held in the Job Network; and (4) access to additional funds for workplace modifications. In addition, open employment services can assist people with disabilities already working and whose jobs are considered at risk, under the Job-in-Jeopardy program. Access to open employment services is controlled in three ways: firstly, by Centrelink assessing the eligibility of individuals, by each agency assessing the suitability of each applicant, and thirdly by capping the number of places available at each service under cased-based funding.

5.5 Group-based employment services

Originally developed from whole of life services and sheltered workshops for people with physical, sensory and intellectual disabilities, business services are funded to provide meaningful employment opportunities for people with disabilities. Each service is encouraged to achieve commercial viability. Token allowances were once paid to disabled workers. Services are now encouraged to pay wages at industrial award rates or according to productivity assessments under the Supported Wage System. Since the introduction of individual supported employment in the 1980s, group based programs have become philosophically unpopular with funding providers who prefer to fund individualised programs where a person's quality of life does not become too dependent on the relationship with a single agency.

Group-based programs such as business enterprises, Clubhouses, community co-operatives and mobile work crews, have applicability to people with mental illness. These can differ widely in design and in the range of career learning experiences provided. Social firms represent the latest evolution in group-based programs. These offer award wage jobs in a real business where a proportion of jobs (but no particular jobs) are reserved for suitable applicants with a psychiatric disability. Anecdotally, the advantage of group based programs are: the sense of belonging to a supportive community; social support from peers and staff; a protective low stigma environment; immediate prospects of structured activities including training or work; additional on-the-job supervision, training and support; access to social and recreational activities; advocacy services; and access to information about health and other community services. Some group-based programs (e.g. Stepping Stone and Pioneer Clubhouses) offer a range of complementary services at one location such as open employment, Job Network, personal support and supported education.

A limitation of group-based services is that only a limited range of career opportunities can be provided within any one business enterprise. In more transitional services, the person may become stuck at pre-competitive levels of functioning prior to attaining competitive or open employment. Another fear sometimes expressed by funding providers, yet to be substantiated, is that the community formed around the service provider may prevent the person from utilising mainstream services and may limit social inclusion in the wider residential community. However, members of group based programs, particularly those where paid employment opportunities are available, often have few complaints and express high satisfaction with the services and the opportunities provided. This is also evident through reports of managers of group-based programs, that throughput can be difficult to achieve because workers with psychiatric disabilities, once adapted, often prefer to continue in their current form of employment. Further research is needed to identify the advantages and disadvantages of group-based programs in comparison to individual approaches to vocational rehabilitation.

5.6 The Job Network

The Job Network is a privatised network where the providers are private or non-government organisations contracted by government to provide a recruitment service for employers and a range of supporting labour market programs. Access to advertised vacancies is controlled by the provider. People with mental illness can access Job Network agencies directly or through disability employment and vocational rehabilitation services, but have reported unfair discrimination by being excluded from interviews for health reasons.
Job Network staff have the least training in mental health, hence are more likely to have the lowest levels of mental health literacy. A recent official pilot study identified ways in which the Job Network can be enhanced to include people receiving the Disability Support Pension (DSP). This project included people with mental illness as part of the DSP group, and achieved improved outcomes for all project participants [91].

5.7 Services provided by consumer organisations

Another type of service often overlooked is the activity, education and advocacy centres run by mental health consumer organisations and schizophrenia fellowships in each State and Territory of Australia. Although these services may not have a designated role in employment, they can provide: (1) the means to communicate with and support consumers and their carers and families; (2) accurate information about mental illness, mental health, income support, and suitable community services; (3) information about local vocational services (for employment, education, training, and voluntary work); (4) a contact point for policy makers, vocational services, and researchers seeking to contact or consult with consumers; and (5) advocacy on a range of relevant issues, and encouragement for those seeking assistance with vocational rehabilitation. This type of service plays an important role in educating consumers, families, and carers about mental health and services issues, and can help educate professionals and service providers about current issues, systemic problems, and the unmet needs of people with mental illness and their families. Without such consumer organisations, people with mental illness and their families would be less informed, and fewer people than at present would succeed in accessing appropriate income support, community support, and vocational assistance.

5.8 Public funded education and vocational training services

Apart from those who experience cognitive deficits subsequent to mental illness or as treatment side effects, people with mental illness are generally not impaired intellectually. Given the frequency of education disruption and the importance of education to career development [14-15,54] it is surprising that in Australia neither Federal nor State Governments support disability-specific education assistance. In the U.S.A. several forms of specialised supported education have been evaluated. Specialised supported education for persons with mental illness is considered more effective than reliance on the generic disability support usually provided at education institutions [92-94]. This support can take the form of: support groups on campus; off campus support groups; or individual coaching and support both off and on campus. The key ingredient seems to be a coordinator trained specifically in the educational barriers facing persons with psychiatric disabilities.

Although supported education is sometimes funded in response to particular submissions, in specific locations, by various state and federal departments, there is no national initiative or agreed structure by which to provide specialised education and vocational services for people with mental illness. Clubhouses sometimes offer informal programs of supported education via regular meetings for members participating in formal study. Throughout Australia, individual training and educational institutions are required by anti-discrimination legislation to respond to the needs of people with disabilities, although the special needs of people with mental illness may not be recognised [54]. Nevertheless, people with mental illness can and ought to approach their local vocational training or tertiary education institution, but may have to provide additional information about their particular education restrictions in order to have their assistance needs recognised.

5.9 Community mental health services

In Australia, community mental health services are not resourced to provide vocational assistance. However, in line with National Mental Health Plan 2003-2008 [9], states and territories promote a recovery philosophy for mental health service delivery. Under this philosophy, rehabilitation services are sometimes provided alongside treatment and community support services, sometimes including prevocational, vocational and education support services. However, recovery outcome measures are
typically confined to clinical dimensions of illness recovery and global assessments of social functioning. Dimensions of socially-valued role functioning are not usually assessed, identified or specifically supported [95-96]. Hence favourable outcomes in terms of improved socially-valued role functioning may remain undetected.

Community mental health treatment and support in Australia is not systematically linked to vocational rehabilitation or disability employment assistance [3]. This disconnection is also found in the U.S.A. In a survey of patterns of usual care for patients with schizophrenia [49], Lehman et al. found that among the unemployed outpatients, only 22.6% had vocational rehabilitation specified in their treatment plans or reported participating in a vocational program. Fewer than 25% of mental health consumers reported connections to vocational rehabilitation services. There is also evidence that psychiatric rehabilitation as provided within the public mental health system (i.e. segregated from vocational rehabilitation) does not improve employment outcomes [2,47].

One of the potential problems facing community mental health services in Australia is the absence of exit strategies for clients who are perceived as capable of more independent functioning. Anecdotally, mental health service staff routinely report the presence of clients who by their retention, limit the service outlet's capacity to assist new clients. A focus on employment and other socially-valued roles (e.g. education, self-development, or caring for others) can be used to motivate mental health self-management and promote exit strategies from public mental health support. This can be a natural progression in Australia because open employment services provide continuing support for employed clients, who may also prefer to see a private psychiatrist once regular hours of employment are established. Hence, a focus on employment and other socially valued roles within community mental health services can lead to the development of appropriate exit strategies.

5.10 Psychiatric disability support services

Independent living assistance, supported housing, disability and lifestyle support may be provided by state and territory governments independently of public health services (as in Queensland), or as an accepted responsibility of the public mental health sector (as in Victoria). In addition, Home and Community Care (HACC, a joint federal-state initiative) provides assistance to people with disabilities and their carers. This assistance can include nursing care; allied health care; meals and other food services; domestic assistance; personal care; home modification and maintenance; transport; respite care; counselling, support, information and advocacy; and assessment.

