

## **Because mental health matters – a response from carers**

**Prepared by Victorian Mental Health Carers Network Inc.**

**July 2008**

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### **SUMMARY**

Carers know that reform of the mental health system in Victoria is urgently required, so we welcome the publication of this discussion paper. The Carers Network has consulted widely with carers and with other organisations in preparing this response. The paper contains many commendable strategies, but overall the essential role of carers as partners in the mental health sector has not been fully recognised.

Carers want action, not just discussions and documents (there have been many already), so they hope to see real change as a result of this government strategy. There is concern that emphasis on new initiatives may mean that core services do not receive the significant funding increases that are needed. Carers see the need for improvement in many areas, but their views are always informed by three key requirements: involvement of family or carer in individual treatment and care, effective participation of carers in system development and direct support for carers.

The material in Part A of the discussion paper has been well received, but the vision and principles could be modified slightly to put consumers and carers at the centre of reform considerations. More importantly, we are concerned that the principles are not fully reflected throughout the paper.

Prevention. We agree that promotion of mental health is very important to achieve better understanding, better capacity to access and a more collaborative approach between stakeholders. Particular attention is required in working with CALD communities, the disadvantaged and the young.

Early intervention. To facilitate early intervention, families and carers need to be educated, supported and involved. Programs such as Mental Health First Aid and Paying Attention to Self should be expanded to improve the understanding of mental illness in the community.

Access. People who are unwell often depend on families/carers to facilitate access to the mental health system. Carers must be treated as partners with clinicians from the first point of contact. Helpline and triage systems need to be well integrated, with staff who are fully aware of local services and accessible at all hours. Support for general practitioners from mental health professionals is vital.

Specialist Care. A new goal is needed to meet carers' major need – to be closely involved in the treatment of their loved ones. To meet this need, family work programs should be promoted throughout the services, responding to the very strong evidence that such programs are beneficial to consumers, carers and clinicians. Attention given in this Area to pre-crisis intervention and post-hospital support needs to be more concentrated and comprehensive. Strategies to enhance carer participation in service development and to consolidate the Carer Consultant should be strengthened by specific goals under Partnerships and Workforce respectively. When the direct needs of carers are considered, special attention should be given to CALD and rural communities.

Complex clients. Coordinated service provision is certainly required. The vital roles that stable housing and employment play in recovery are recognised here - they are important factors for all people with mental illness. There is a desperate need for both step-down and long-term supported accommodation, particularly in rural areas.

Workforce. All workers need training in how to work with families, both in initial education curricula and in ongoing professional development. Culture change is needed and will require strong leadership. Core funding and development of the Carer Consultant program should also be a high priority. Improved leadership will be vital in developing this reform agenda.

Partnerships. The prime consideration here should be a partnership between government, consumers, carers and clinicians in all aspects of service planning, delivery and evaluation. Participation of consumers and carers should be a key factor in accountability and research. The government must take the lead by taking consumers and carers as partners in the reform process.

There are many areas of mental health reform of concern to carers. The most important are probably family involvement in individual treatment and care; training the workforce for family work; carer participation in service development; consolidation of the Carer Consultant program; step-down and long-term supported accommodation.

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## **CONTENTS**

<b>Introduction</b>	1
<b>Carers' responses</b>	2
<b>Part A</b> Vision and Principles	3
<b>Part B</b> <b>The community and the service system</b>	4
Focus Area 1    Prevention	4
Focus Area 2    Early Intervention	6
Focus Area 3    Access	8
Focus Area 4    Specialist Care	10
Focus Area 5    Complex Clients	15
<b>Enabling strategies</b>	
Focus Area 6    Workforce	17
Focus Area 7    Partnerships	20
<b>Appendix A</b> Working with families – the evidence base	23

## INTRODUCTION

The Victorian Mental Health Carers Network welcomes the Victorian Government's consultation paper *"Because mental health matters"*. We have been pleased to assist in arranging the attendance of carers at stakeholder forums, a carers' forum and roundtable discussions that have been organized by the Department of Human Services (DHS).