Disability support services are often provided via non-government organisations. Apart from Australian Government services (e.g. HACC and PSP - see 5.2), the availability of psychiatric disability support varies by state and territory, as does the nature and intensity of the services provided. In some states psychiatric disability support is rarely available, whereas in other states (e.g. Victoria) psychiatric disability support is well established and represents another service sector. Where disability support services are provided independently of mental health and vocational services, additional inter-sectoral difficulties can arise.

5.11 The need for inter-sectoral partnerships

The National Mental Health Plan 2003-2008 [8-9] and reviews of the national strategy [10-14] have identified the need to promote innovative inter-sectoral partnerships. Intersectoral partnerships were a key policy direction of the first National Mental Health Plan but translating that policy direction into enduring changes has not been actively pursued [8]. Intersectoral partnerships are considered critical to successful outcomes in community mental health care [14] because services other than health (e.g. housing, education, employment, criminal Justice) can have an overshadowing impact on the lives of people with mental illness. Inter-sectoral partnerships are needed to address difficulties in several sectors: employment, education, public mental health, private mental health, income support, and disability support.
Inter-sectoral partnerships can be developed by encouraging community mental health services, or community disability support services, to provide a partnership structure such as systematic brokered referral to agencies funded to provide vocational and or educational services. Under this arrangement, each person’s individual treatment and recovery plan could include vocational referrals. Hence in this example, referrals to suitable agencies could become systematic, regularly monitored, and strengthened by the mental health service providing mental health training for local vocational staff. Existing funding structures could support a shift towards establishing more effective, systematic and monitored links to appropriate vocational services.

Another approach, which has the potential to overcome the inter-sectoral difficulties outlined, involves integrating specialised individual employment assistance with community mental health support at one site. Co-location of mental health support and vocational services has been shown to facilitate collaboration and knowledge development in both sectors and can improve both clinical and employment outcomes of participants [20].

5.12 Service evaluation and outcome measurement

The utility and efficacy of Australian vocational services for people with mental illness remains largely unknown due to multiple disconnected programs and fragmented data collection. Australian Government Departments and agencies collect data of varied quality, independence, and researcher accessibility. Confidentialised high quality data sets are needed which link information about: diagnosis, role functioning, demographics, benefits and pensions, earnings, hours of employment, employment restrictions, and vocational services sought and received over time. At present the most suitable data are found in five yearly ABS national surveys, although limited information is collected about vocational assistance received.

Similarly, in the community mental health sector, role functioning and vocational activity variables are not routinely collected. Hence it is not currently possible to investigate the contribution of community mental health services to supporting vocational functioning. Data collection reform across sectors is needed to establish a common method for tracking individuals over time to ascertain the nature and extent of all relevant public funded assistance and the direct costs of that assistance. A promising data set is the FaCS and DEWR Longitudinal Data Set, which consists of a 1% random sample of people receiving Australian Government income support payments. This data set could be enhanced by the addition of vocational variables and more precise specifications of disability and mental health conditions.

Improved and coordinated data collection is needed for describing the nature of disability support, income support, and employment assistance provided, which can then be linked to clinical and health outcome variables collected in the mental health sector, in a strategy common to all states and territories. Such a common and minimum data set would enable on-going evaluation of the efficacy and efficiency of disability employment, vocational rehabilitation, disability and personal support, and labour market programs, with respect to people with mental illness.

5.13 Implications for policy development

The main implication for policy development is the need for ongoing evaluation of existing vocational services in terms of effectiveness and cost-effectiveness for assisting people with mental illness. At present evaluation is ad hoc, consisting of occasional reports into specific programs. Hence, it is difficult to identify the effective programs, or the effective ingredients of programs that can lead to improved service development. Data collection reform across sectors, programs, and services is needed as a priority to enable high quality usable data to be collected which can be used for on-going service evaluation and service development.

Although the Australian Government's current generic approach to employment for people with disabilities is understandable on efficiency grounds, outcomes for people with mental illness are unlikely to improve unless disability-specific data are similarly collected across sectors. Although services to
people with disabilities can be provided generically, improving processes and outcomes for people with mental illness requires a disability-specific approach because psychiatric disabilities, unlike other categories of disability, are typically fluctuating and episodic and often require on-going or periodic treatment, which needs to be coordinated with vocational interventions and activities.

Demonstration projects specialising in cutting-edge vocational services for people with mental illness are needed in a range of Australian urban and rural sites to assess the feasibility of more evidence based practices and the range of methods by which the inter-sectoral problems can be overcome. Such demonstration projects could also be used to identify data management issues to progress the development of common and minimum data sets.

In the meantime, funding policies can support a wide spectrum of promising and evidence-based ingredients derived from all promising service approaches to enable consumers to have a choice of suitable providers, and an opportunity to obtain a varied range of assistance. Although, group-based services have been the least researched and are the least favoured by more recent research on individual supported employment, it is premature to conclude that group based programs are not effective at advancing vocational recovery. The greatest risk of group-based services is that people get stuck at pre-competitive levels and experience vocational stagnation. However, this risk can be countered by linking group-based programs to supported employment opportunities at the same location. In addition, group-based services can utilise the new multidimensional scales of role functioning for tracking pre-employment progress and alternative role activities to protect against vocational stagnation [95-96].

6. How mental illness produces barriers to employment

6.1 Direct and indirect barriers to employment

Psychiatric disabilities are both directly and indirectly associated with barriers to employment. Employment barriers can result from the positive, negative and disorganised symptoms of psychosis, from side effects of antipsychotic, mood stabilising, and anti-depressant medications, and from subsequent impairments to social skills, sense of self, personal confidence, and self-efficacy [97-98]. In addition, indirect barriers to employment can result from the negative experiences of stigma and unfair discrimination, and from the timing of illness onset, which can disrupt formal education and training, impede school-to-work transitions and damage the formation of work-values and core work-skills.

6.2 Cognitive impairments as barriers to employment

Mental illness can produce cognitive, perceptual, affective, and interpersonal deficits, each of which may contribute to employment barriers [98]. Of these, the cognitive deficits have more consistent association with unemployment [99-101] and poor work performance [52,102-103]. Cognitive deficits consistently found in schizophrenia or schizoaffective disorder include generalised deficits such as lowered full-scale IQ and a reduced capacity for information processing [104]. Green [105-106] found a wide range of both specific and general cognitive deficits in the majority of people with schizophrenia although a characteristic deficit profile did not emerge. Specific deficits can include problems with attention, sustained attention, memory and executive functioning [104,107].

Cognitive deficits received little research attention until recently [101]. Previous literature reviews may have discouraged the investigation of cognitive deficits through findings that cognitive functioning was inconsistent or non-predictive of employment outcomes [108]. However, an alternative explanation may be that cognitive deficits cause employment restrictions, yet many of these may have been neutralised by appropriate vocational choices, job matching, and other vocational interventions (see Table 1).

Recent studies indicate that cognitive symptoms are likely to cause employment restrictions [71,109], which limit occupational choice through restricting the type of work activities which can be successfully performed. Industry and job choices can be restricted, work hours and work performance may be limited, and the need for on-going assistance to retain employment may be increased [110-112]. In addition,
general cognitive deficits as well as deficits in social cognition [113] are associated with impaired work-related social skills, and may underlie the impaired social competence which can influence vocational outcomes [83,101,114-115].

### 6.3 Other clinical symptoms as barriers to employment

Almost all the clinical symptoms associated with mental illness can, at an individual level, directly contribute to employment barriers. As Rutman [98] notes, people with schizophrenia can present as personally unattractive and display socially inappropriate or unusual behaviour. The symptoms which may contribute to employment barriers include comorbid symptoms of anxiety and depression, personality difficulties, thought disorders (bizarre thinking, delusions), anosognosia, disturbances of perception (auditory hallucinations in particular), negative symptoms of apathy, inertia, anhedonia, alogia, disorganised symptoms, affect disturbances, and disturbances of communication [17,47,116-117].

In addition, clinical symptoms may impair social skills development although the precise mechanism remains unclear [114]. Exploratory studies have suggested differential roles for the major symptom clusters. For instance, Smith et al. [118] in a small study of rehabilitation readiness (n=25), proposed that negative symptoms effect motivation, disorganised symptoms influence regular participation, and positive symptoms influence social functioning more so than the negative and disorganised symptom groups.

Psychiatric symptoms are potentially disabling and can vary over time, yet are not consistent predictors of vocational outcomes. Numerous investigations and several reviews [101,108,119-120] have found that few clinical variables predict employment outcomes at the individual level. Tsang et al. reviewed controlled studies between 1985 and 1997 and found in particular that diagnostic category and psychiatric symptoms were inconsistent predictors. The most consistent predictors of employment outcomes were found to be work history, premorbid functioning and current social skills.

More recent studies have found that longitudinal course patterns of illness can predict employment outcomes. In an examination of course of illness as a barrier to employment some authors [121-123] have used repeated formal assessments to derive course of illness type, which in turn predicted progress in vocational rehabilitation. Others [2,124-125] found that a less technical classification of course type based on self-report also predicted employment outcomes among people with schizophrenia. These findings support the differentiation of course patterns of psychotic illness over time, as an alternative to cross-sectional symptom profiles, for predicting initial assistance needs in psychiatric vocational rehabilitation.

### 6.4 The episodic nature of the disorders as a barrier to employment

Mental illnesses can be episodic and fluctuating in nature despite optimal pharmacological treatment and good psychological and social support. The first and subsequent episodes can be frightening and traumatic experiences which damage a person’s stability and identity, weakening their ability to commit to longer term endeavours such as vocational rehabilitation [98]. In addition, during relatively stable periods people can have their assistance needs underestimated by providers of housing, disability, income, family, and employment assistance, which can lead to refusal of services or under-provision of support, leading to adverse events causing frustration and hopelessness, further weakening the person's capacity to manage vocational challenges.

Reliance on clinical symptom measures can lead to the flawed conclusion that reduced symptoms indicate reduced employment or education assistance needs. A better way to assess career related assistance needs is to take account of predictors and correlates of employment outcomes, namely level of employment restrictions, lifelong course pattern of illness, premorbid functioning, educational attainment, relevant work history, relevant vocational skills, and current social skills [2-3,30-31].

### 6.5 Treatment interventions as indirect barriers to employment

Both pharmacological and psychological treatment interventions can produce additional barriers to obtaining and retaining employment. The known side effects of anti-psychotic, anti-depressant, and mood stabilising medications [98,126] and the time taken to establish optimal medication type and dosage, can
cause difficulties for the provision of vocational assistance. In addition, sub-optimal treatment can contribute to poor adherence, which in turn can exacerbate symptoms, interfere with planned treatment, and undermine vocational interventions.

Treatment and vocational rehabilitation interventions need to be coordinated so that changes to treatment plans (e.g., a new medication trial) do not conflict with planned vocational activities. Sometimes treatment goals need to be balanced by vocational goals. For instance, some residual positive symptoms may be preferred to a symptom-free state with lowered energy levels, insufficient to sustain preferred hours of employment. Failure to actively coordinate interventions by treating and vocational professionals may create a coordination barrier to employment, placing the onus on the person least likely to manage this responsibility, to coordinate treatment interventions with rehabilitation activities.

Psychological and psychosocial treatments are now commonly used in support of pharmacological treatments. Cognitive behavioural therapy [127], cognitive remediation [105], psycho-educational family therapy, assertive community training [127], family and peer support [1], motivational interviewing [128], pre-vocational interventions such as illness management and social skills training [129] and structured feedback on work-performance [130] are now available. Recent reviews suggest that when used appropriately, these interventions can contribute to symptom reduction, reduced relapse and improved psychosocial rehabilitation outcomes. However, these programs are not without risk. Participants may develop dependency on the programs or the practitioners offering the services [98] or may become stuck in the role of client or impaired person and may resist moving on in the rehabilitation process [131].

6.6 Low vocational expectations by health professionals

Blankertz and Robinson [132] believe that health professionals' low vocational expectations of service users is a major problem because it prevents the majority of people from receiving vocational rehabilitation and supported employment services. Mental health professionals often report that people with psychiatric disability have unrealistic work expectations and goals [133]. In examining programs with low rates of people with psychiatric disability in competitive employment, it was found that the onus was left on individuals to bring up their interests in employment with the service provider. In addition, service providers tended to emphasise prevocational programs devoted to job preparation, did not pursue rapid assessment to capitalise on the service user's motivation for work, had limited contact with vocational services, had little direct employer contact, and provided minimal support to people once they were in employment [134].

6.7 Community stigma as a barrier to employment

In general, the public does not understand the impact of psychiatric disability and frequently fears people with these disorders. Members of the community withhold opportunities related to housing, work, and community participation [7]. People with psychiatric disability have fewer opportunities to work than the general population, mostly owing to the many misperceptions and prejudices about their abilities and needs. They are not expected to work, and indeed they are often considered not fit or well enough to work [135]. The lack of work serves to reinforce negative stereotypes and social exclusion associated with psychiatric disability. By not appearing within employment settings, it is mistakenly believed that people with mental illness are too incapacitated to work [135]. An additional issue is that some people with mental illness also endorse stigmatising attitudes about psychiatric disability. This internalised stigma affects the individual’s self-perception and has the potential to impact on the success or failure of employment opportunities [136].

Community stigma and unfair discrimination are frequently reported by people with psychiatric disabilities [85,137] as adding to the difficulties of obtaining and retaining employment. The extent of past stigma experiences and reactions to those experiences can influence personal decisions about whether or not vocational goals are adopted. In addition, past stigma experiences may exert a strong influence on disclosure preferences throughout psychiatric vocational rehabilitation [76]. For example, an avoidant
disclosure strategy influenced by negative disclosure experiences can create additional barriers to employment through limiting the provision of workplace accommodations. To overcome the adverse effects of prior community stigma, vocational professionals can provide stigma assessment and counselling, and develop ongoing stigma countering and disclosure strategies within each individual's vocational rehabilitation plan.

6.8 Stigma among helping professionals as a barrier to employment

Community stigma is sometimes exacerbated by unhelpful attitudes among health professionals and vocational professionals, expressed as undue benevolence or authoritarianism, or an unsubstantiated belief that employment is either not feasible, will adversely affect mental health, or is not a mental health provider priority [69,76]. This is common in Australia, where due to sectorisation, few clinicians become involved in specialised vocational rehabilitation, and hence do not get to see the positive and life-changing outcomes that can be achieved. A clinician’s illusion can prevail, that people with mental illness cannot work, if clinicians only see those patients who are admitted to hospital or who are chronically relapsing. Specialised vocational professionals can help reduce this form of stigma by involving clinicians in the process and outcomes of vocational rehabilitation, and by informing mental health professionals and non-specialised vocational colleagues about the methods, outcomes and efficacy of specialised vocational rehabilitation.

Among vocational professionals, stigma can manifest as a reluctance to assist people with psychiatric disabilities if staff lack confidence or are inadequately trained to assist this category of disability. The pressure on staff to achieve employment outcomes is likely to favour the selection of clients with more familiar and stable health conditions. The lack of a requirement to complete accredited training in psychiatric vocational rehabilitation, means that rehabilitation expertise is unlikely to be well distributed throughout the vocational sector. Consequently, people with mental illness may be unfairly excluded from vocational assistance, have their support needs incorrectly estimated, or may not receive suitably intense or continuous forms of assistance.