In addition to these meetings, we have held five forums for carers around the state – in Melbourne (jointly with the Carer Consultants Network Victoria), Colac, Seymour, Sale and Mildura. We have participated in discussions with five CALD consumer and carer support groups (facilitated by Action on Disability in Ethnic Communities (ADEC)) and consulted jointly, by ADEC and the Carers Network. Input from Carers Victoria has also been an important component of our response.

This submission reflects carers' voices and views of Network members, responding to the discussion paper. We trust that the Government will find value in the points made and the issues raised. Reflecting carers' views, the Carers Network shares the Government's desire for improved treatment and care for those with mental health problems. We are pleased to be partners with the Government in this endeavour. The Carers Network looks forward to the publication of the final strategy paper. We stand ready to provide support in further discussion and in preparation of subsequent action plans.

An overall reaction to the consultation paper has been that the involvement of carers as partners in the mental health sector has not been fully recognised and valued. The National Strategy Plan 2003-2008 and several Victorian government reports have emphasized the importance of carer participation at all levels, including individual treatment plans, service delivery, planning and policy. In earlier consultations on the strategic reform agenda, DHS included "Strengthening support to families" as the second of six strategic directions. It is disappointing that the strong focus on this topic has not been retained.

The essential contribution of families and carers to mental health practice and its reform needs to be built into the reform framework and acknowledged throughout the strategy document, rather than confined to one goal in one area. In some parts of the discussion paper, carers are portrayed as passive recipients of service, rather than as active agents within the system. Unless consumers and carers are recognized as partners at the heart of the mental health sector and in its reform, it will not be genuinely responsive to their needs and will not deliver the desired outcomes of best-practice care and optimal recovery. As one carer has said: *"Unless consumers and carers are involved, it's just them doing things about us without us"*.

The need for local self help groups providing information, skill development and peer support has been expressed strongly by carers and is neglected in the document.

## CARERS' RESPONSES

Carers are very pleased to see this discussion paper on mental health reform. They know that reform is needed, in both the structure and the culture of the community service sector.

### The need for action

A dominant feature of our discussions with carers is this simple message: “Carers are tiring of discussion” – not because of a lack of interest or passion, but because many have been part of very similar consultations on the same topics over many years, have seen good reports and recommendations for change, but have seen little action in response to these. As always, carers are hopeful that this time it will be different. They will wait expectantly to see the focus of the “white paper” version of the reform strategy. More importantly, they want to see real action, significant changes, more resources, better outcomes.

### Funding priorities

Carers note the emphasis on prevention and early intervention in the consultation paper and in presentations made at DHS forums. No-one disagrees with these ideas, but there is concern that funding these new directions may mean that the crucial services for those suffering with serious mental illnesses will not receive the additional resources that are clearly needed. It will not be satisfactory if the central mental health services just retain their current levels of funding. Without a significant boost, they will continue to be crisis-driven, unable to provide early-in-episode intervention or to support post-crisis recovery.

### Carer-specific issues

There are three key issues that always inform carers' views:

- (1) **Family involvement** Whenever possible, the family and/or carer should be involved as partner(s) with clinicians and with the consumer in planning, carrying out and reviewing the treatment and care of each individual with a mental illness. This is recognized on page 84 of the consultation paper and in notes provided for DHS forums. The benefits of family inclusion are supported strongly by research evidence and can be as effective as medications (see Appendix A). In spite of this, as the DHS forum notes go on to acknowledge, “*carers are not consistently involved in treatment and care planning*”. This must become a key element of mental health reform – we refer to it in our comments below on several Focus Areas.
- (2) **Carer participation** Carers and consumers should participate in all aspects of planning and evaluation of services, at state government level and at a local service level, in planning of service programs and in development of overall strategy. Such participation is supported in many recent reports and practice guides, but is not consistently practised. Rather than being somewhat isolated under Goal 4.3, this should be a key partnership developed in Focus Area 7 and must be a feature of development of this reform strategy.
- (3) **Carer support** The needs of carers (eg for information and advice, peer support, respite) should be recognized and met – see our comments on Focus Area 4. Carer Consultants, Carer Resource and support workers play a key role in supporting carers. The need for rigorous definition and core funding of the Carer Consultant program is an important part of workforce development. CALD carers and families face language and cultural barriers that result in poor service usage and sometimes in adverse treatment. The service system needs to be much more assertive in communicating with them to understand their particular needs, in providing appropriate information and in facilitating access to services.
- (4) **Wider concerns** When carers discuss the mental health system, they do not concentrate only on carer-specific issues. They are concerned about all matters that impact on the health of the persons for whom they care. We reflect this fact in the wide range of comments that we submit below.