6.9 Comorbid disorders as a barrier to employment

People with mental illness co-morbid with other health conditions or disabilities, may be more likely to be excluded from vocational assistance through being perceived as too difficult to assist. This appears to be a workforce training issue, because overseas evidence [20] indicates that comorbid: substance use disorders, personality disorders, physical health conditions, intellectual disability, acquired brain injury, or mental illness associated with a forensic history, are not valid grounds on which to deny people access to vocational services. In Australia the anecdotal evidence suggests that people with comorbid disorders are more likely to be denied assistance, even by services which specialise in psychiatric disability. People can be easily excluded from vocational assistance in Australia because the service provider makes the final decision on acceptance into the more intense forms of assistance. Research is needed to investigate the extent that people with more severe and complicated forms of mental illness are able to equitably access appropriate vocational services.

6.10 Workplace stigma

The attitudes of employers towards people with mental illness may reflect the ignorance and stigma prevalent in the wider community [76]. This then may result in the belief that people with mental illness are unable to work, or that it is not possible to accommodate psychiatric disorders within the workplace. Negative employer attitudes have a number of implications, including that an employer will not hire a person with psychiatric disability or advance or retain people with these disorders [86]. When a person with a mental illness is hired, they may be treated differently from other workers. For example, Murphy [138] reported that people with psychiatric disability faced discrimination and prejudice by employers and co-workers once they knew the person had a disability. This included that the employer began to be afraid of the person, verbal abuse, harassment, and belittling the person’s ability and judgement.
6.11 Confusing terms, definitions and measures as barriers to employment

Conflicting descriptions and definitions of mental illness and psychiatric disabilities and multiple overlapping mental health terms create confusion among policy makers and service providers, often preventing the different service systems from adequately responding to the needs of individuals and sometimes creating tension between different service systems [98]. This can happen in Australia where income support or vocational service staff with less mental health training may fail to differentiate the level support needs among people with mental health problems from more severe clinical conditions which may need more intensive and more continuous employment assistance.

Furthermore, there are no widely accepted systems for classifying level of disability, assessing work-readiness, or for assessing level of need for vocational assistance. Hence, the need for vocational assistance may not be well matched to the vocational services provided. This problem is particularly evident in Australia where eligibility for public funded community mental health services, income support payments, personal disability support, disability employment assistance, and vocational rehabilitation, are determined by service providers using independent criteria which can confuse consumers and their families, and which may be unrelated to a person's actual level of disability and employment restrictions [3,16,30].

6.12 Government funding structures as barriers to employment

At present, state-federal funding arrangements and departmental responsibilities define mutually exclusive roles, which form additional barriers to employment service delivery when health, education and employment services are required across multiple sectors and agencies simultaneously. With respect to employment, there are opportunities to improve outcomes by pooling rather than fracturing the acquired expertise. Community mental health knowledge (e.g. familiarity with the latest treatment methods and understanding day to day illness management) could supplement the specialised employment and vocational rehabilitation expertise acquired in the vocational sector.

For instance, a person with a mental illness may receive help from a Clubhouse, a specialised or generic open employment service, or from CRS Australia to prepare for work, and may need access to vacancies held by a Job Network agency when job searching. To retain employment, ongoing help may be needed from an Open Employment service. In addition, a TAFE College may be assisting with tailored vocational training to improve employment prospects, or as part of a traineeship package. These programs need coordinating. However, unless one provider can adopt a coordination role, the onus for coordination, by default, falls on the person least able to perform this role, the person with a mental illness. Without proactive coordination of essential multiple services, the stigma literature suggests that inadvertent program exclusion is the most likely outcome, especially if service staff have low mental health literacy [76].

Another type of barrier to employment may be created by case-based funding for disability employment services, CRS Australia, and for the Job Network. Although a method is in place via Centrelink to independently assess support needs to several levels of funding, the total number of places is capped for each disability employment service. When demand exceeds the places available, a barrier to employment is created because the final admission decision is the service responsibility. Hence, the capping of places can allow some services to rarely accept new clients. This can happen because a substantial proportion of people with more severe mental illness, through the fluctuating nature of mental illnesses, may have previously discontinued participation, or failed to achieve an employment outcome. Such inactive cases can often be reactivated, enabling the service to re-admit a well-known client, and avoid admitting an unknown and potentially more challenging client. Anecdotal reports indicate that people with more severe forms of mental illness have difficulty accessing the most suitable forms of vocational assistance in Australia. This is supported by evidence from a recent national survey where no persons with psychotic disorders [3], and only 2.5% of people with anxiety disorders of working age [30-31] were receiving job placement assistance.
6.13 Disincentives in the health and income support systems

Another systemic barrier to employment is caused by work disincentives within the health, social welfare and income support systems [98]. This may be particularly important for people with psychiatric disabilities because of the difficulties qualifying for income support due to the episodic nature of the disorders and the greater difficulty with employment retention compared to other disability categories. In the U.S.A. health benefits associated with income support may be lost when part-time employment is obtained without employer sponsored health benefits. To find solutions to these potentially strong disincentives, Bond [20] recommends special attention be given to health and welfare benefits counselling in the early stages of vocational assistance.

Similar disincentives occur in Australia even though more substantial income support and public health services are available compared to the U.S.A. A recent study [91] found several disincentives acting as barriers to employment for those receiving Disability Support Pension (DSP). These included anticipated difficulty re-establishing entitlement to DSP; lack of knowledge of DSP suspension arrangements, lack of knowledge of earnings credits and applicable income tests; and lack of knowledge of assistance available to obtain employment. People surveyed also reported uncertainty about the type and amount of work their disability would enable them to perform [91].

6.14 Rural and remote locations as barriers to employment

Although health and vocational services are available throughout Australia, those living in rural and remote locations can be more disadvantaged by reduced availability of: public mental health services, private psychiatrists, general medical practitioners, disability employment services, vocational rehabilitation and Job Network services. In addition, career opportunities can be restricted to pastoral, mining and rural service industries. Relocating to improve access to support systems and employment opportunities can be difficult for people with mental illness who may need to live near families, friends and relatives to obtain sufficient social, economic and health support. The lack of services in some geographical areas can mean that only general health services are available, and vocational services may be unavailable or limited to one Job Network provider with staff untrained in psychiatric disability.

6.15 Career immaturity as a barrier to employment

Mental illness can create unique individual experiences which can lead to inappropriate values, attitudes and aspirations regarding work and careers [98]. Impaired work values and impaired perceptions of current work skills can cause unrealistic vocational goals, where perceptions of own work skills may diverge from actual skill levels and experience. These experiences may also represent career immaturity [131,139] thought to result from the lack of exposure to typical life experiences, responsibilities and roles which help a person form appropriate work perceptions, work confidence, work interests, work values and work ethics. Although the precise psychological processes are unclear, it is likely that career maturity is influenced by the person's life experiences, personality, perceptions of illness experiences, family background, educational attainment, work values, and knowledge of workplaces and employer requirements.

6.16 Subjective experiences and personal resources as barriers to employment

Internal barriers to achieving vocational goals include unpredictable sleeping patterns, fear of failure, fear of relapse, lack of confidence in vocational abilities, difficulties with concentration, and fear of resuming work after years of unemployment [7,140]. In addition Waghorn et al. [141] found that a range of varied subjective experiences perceived to impact on work functioning, and self-efficacy for specific work-related activities were closely associated to employment status.

Mallick, Reeves, and Dellario [142] found that financial resources, employment resources, and vocational skills presented the greatest barriers to community integration. Financial resources included money to meet financial obligations such as rent, food and other daily expenses. Employment resources were employment opportunities and available resources to find a job and maintain employment. Waghorn et al. [143] found that self-efficacy for core employment activities includes, career planning, job securing skills,
job-retaining work skills (e.g. start work soon after arriving, complete tasks in the time required, identify and correct own mistakes), and job-retaining social skills (e.g. can follow instructions without resistance, can cooperate with co-workers to perform a group task, can check instructions with supervisors).

6.17 Implications for policy development

The barriers to employment among people with mental illness can be extensive. Collectively these are unique to each individual. Employment barriers cannot be precisely predicted from symptom profiles and diagnostic categories, and are often exacerbated by community stigma, including the stigma perpetuated by helping professionals. The main implication for policy development is that the specialised vocational knowledge needed for identifying and overcoming barriers to employment among people with mental illness, needs to be available to staff of non-specialised vocational services, employers, consumers, carers, clinicians and mental health staff in community health care settings. Hence, much can be done to educate these groups about how barriers to employment are overcome throughout the vocational rehabilitation process. Funding providers do not currently allocate resources for staff training in this area with the possible consequence that people with psychiatric disabilities may be unfairly refused assistance through being incorrectly perceived as unable to succeed in vocational rehabilitation.

The capping of more intensive places appears to create additional barriers to employment which need to be investigated further. It is possible that capping, combined with the policy of allowing each service to make final admission decisions, only results in recycling of clients well known to the service and prevents access by clients who have not previously sought or received vocational assistance. It would be interesting to know the extent that people with mental illness receive multiple services to little effect, and whether some services avoid clients with more severe employment restrictions.

7. Evidence-based vocational interventions

7.1 The range of vocational interventions

Various vocational interventions suitable for people with psychiatric disabilities have evolved over time. These are reviewed elsewhere [19-21,84,144]. Although each approach to vocational assistance has its advocates, a positive development in the literature is a new focus on the ingredients of effective vocational rehabilitation specifically designed for people with psychiatric disabilities. This development transcends the unproductive model-versus-model debate. Vocational interventions for people with mental illness have included unpaid voluntary work [84]; the Boston University psychiatric rehabilitation model (Choose-Get-Keep) with extended pre-vocational career exploration; job clubs [84,145]; the program of assertive community treatment (PACT) [84,146]; generic supported employment [84]; Clubhouse transitional employment; specialised supported employment (also known as the Individual Placement and Support model of Supported Employment); generic vocational rehabilitation; and specialised vocational rehabilitation [16,144].

In addition, there are promising group-based interventions such as business services (sheltered workshops), work-crews, community co-operatives and social firms. These services are usually designed to increase employment opportunities for people with disabilities by providing supportive and low stigma work environments, and by producing goods or services in order to pursue employment as a social justice mission. In social firms, a more recent development in Australia, the proportion of disadvantaged workers does not exceed 30-50% and every worker is paid industrial award wages or a productivity-based wage. Both disabled and healthy workers are intended to have equality in terms of opportunities, rights and responsibilities.

Australia also has a supported wage scheme [16] which enables an industrial award to be modified by a person’s measured productivity in a particular job on a pro rata basis. Independent assessors can be arranged at no cost to the employer and the worker with a disability can have their performance assessed and reviewed on a regular basis to ensure that wages continue to match productivity.
7.2 Principles of specialised supported employment

Specialised supported employment [147-149] is important for both its evidence base of randomised controlled trials and day centre conversion projects, and for the empirical identification of its underlying theoretical principles. Previously known as the Individual Placement and Support (IPS) approach to supported employment, evidence is accumulating that this form of specialised supported employment is effective for 40-60% of volunteers [20,150]. A consensus is emerging as to the evidence base for each of seven principles while research efforts continue to identify program enhancements. According to reviewers [20] there is consistent evidence for the first four of the following seven principles, while the evidence for the latter three remain relatively weak:

1) Eligibility based on consumer choice;
2) Integration of vocational rehabilitation with mental health care;
3) A goal of competitive employment;
4) Rapid commencement of job search activities;
5) Services based on consumer preferences;
6) Continuing support to retain employment;
7) Income support and health benefits counselling.

Service eligibility is based on consumer choice [151]. No attempt is made to screen out participants on other than individual preferences and motivation. This approach has been found to be more effective when integrated within the mental health treatment team [49,134,152]. Integration is considered advantageous in four ways: (1) better engagement and retention of clients; (2) better communication between employment specialists and clinicians; (3) education of clinicians about employment issues; and (4) incorporation of clinical information into vocational plans [153].

The main goal is competitive employment rather than participation in day programs or sheltered work, which are usually not provided. The evidence suggests that interventions not focusing directly on competitive employment have little or no impact on competitive employment outcomes [20]. In addition, competitive employment outcomes are more desirable and recovery-oriented than other forms of paid employment [20].

The early use of supported job searching and job placement whenever possible is considered important to prevent people losing interest in the necessary elements of job preparation and training in specific job skills. Although empirical support for rapid job searching is strong [19,21] it is not yet a widespread practice among other vocational services in the U.S.A. For instance, a recent study of a Clubhouse program found that the average time prior to the first transitional employment placement was 356 days [154].

Other interventions when provided, are provided in parallel not in series with job searching or job placement. Bell et al. [130] found cognitive skills training provided concurrently with supported employment, was a successful parallel intervention which need not delay either job searching or job placement. Both treatment and vocational interventions are tailored to the type of job searching or work tasks required [20].

Services provided are based on consumer preferences, strengths, prior work interests and experiences rather than on a pool of available jobs. The evidence shows that the majority of clients have stable and realistic job preferences [155] and jobs matched to initial job preference had a longer job tenure than those not so matched [156].

Follow-on support is available continuously over time with no closure date, so that on-the-job or behind-the-scenes support is available when needed. Employment specialists stay in regular contact with clients and employers without arbitrary time limits, although the intensity of support may reduce to a maintenance level of regular contact only. McHugo et al. [87] found supporting evidence at 3.5 years from commencing employment, where 71% of those who continued receiving support were still employed,
compared to 28% of those who had discontinued support. Support is provided proactively. Assistance is not withdrawn denied punitively to people who fail to attend appointments or who do not achieve agreed milestones. Support is actively provided in partnership with the person with a mental illness.

Health and welfare benefits counselling is provided although the current supporting evidence is relatively weak [20]. Consumers are helped to make well-informed decisions about their entitlements to welfare benefits and health insurance coverage to ensure that benefits entitlements do not add unnecessary disincentives to employment.

7.3 Unique principles of transitional employment

Although on-site support is commonly provided in supported employment and vocational rehabilitation, an important and unique principle of Clubhouse transitional employment programs is the continuous availability of intensive on-site support [157]. This aims to overcome employment barriers in the workplace by demonstrating core work skills and appropriate work behaviours, using on-site training to teach and reinforce good work attitudes, behaviours and performance. Consequently, the close relationships formed between Clubhouse staff and employers enables a suitable training environment to be created for assisting new members at work, and for countering stigma by educating others in the workplace about mental illness and mental health.

Transitional employment is a form of psychiatric vocational rehabilitation developed specifically for people with psychiatric disabilities [50,78,154,158]. Intensive forms of on-site assistance are routinely provided at each entry-level job held by the Clubhouse. Staff members learn the job in order to perform the duties on days when the member or members selected to perform the job for a specified period are unwell or unable to attend. The aim is to provide members with real employment experiences (paid at award wages) to overcome career immaturity and to help people form and test career goals. Transitional employment placements are typically part-time, linked to prior participation in Clubhouse day programs (the work-ordered day) and limited to a duration of 4-6 months, to enable other members to share the available opportunities. Clubhouses may also offer housing, social recreation, and supported education programs [159].

Although not formally identified as contributing to employment outcomes, the Clubhouse member-based organisation provides an appropriate infrastructure for people with mental illness. Like social firms, Clubhouses provide safe, low-stigma environments, which encourage vocational recovery and support general illness recovery through peer support, sharing of resources, and increased social and recreational opportunities to help rebuild personal and social confidence.