## PART A

### VISION AND PRINCIPLES

Carers applaud the population-health approach in this paper, the recognition that the current mental health service system is crisis-driven and the strong focus on early intervention and recovery. References made in the DHS-sponsored consultations to intervention “early in life, early in illness and early in episode” have been particularly well received. Many carers recall times when intervention came too late.

#### Vision

The “overarching vision” and the descriptive points presented on page 22 have some excellent components. We suggest that two extra points should be included:

- consumers are central to all activities in the mental health service sector
- families and/or carers are involved as partners with clinicians and consumers in individual programs of treatment and care

These key points are different from and should be included in addition to the general point which refers to meeting expectations “in respect to access, rights, equity and respect”.

#### Principles

The “**overarching principles**” that follow are also commendable. Again we suggest an important change in emphasis. Principle 5 should be separated into three:

- Consumer-centred approach. Recognizing that the humanity and human rights of consumers should inform service system reform; addressing the full range of needs that contribute to a person’s long term health and social and emotional well-being.
- Family/carer involvement. Involving the family or carer as partners in the treatment of an individual with mental health problems, noting the strong evidence that such an approach brings benefits to the consumer, the carer(s) and clinicians.
- Consumer and carer participation. Ensuring that consumers and carers participate in all aspects of planning, development, reform and evaluation of mental health services.

With the modifications suggested above, we support the vision and principles, but are concerned that they are not fully reflected throughout the discussion paper. Details of our concerns and suggestions for changes and additions to Part B follow.

## **PART B**

### **THE COMMUNITY AND THE SERVICE SYSTEM**

#### **FOCUS AREA 1 PREVENTION**

As noted in the green paper, “*growing evidence indicates that promotion and prevention strategies targeting risk and protective factors for common mental health problems, such as anxiety and depression, can be effective*” (p. 48). The following concerns and recommendations build on this statement, recommending strategies that promote protective factors and reduce risk factors in order to make a meaningful difference to mental health in the community.

#### **Healthy living/cultural and recreational programs**

The Network applauds the goal of creating wider opportunities to promote mental health in local communities (Goal 1.1). “Healthy living” programs – including cultural and recreational projects – which provide benefits to mental health should be an important part of this promotion, and need to be developed and expanded, with participation in them both encouraged and subsidised. Programs need to be available to, and designed in response to the needs and interests of CALD communities. Programs also need to be accessible to both low-income earners and rural communities.

#### **Mental health and mental illness prevention information**

VicHealth could profitably take a more active role in the promotion of mental health by including mental health issues and illness prevention information as part of their public information and education campaigns.

There are three particularly important barriers to greater mental health awareness that need to be addressed :

- There is a lack of knowledge throughout the community, but particularly in rural areas, regarding mental health issues
- The stigma associated with mental illness frequently prevents people from seeking out and absorbing mental health information
- For CALD carers and consumers, stigma leads to even more pronounced reluctance and delay in the uptake and seeking out of services compared to the general community; this is further exacerbated when CALD carers and consumers experience bullying or racism in the general community (particularly in the workplace). Current analyses from the Victorian case register suggest delays of between 6 and 18 months for first registration for CALD patients with schizophrenia over and above the existing delays experienced by those born in Australia (Klimidis, see appendix A, references).