7.4 Unique principles of specialised vocational rehabilitation

In a recent comparison of the CRS Australia service model with the effective ingredients of supported employment, McDonald [84, p. 64] argued that the allied health professionals employed by CRS Australia in the three sites specialising in psychiatric disability, represent the provision of another service ingredient, the multidisciplinary team [160]. McDonald states that the multidisciplinary team provides a form of coordinated mental health care and vocational services through team members being typically experienced in mental health treatment, and through close liaison with the client's treatment professional. In addition, allied health professionals on the team design supplementary interventions often deriving from cognitive behaviour therapy, narrative therapy, motivational interviewing, and observations of vocational behaviour. These interventions aim to reduce employment restrictions and improve independent functioning, work attitudes, and work performance. Anecdotal reports suggest that these interventions, through added employment motivation leverage, can be more successful than when provided in a general health or psychiatric setting.

The rehabilitation alliance appears to contribute to service effectiveness in vocational rehabilitation although this has not yet been identified as an evidence-based ingredient of supported employment. The rehabilitation alliance is based on a shared understanding of both the staff member's and the consumer's roles in rehabilitation. Vocational staff undertake to provide timely and proactive assistance according to
mutually agreed needs for assistance which are constantly reviewed. This usually involves active outreach, where meetings can take place in the consumer's local environment, and follow-up action is initiated immediately problems occur, such as when appointments are missed, in order to promptly provide any additional assistance needed. The rehabilitation alliance is supported by evidence in non-specialised vocational rehabilitation that strong partnerships, as rated by both staff and clients, are associated with better client employment outcomes [161-164].

7.5 Emerging candidates for evidence-based components

The use of explicit strategies to counter workplace stigma, and structured counselling to optimise disclosure strategies, are also expected to enhance outcomes in psychiatric vocational rehabilitation by improving job commencement and job retention. Although there is not yet any clear evidence to support this strategy, the fact that job retention remains the major challenge in all vocational approaches, indicates this item warrants inclusion in Table 1. Some people may fail to seek, obtain, or retain employment, because of past stigma experiences [165] or previous work-place discrimination [86]. Hence, strategies are needed throughout vocational rehabilitation [76] to counter past and present stigma and strategically manage disclosure of personal mental health information in the workplace.

To prevent negative stigma experiences in a particular workplace, a plan for workplace education can be developed along with the vocational rehabilitation plan. Initial education can be provided to increase mental health literacy generally and to counter stigma-based beliefs prevalent at the supervisor and manager level [86]. Mental illnesses such as anxiety disorders, depression and even schizophrenia can be discussed in the context of occupational health and safety, the work environment, and general mental health and wellbeing, which are topics of interest in most workplaces. Ongoing support plans for the individual can encompass a plan to increase mental health literacy, and prevent and counter stigma in the workplace over time. This can be achieved by: (1) facilitating co-worker social interaction; (2) teaching specific work-related social skills to the worker with the mental illness; (3) the use of peer support arrangements; (4) ongoing strategic and ethical disclosure of health information relevant to work performance; and (5) by planned ongoing education of employers, supervisors, co-workers, and third parties throughout the vocational rehabilitation process [76].

However, some people may report such negative stigma experiences that they are currently unwilling to consider an open employment placement. For these people, stigma-safe environments may be needed to enable rebuilding of work and social confidence. Hence to meet a broad spectrum of assistance needs, alternatives to open employment approaches such as transitional employment, business services, social firms and community cooperatives, can contribute by providing low-stigma work environments as a bridging option towards open employment.

7.6 Principles of effective vocational services in-use in Australia

The evidence-based and unique ingredients of specialised supported employment, transitional employment, and specialised vocational rehabilitation indicate the distribution of empirical principles underpinning vocational services in Australia (see Table 4). Of the eleven principles shown, six are provided by open employment services, six by CRS Australia, five by transitional employment, and three by the Job Network. One principle (the rehabilitation alliance) is sometimes provided by Community Mental Health services in Australia. The principle in the last row of Table 4 (stigma and disclosure strategies) may be addressed when issues arise, but is not known to be routinely provided as a formal strategy to support vocational activities.

7.7 Implications for policy development

Research into the effectiveness of vocational rehabilitation of people with mental illness has recently begun to focus on service ingredients and how each contributes to vocational outcomes. Most research has been conducted with respect to specialised supported employment in the U.S.A. However, promising ingredients are emerging from other approaches, which warrant further investigation (see rows 8-11 of Table 4).
Funding providers can plan vocational service development for people with mental illness by funding a broad mix of evidence-based ingredients (see Table 4) within each local region. This approach avoids the counter productive model versus model debate, and promotes funding for both emerging and established evidence-based ingredients in psychiatric vocational rehabilitation.

8. Linking vocational interventions to mental health care

8.1 The impact of untreated psychosis

The disruptive and disabling effects of first episodes of psychosis coincide with the maturational issues of mid to late adolescence and early adulthood. Most psychotic disorders occur between the age of 10-30 years, a critical developmental period in the lifespan, in terms of social and emotional wellbeing [166]. Young adults need to gain independence from their families, develop interests, hobbies and social skills, discover and experiment with sexuality, form and maintain relationships; and make the transition from secondary school to employment or further study [167]. The onset of a mental disorder can threaten sense of self and identity, delay maturity, disrupt valued roles and degrade social status.

Untreated psychosis affects social, psychological and biological domains [167]. Interpersonal relationships, education, employment, and accommodation stability may be affected. Psychologically, young people with untreated psychosis may experience fear, despair, demoralization, loss of self-confidence, anxiety, difficulties with personality development, depression, and have an increased risk of suicide. Biologically, untreated psychosis is associated with reduced rate and level of recovery, increased risk of poor physical health, increased risk of substance and poly-substance misuse [167,168], and increased risk of life long problems in mental health and social well-being [166].

8.2 Vocational interventions as part of an early intervention approach

Early intervention is increasingly seen as having the potential to produce better outcomes for people with psychotic disorders. Effective early intervention offers the hope of restoring normal social and psychological development [169]. Early intervention can: decrease disruption to the family, education and employment; decrease the need for inpatient care; decrease relapse risk; lower risk of suicide; and can reduce the total cost of treatment [167].

An early intervention framework requires a shift from the more traditional medical model and treatment approach to one which focuses on individual empowerment, individual strengths, and building individual capacity for community participation. A wellness promotion approach can be used to focus on enhancement and optimisation of positive functioning. Creating opportunities for people to exercise existing capabilities as well as developing new competencies is central to empowerment models. Utilising a strengths-based approach recognises the assets and talents of people and helps people to use these competencies to strengthen functioning. Resource-based approaches are also applicable. These utilise a broad range of community opportunities and experiences [166].

For effective early intervention, service providers need to identify those likely to be experiencing an early stage of illness or a first episode of psychosis, and need to be alert to factors (e.g. substance misuse) which can precipitate illness, personal crises, and illness relapse. Early intervention service providers typically work within a multidisciplinary team framework [170] and are able to engage with young people experiencing early psychosis and their families. To include adequate vocational interventions as early interventions, service providers may either employ vocational specialists, or obtain a detailed knowledge of local sources of assistance suitable for helping young people continue with education, vocational training and employment. An advantage of including a vocational dimension with early mental health interventions is that expectations for career path recovery can be maintained and the problem of low vocational outcome expectations by clinicians can be avoided.
Table 4. Principles of effective vocational services in-use in Australia

<table>
<thead>
<tr>
<th>Principle</th>
<th>Open Employment Servicesa</th>
<th>CRS Australiaa</th>
<th>Job Networka</th>
<th>Clubhouse (TE), Business Services, Social Firms</th>
<th>Community Mental Health Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Eligibility based on consumer choice</td>
<td>No. Applicants are screened according to the particular service’s own definition of readiness.</td>
<td>No. Consumers are screened for capacity to make substantial gain as determined by the rehabilitation consultant.</td>
<td>Yes provided consumers are referred by Centrelink. Less intensive labour market services are provided to mainstream jobseekers.</td>
<td>Yes. Limited screening if sufficient places are available. Waiting lists may be used.</td>
<td>No. Consumers are screened by the severity of their diagnosis. In practice this can mean that only people with psychotic disorders obtain access.</td>
</tr>
<tr>
<td>2. Integration of employment service with mental health treatment</td>
<td>No. Treating professionals are usually contacted for confirmation of diagnosis and for clearance to work in a particular job or industry.</td>
<td>No. Allied health professional staff routinely contact treatment professionals to ensure no conflict between work and treatment plans.</td>
<td>No. Contact with treatment professionals is minimal. Sometimes a medical certificate as proof of fitness to work is required.</td>
<td>No. Contact with treatment professionals is not routinely sought.</td>
<td>No. Employment services are rarely provided. Acute and continuing treatment and care are provided.</td>
</tr>
<tr>
<td>3. A competitive employment goal</td>
<td>Yes. Competitive (open) employment is the primary outcome goal.</td>
<td>Yes. Competitive (open) employment is the primary outcome goal.</td>
<td>Yes. Competitive (open) employment is the primary outcome goal.</td>
<td>No. TE aims to develop core work skills.</td>
<td>No. Competitive employment is not an official goal. However, some staff provide support for employment or education roles.</td>
</tr>
<tr>
<td>4. Rapid commencement of job searching</td>
<td>Yes. Rapid job search is a recognised goal. Job search usually commences as soon as possible once vocational goals are clarified.</td>
<td>Yes. Rapid job search is a recognised goal. The work preparation phase can include additional treatments to reduce employment restrictions.</td>
<td>Yes. Rapid job search is the main expectation. Few other services provided are suitable for people with psychiatric disabilities.</td>
<td>No. Commencement of TE depends on the available opportunities. Job searching is not required.</td>
<td>No. Consumers are not expected to look for work and may be discouraged from doing so.</td>
</tr>
<tr>
<td>5. Services based on consumer preferences</td>
<td>Yes, within the range of services normally available.</td>
<td>Yes, within the range of services normally available.</td>
<td>No. Other than access to advertised vacancies, no further assistance is available unless sought by the Agency or by Centrelink.</td>
<td>No. Services are confined to the support needed for the position selected.</td>
<td>No. Treatment and case management services are provided with limited input from consumers and their families.</td>
</tr>
<tr>
<td>6. Ongoing support to retain employment</td>
<td>Yes. Continuing support is available.</td>
<td>No. Support for 13 weeks post-job placement is available.</td>
<td>No.</td>
<td>Yes. Ongoing support is available through additional workplace supervision and training.</td>
<td>No. Continuing health care is available but does not usually include support for employment.</td>
</tr>
<tr>
<td>8. Intensive on-site support</td>
<td>No. Can be provided but behind the scenes support is more likely.</td>
<td>No. Can be provided for 13 weeks but behind the scenes support is more likely.</td>
<td>No.</td>
<td>Yes. Routinely provided.</td>
<td>No. Not usually provided.</td>
</tr>
<tr>
<td>9. Multidisciplinary team approach</td>
<td>No.</td>
<td>Yes. Including help</td>
<td>No.</td>
<td>No.</td>
<td>No. because employment specialists are not employed.</td>
</tr>
<tr>
<td>11. Stigma and disclosure strategies</td>
<td>Not systematically provided at present. Can be provided.</td>
<td>Not systematically provided at present. Can be provided.</td>
<td>No.</td>
<td>Can be provided. These services also offer low stigma work-environments.</td>
<td>No.</td>
</tr>
</tbody>
</table>

Notes: a. Both generic services (mixed disability types) and specialised services for people with psychiatric disabilities are available. b. A recent pilot project trialed the provision of more intensive assistance to people receiving Disability Support Pension via Job Network agencies. The services provided by this successful pilot project are not shown (see Commonwealth Department of Employment and Workplace Relations, 2004).
8.3 Vocational interventions and a recovery framework

Recovery is defined as the process of overcoming symptoms, psychiatric disability, and social handicap. It can involve a redefinition of the self, the emergence of hope and optimism, empowerment, and the establishment of meaningful relationships with others [171]. Recovery is oriented towards the reconstruction of meaning and purpose in one’s life, the performance of valued social roles, the experience of mental health and well-being and life satisfaction. It means maximizing well-being within the constraints imposed by health status. A recovery framework incorporates continuing care with relapse prevention plans and psychosocial rehabilitation [172]. The lived experience of the person with the mental illness is also acknowledged and attempts are made to maximise their wellbeing along with that of their family [172].

As an evidence-based form of psychosocial rehabilitation vocational rehabilitation is ideally suited to a recovery framework. Recovery planning can incorporate a discussion of preferred socially-valued roles, and if vocational roles are chosen, vocational activities can become the focus of the recovery plan. Anecdotal reports indicate that recovery plans that include vocational activities can deliver new opportunities to observe signs of both recovery and deterioration in mental health, and help prevent relapse, because deterioration is often first observed in vocational rehabilitation activities or in work performance. A comprehensive recovery plan can also include crisis planning, a list of things that people have done in the past to help themselves to stay well, and a list of things they could do to help themselves feel better when things are not going well [172].

8.4 How employment and education contribute to recovery

Having a reason to get out of bed and to have something meaningful to do during the day is essential for the wellbeing of people with psychiatric disabilities. Work has an important role in the recovery of people with psychiatric disabilities and many of the goals of rehabilitation are best served by addressing the person’s vocational aspirations [7]. Employment contributes to the recovery process through being perceived as a means of self-empowerment, and by promoting a sense of self-actualisation [140]. Meaningful activities can also contribute to the recovery process, through active participation in structured social, recreational, volunteer work, arts, and education.

Assisting people with mental illness to participate in education through the use of specialised strategies for psychiatric disabilities is known as supported education. Supported education has been investigated extensively in the U.S.A., and when tailored specifically for people with mental illness, can contribute to career development. A recent longitudinal study [52] and a secondary analysis of data from the USA National Health Interview Survey on Disability, 1994-95 [53], linked educational attainment to increased employment outcomes and higher employment status in the U.S.A. In Australia, educational attainment is closely associated with employment outcomes. Two national surveys [2,54] found positive links between educational attainment and both current employment and durable employment among people with psychotic disorders. Among those not completing secondary school, 11.6% of people with psychotic disorders reported current employment. The employed proportion increased with secondary school completion (22.1%), vocational qualifications (34.3%), and attaining Bachelor degrees or higher (46.7%). There is also evidence that supported education contributes to community integration [173].

8.5. Implications for policy development

Vocational interventions are suited to integration with early intervention and relapse prevention strategies in the mental health sector. The provision of vocational assistance, even by brokered referral, can support a recovery based approach and help prevent social and economic marginalisation by attempting to preserve vocational roles or restore vocational functioning as soon as possible following illness onset. Each person accessing public mental health services can be assisted with a comprehensive recovery plan which takes into account personal goals, treatment goals, education and vocational goals, along with specific action plans for the next 1-5 years.

The need to restore educational attainment following disruption by mental illness is recognised by the National Mental Health Plan 2003-2008 [9, p. 22]. However, this need was overlooked by Australian welfare, vocational rehabilitation, and disability employment service reform throughout the 1990s which
addressed obtaining employment to the exclusion of higher education and substantive vocational training. More specific strategies are needed to provide supported education for people with mental illness over and above the disability assistance currently available to all disability groups via education and vocational training institutions.