The Network asks DHS to consider supporting the expansion of the partnership between the Carers Network and the Victorian Multicultural Commission to extend the mental health tips project. Mental health promotion could be further encouraged by promoting the dissemination of information through partnerships with the Dept of Planning & Community Development, encompassing Sport, Recreation and Youth Affairs, Multicultural Affairs, the Office for Youth, and Planning and Local Government.

#### **Social inclusion**

As the discussion paper acknowledges (p. 52), research indicates that social, environmental and economic factors play a significant role in influencing mental health. In light of the aim of strengthening social inclusion (Goal 1.2), there needs to be a much greater emphasis on the influences that socio-economic factors exert in relation to mental health. Employment, housing, financial supports, social and recreational opportunities all have a part to play in prevention.

Information, training, counseling and support services need to be available to help prevent family breakdowns, the occurrence of which can often result in homelessness, a significant risk factor for mental illness.

### **Substance misuse**

The reduction of risk factors for poor mental health associated with substance misuse (Goal 1.3) has the potential to be a valuable prevention strategy. The Network suggests the introduction of a program designed to identify young leaders from both well-functioning and at-risk groups, as well as community leaders and sporting identities. These potential leaders could be trained and engaged in developing cultural change in their communities in relation to drug and alcohol use. Partnerships between VicHealth, the Office for Youth and local governments should be developed to facilitate these leadership initiatives.

The Carer and Consumer Experience research project (for more comment on this project see our comments on Focus Area 7 – Partnerships) could profitably be extended to explore ways in which carers and consumers could contribute to reducing substance abuse.

Police, GPs, local government, teachers, parents and young people should be provided with relevant information about substance abuse and mental illness alongside general health information. As the discussion paper indicates (p 54), information that is provided should educate professionals about substance misuse indicators and risk factors so that at-risk individuals can be preemptively identified.

### **Suicide prevention**

In relation to the government's aim, expressed in Goal 1.4, to enhance suicide prevention measures through a wider range of programs, the following points are made. More open discussion about suicide should be facilitated in the community and in schools. Youth workers, family counsellors, health and mental health professionals and school teachers need training in the importance of communicating with and involving families in cases where the possibility of suicide becomes an issue.

Emergency departments have often responded poorly to people with mental illness, and individuals who present following suicide attempts. Initiatives such as the Western Area Suicide Prevention (WASP) strategy have had some success in reducing rates of suicide. Analysis of previous prevention strategies should inform the development of new models of care to ensure best practice. It is important that suicide prevention strategies are appropriately integrated with emergency departments and that follow-up support is a component of such strategies.

Finally, young people, especially young leaders, need to be educated about suicide prevention and about the importance of sharing concerns regarding suicide with parents or other appropriate adults.

## **FOCUS AREA 2 EARLY INTERVENTION**

### **Importance of family/carer involvement**

To facilitate early intervention, carers need appropriate and timely information and support regarding illness issues, and also information and support regarding services, programs, and interventions available in the community. Information needs to be provided to carers (and consumers) by GPs and other service providers at first contact with the system. Information also needs to be widely disseminated and available throughout the community. These are important means of achieving the strengthened capacity for early identification and intervention articulated in Goal 2.1.

Families need to be involved, supported and educated by clinicians and other professionals right from the beginning of their involvement with the mental health system. An important component of this principle is the development, between carer and clinician, of treatment and response plans to facilitate an early-in-episode response, as alluded to on p64 of the discussion paper

### **Information and education**

Staff working in early childhood services and schools, general practitioners, parents and students need education in mental health issues which includes information on early warning signs and signs of relapse (as alluded to on pp 58-9). Professional staff, in both general and mental health services, need to be aware of, and pass on, information about community support and treatment services, as well as information regarding the different avenues of access to public and private services.

Another means of enhancing the community's capacity for early intervention is to incorporate Mental Health First Aid into general First Aid programs, and make these programs available to parents and others through schools, parent-groups and the wider community. These need to be both financially and geographically accessible.

### **Service options**

Goals 2.2 and 2.3, which refer to delivering timely support and treatment to young people, should apply equally to the adult and aged sectors as well.