9. Conclusions

9.1 Summary of findings
The key findings from this report are consistent with and support the previous findings of Bulletin 3 of the recent national survey of mental health and wellbeing [55]. The key findings are:
(a) Equitable access to career opportunities is a right of Australian citizenship;
(b) Career pathways are not restored by mental health care alone;
(c) Governments have an obligation to address the extensive social and economic marginalisation associated with mental illness;
(d) Strategies are needed to enable and encourage labour force participation throughout the whole working life;
(e) Older people with mental illness can have additional and complex assistance needs;
(f) Employment restrictions and low educational attainment impact on labour force participation and employment;
(g) A substantial proportion of people with mental illness have both the capacity and desire to work;
(h) Employment is feasible even for those with severe to profound employment restrictions, provided suitable forms of assistance are provided;
(i) Disability-specific supported education strategies are needed;
(j) Support is needed for socially-valued roles other than employment, to help people gain a valued place in the community;
(k) Employment can contribute to mental health and can help reduce the community-based stigma experienced by people with mental illness;
(l) Employment is highly valued by some individuals and can have positive life-changing consequences;
(m) Transitional arrangements are needed for those who are not yet ready for competitive employment;
(n) A coordinated data collection strategy is needed to support ongoing service evaluation, the development of innovative services and high quality research. More information is needed about the type of mental illness or psychiatric disability, whether co-morbid health conditions are present, the level of employment restrictions reported, the nature of assistance provided, and whether other forms of vocational assistance are being provided or were provided in the past year;
(o) Multidimensional role functioning and role satisfaction measures can protect against vocational stagnation in transitional services where the vocational goal does not yet extend to open employment;
(p) Both the vocational and mental health workforces could benefit from accredited formal training in psychiatric vocational rehabilitation;
(q) Barriers to employment are numerous. Although some are directly caused by mental illness and the side effects of medication, others are systemic, resulting from community and workplace stigma and the way health and vocational services are organised in Australia;
(r) Most if not all barriers to employment can be overcome with appropriate, sometimes intensive, and creative, specialised vocational assistance. The evidence for this is found in the controlled trials of supported employment in the U.S.A. where 40-60% of people with severe mental illness obtained competitive employment;
(s) Different approaches (supported employment, vocational rehabilitation, Job Network, clubhouses, social firms, business services) can contribute unique, promising, and established evidence-based ingredients to a broad mix of evidence-based options for people with mental illness;
(t) Policy makers and funding providers can focus on the breadth of ingredients covered in a particular
region, to ensure that the available funds engage the full spectrum of evidence-based and promising service ingredients including supported education;

(u) Policy makers and funding providers can help by funding a series of demonstration projects aimed at maximising the spectrum of evidence-based practices, in comparison to usual services. Different locations (urban vs. rural) and different forms of intersectoral partnerships can be included in demonstration designs;

(v) Public mental health services can adopt a recovery-based approach where for each person, goal orientated strategies link early intervention, relapse prevention, personal goals, treatment goals, housing, education and vocational goals, to specific action plans involving those services;

(w) Accredited training in psychiatric vocational rehabilitation is needed in the following sectors in order of priority: vocational, mental health, disability support, and vocational training and education sectors.

9.2 Implications for policy development

The main implication for policy development from this investigation is that existing service types individually offer at most 6 of 11 promising evidence-based ingredients. However, with adjustments to funding structures, accredited workforce training, formal links among different types of vocational services, and with formal links to the public mental health sector, it is possible to provide more effective, intense and continuous forms of psychiatric vocational rehabilitation in Australia than is currently provided. Specific inter-sectoral policies appear needed to broaden mental health care and link it to disability support, vocational services. Mental health care can also be linked to support for other socially-valued roles, in order to prevent the life-long social and economic marginalisation associated with mental illness in Australia.

There are several ways this can be achieved. Referrals to vocational services from community mental health staff could be funded separately outside current case-based funding caps, where the costs of ongoing support in employment or education could be shared by the health sector. Alternatively, innovative funding could be made available for services to establish formal links in their local regions which both endure and involve a seamless coordination of health and vocational services to people with mental illness and their families. Such links could range from allocating responsibilities for coordination to individual staff, through to co-locating staff on the business premises of the partner service. In addition, each sector could offer accredited training to the other sector to promote knowledge transfer within and between sectors.

Consultation involving a wide range of stakeholders (including employers and staff of education institutions) is indicated at local, regional and national levels. Such consultation could lead to more innovative systems for providing coordinated mental health care, vocational services and employment opportunities using the latest evidence-based practices.

9.3 Implications for on-going service development

A coordinated data collection strategy is needed to assess the effectiveness of existing services and support innovative and evidence-based service development. Common methods and variables are needed across vocational services, similar to the Disability Services Census [174] and which include CRS Australia and the Job Network. Because every funded program can require collection of a different data set, rationalisation of collections may be needed as well as the addition of new mental illness variables to ensure that the data can inform service development for people with mental illness. Other organisations such as the Australian Bureau of Statistics could assist in designing a more independent and rationalised data collection strategy, which can underpin service development and be updated as services and funding structures evolve over time. At present, separate data sets are collected by State Health Departments, HACC, Disability Support providers, Centrelink, FaCS, DEWR and CRS Australia, with no apparent attempt at standardisation or integration to reduce duplication or to increase the pooling capacity of the data collected.
9.4 Implications for service consumers and their families

Effective community mental health care coordinated with vocational services are needed, which have sufficient expertise and resources to help people with mental illness achieve personal recovery goals and restore career pathways. People with mental illness and their families need prospects of social and economic participation. Work, employment and education are more than feasible when assistance is available through evidence-based ingredients, including appropriately intense and continuous assistance. Families and carers can play an active part by helping support a person behind the scenes, without taking away their decision making responsibility, and without providing more assistance than is sought or needed. Families and carers can also assist the vocational team by letting them know when things are not going well, when systemic barriers arise, or when services become uncoordinated. Therefore, families and carers can be included in the development of medium term vocational and recovery plans.

Consumer based organisations can play an active part by providing education and advocacy services and by promoting accredited training in psychiatric vocational rehabilitation. Advocacy and mental health education is an essential service to the community which can be provided independently of vocational and mental health services and warrants financial support by local community, businesses, state, territory, and federal Governments.

9.5 Priorities for policy makers and funding providers

Although a range of promising vocational services and programs are available in Australia, the forms in which these are provided are the result of service systems evolving over time. The current organisation of services reflects more upon state-federal funding arrangements and traditional approaches to other types of disability, than to the current needs of people with mental illness and psychiatric disabilities. Policy adjustments are needed to enable Australia to take the lead internationally on psychiatric vocational rehabilitation and supported employment for people with mental illness. Six suggested priorities for policy makers and funding providers are:

(1) shifting towards evidence based practice, by encouraging innovation and by funding demonstration projects to provide a greater range of evidence-based practices;

(2) providing accredited training in psychiatric vocational rehabilitation for the workforces (at 2-3 different levels) in the vocational, disability support, and health sectors;

(3) encouraging inter-sectoral partnerships between the specialised vocational sector and the other sectors by funding local proposals to implement ongoing partnership structures;

(4) removing barriers to services providing more evidence-based assistance to people with mental illness across the working-life;

(5) reforming data collection and data management systems across programs and sectors to ensure common and minimum data sets are collected which enable ongoing evaluation of service effectiveness, efficiency and cost-effectiveness;

(6) inviting service providers and service consumers to help decide how services can be better organised in their local region to most efficiently combine and coordinate services for optimal use of evidence-based practises, and to improve access and outcomes for people with mental illness.
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This report shares content (particularly the sections covering barriers to employment and evidence-based ingredients) with a doctoral thesis recently completed by the first author [175].

References