One of the biggest issues for those in contact with the mental health system continues to be that services often only respond to crisis – carers' attempts to access help pre-crisis are often ignored or rebuffed. This causes great distress for carers, deterioration in consumers' conditions, and eventually an even greater burden on clinical bed-based services when a crisis-point is reached. There needs to be a range of *accessible* options (information about which should be widely disseminated) for early intervention – including outreach, social health support, intensive community treatment, and access to PARC facilities.

The advent of Child First programs has, by diverting focus to cases involving child abuse and neglect, led to a gap in preventative services such as family counselling and support services dealing with mental health issues, family violence, and drug and alcohol issues. This is particularly important in relation to Goal 2.2 of the paper, concerning the provision of earlier treatment and support to young people with mental health issues and their families.

Young people can benefit greatly from the support and guidance that mentors and role models can provide. Services that build resilience also need to be available, such as the Paying Attention to Self (PATS) program – funding for which was unfortunately ceased – previously delivered through the Centre for Adolescent Health. The "Mirror Families" program is an option that also merits further exploration. These programs have the capacity to significantly contribute to the aim of developing stronger and more resilient families, articulated in Goal 2.4 of the paper.

Ideas about mental health supports for young people should be sought from young people and their carers. This could be accomplished with the involvement of the Carer and Consumer

Experience research project (for more on this project, see section on Focus Area 7 – Partnerships).

## **FOCUS AREA 3 ACCESS**

### **Family involvement**

Mental illness can affect one's insight and capacity to judge and act, meaning that people who are unwell often depend on carers to access help on their behalf. Carers of people with mental health problems consistently report that the mental health system fails to facilitate access to the help needed for their family member or friend. This frustration is acknowledged in the discussion paper, which recognises that Victoria's mental health system is crisis-driven, a fact reflected by the unacceptably high proportion of people receiving treatment on an involuntary basis.

Carers are uniquely positioned to notice when the mental state of the person they care for and know changes. Yet often carers report that they are not listened to, that their views are not wanted. Professionals involved in arranging access to mental health services need to be trained in working productively with families and other carers, to treat carers as partners from the time of first contact. The Bouverie Centre Beacon project of Building Family Skills together is an excellent example of engaging and training services to work with families.

### **Information and system navigation**

The discussion paper acknowledges (p. 68) how the complexities of Victoria's mental health service system cause barriers to access for those needing service and problems for those working in it. These complexities are now at such a level that we must use precious resources to help people to navigate the system rather than use those resources for direct service delivery. State budget announcements of a new 24/7 telephone helpline (p70) have been met with considerable interest by carers, many of whom have used similar helplines with mixed success. Carers talk of being "hand-balled" from service to service when seeking help. Duty of care and medico-legal issues dictate that advice given is often cautious and limited. It is understood that the role of a telephone helpline is largely to assist in service system navigation. Such a role can be of value if it streamlines access.

Carers often require supported referral rather than just information. An information service such as this must be resourced adequately and well led so that practitioners within it always keep themselves abreast of current services, protocols and issues. A significant proportion of each telephone worker's time should be spent doing this to ensure a high quality service. Training, staff selection, service leadership and measures should all enhance the ability of the service to work with carers. It is also vital that there are sufficient resources for multi-language services and that worker's have the training and confidence to use them appropriately.

However, carers are also concerned that the new 24/7 statewide service should not be a substitute for locally available and accessible information and services.

### **Triage role and capacity**

The discussion paper asks how the current triage system can be improved (pp 68-71). High demand on acute services is a symptom of the need for a more systemic approach to service design. In spite of the recognition of the need to deal with these issues in their systemic context, most of the Focus Area 3 material reads as if it is concerned only with the acute parts of the system. Triage teams must be positioned to offer earlier and less intrusive interventions, including advice and information about community-based supports such as PDRSS, GPs and other health and welfare services, both private and public. There may be limitations on triage's ability to take on this more holistic role if they remain situated, funded and managed through clinical services. For example, some needs may be more properly met if access to some accommodation and support was available on a 24-hour basis through PDRS services.

Triage services should also be resourced adequately to allow for more of the work to be done face to face rather than over the telephone. The limitations of telephone assessment are shown in particularly stark ways when a person with a mental illness and/or family members, do not speak English as their first language. It is arguable that triage and information services have not

yet addressed issues of language difficulties adequately. People from non-English-speaking backgrounds wanting to access services often talk of needing to find a family or community member to interpret for them, a circumstance fraught with problems for both families and practitioners.

### **Role of General Practitioners**

General practitioners are respected by the community and relatively accessible. General practice does not have the stigma that specialist mental health clinics may carry. This means that GPs are often the first point of call for people needing assistance of any kind. Expectations by the public and demand on GPs may be unrealistically high. Anecdotally, many GPs feel unsupported by the specialist mental health system and cannot afford the time to navigate cumbersome triage systems. Evaluation of recent changes to MBS items is predicted to show that access is inequitable and does not favour those with more serious presentations or limited financial resources. Allied health professionals working alongside GPs have an important role to play here. There are successful partnership models existing within some community health services. Cooperative action by commonwealth and state jurisdictions could achieve better coordination of specialist mental health and general practice resources.

GPs must be encouraged to use Primary Mental Health teams and not to think of referral only to private mental health professionals. This is particularly important in rural areas, where private referrals often mean long-distance travel.

GPs need to understand the importance of getting information from family and carers if they are to understand their patients' issues more accurately. GPs also need to appreciate the importance of ensuring that families receive information and emotional support to help them cope effectively. This will sometimes mean overcoming perceived difficulties with confidentiality.

## **FOCUS AREA 4 SPECIALIST CARE**

We recommend renaming this Focus Area “Care, treatment and ongoing support”. This would avoid the implication that the emphasis is on care in the specialist services; it would be more faithful to the principle of the need for a service system that is person- rather than service-orientated; it would allow greater focus on the urgent need for ongoing support after discharge from acute care.

The Carers Network agrees broadly with the aim of broadening system responses to be more proactive, preventative and supportive (p. 76 of the discussion paper). People with mental health problems and their carers often access services only when in severe crisis and all too often this then entails traumatic and intrusive service responses. Others with mental health problems receive no service at all. When carers are asked about what they would most like to see change, there is consensus that the people they care for need better core services and ongoing support.

### **Early-in-episode intervention**

Most carers recall times when opportunities for intervention early-in-episode were missed and the agonies of a crisis followed soon after. Some ideas related to this are spread (rather thinly) under Goal 4.1 and 4.2 – assertive outreach, increased capacity to allow shift from crisis-driven service, stronger family-focused care, integration of PMHEI services, support and training for primary care providers, step-up facilities in PARC.

It would be useful to acknowledge early-in-episode intervention as a vitally important reform area and to consolidate the relevant strategic concepts in a single part of this Focus Area – it could be done under Goal 4.1. The emphasis must be on optimal care for the consumer, not just on reducing hospital admissions for the sake of the system. Sometimes hospital admission may be necessary – often the carer and maybe the consumer will know this. Somewhere in the mental health system there must be clinicians dedicated to providing pre-crisis service, not distracted by the pressures of crises.

### **Ongoing support**

“After hospital, there is nothing!” – that’s a common desperate call from carers. People with mental illness need support after discharge from acute care, both as a transition before returning home and to facilitate their ongoing recovery. Our aim for those with chronic illness should be an ever-improving life in the community, not just the avoidance of relapse.

There are some excellent support programs in the PDRSS sector, but these are too thinly stretched and cannot be made available to all those in need. Development of PARC facilities is widely acclaimed, but this service is not available in most locations and is only available to the adult sector. This is a particular problem for the aged sector, as it results in consumers either unnecessarily taking up acute beds or using the respite care system, which does not address their treatment or rehabilitation needs.

As with pre-crisis intervention discussed above, we would like to see strategic directions for improvement of ongoing support grouped together under Goal 4.1. Before consideration of logistical questions, there needs to be recognition of the needs for ongoing support in these areas:

- Discharge planning. Frequently carers are not involved or even informed, even though they have to assume responsibility for ongoing care.
- Medical care by mental health professionals. In many cases, the expectation that general practitioners can provide care after discharge has led to unsatisfactory outcomes.
- Case management. Often the carer is left as the de facto case manager.
- Step-down accommodation and support before returning to home and carer.
- Long-term supported accommodation for the chronically ill, currently in desperately short supply, particularly in regional areas. Ageing parent carers always have concerns about

their children's long-term accommodation and care. Goal 5.2 deals with accommodation but seems misplaced in Focus Area 5 – this is not an issue specific to complex clients and not just about homelessness.

- Employment. Again the material under Goal 5.4 is applicable generally, not only to complex clients.
- Social inclusion. Although the title of Goal 5.4 makes general reference to social and economic participation, the material presented deals solely with employment. Support must be given to people with mental health problems to participate in society in other ways. The stigma of mental illness means that it can be difficult for people to enjoy the same access to social, recreational and educational opportunities. Examples of good practice exist where PDRSS day programs work proactively with the interface between the mental health service system and the broader community. These services need to be better financed and their staff would benefit from increased training opportunities. Increased provision of services such as the Personal Helpers & Mentors Service (PhAMS) would aid the recovery of consumers, as well as providing much needed breaks for carers. PhAMS is Commonwealth funded, but the State has a role to play in supporting these types of programs too.
- Education. The first onset of mental illness often occurs when the person involved is a teenager or young adult. As a result, people with mental illness problems have lower educational attainment than other people and lower rates of workforce participation. Any initiatives to increase workforce participation must address the question of access to education and training. There are opportunities here to improve links between mental health services, educational providers and employment support services.

### **Achieving a more integrated response from mental health services**

The respective roles and responsibilities of the Area Mental Health Service Continuing Care Teams and the PDRSSs need to be rationalised on an evidence basis and energies need to be devoted to ensuring that the interface operates smoothly in the best interests of consumers and carers. In defining these roles, consideration should be given to the need for a more holistic, recovery and person-centred service system that includes families and friends as appropriate.

### **Accessing a wider range of bed-based care options**

The Carers Network welcomes the emphasis on this topic (pp. 80-3). Responsive and long-term community supports are often lacking, leaving carers to provide support as best as they can with inadequate support themselves or, when families are not directly involved, leaving people with mental health problems to manage on their own. PARCs are widely welcomed as they roll out – there remains much work to be done to achieve state-wide coverage, particularly in rural areas. We also welcome the discussion paper's point that hospital beds are only one part of what is needed. As mentioned, the Boston Consulting Group's report provides a useful analysis of the impact of bed blockages on the mental health system. It is possible to advocate convincingly for more community-based options on the grounds that they are less expensive than acute services. It is even more appropriate to advocate on the grounds of the increased success of less intrusive forms of intervention and the benefits of increased access to the system.

The discussion paper states that the bed capacity of psycho-geriatric residential care services will not be increased. It is curious that no mention is made of the rationale for this, in spite of the well-known and stated demographics of an ageing population.

### **Involvement of families and carers in individual programs of treatment and care**

For many carers, one of the most important statements in the consultation paper appears on page 84 - *"Outcomes for consumers are significantly enhanced through partnerships between carers and mental health professionals"*. Notes provided for DHS forums state: *"Research informs us that when carers are viewed by professionals as an integral part in the care relationship and proactively and respectfully involved in treatment planning, the outcomes for*

*carers and consumers can be improved*". Although there are valuable notes under Goal 4.3 on carer needs and on participation in systemic planning and development, there is little further reference to the involvement of carers as partners in individual treatment and care programs. Section 2 of goal 4.3 concentrates on consumer involvement.

Translating into practice the strong evidence base for working with families (see Appendix A) would lead to new models of mental health care and new workforce roles. Outcomes indicated would be a reduction in relapse rates, fewer hospitalisations, better medication compliance, reduced psychiatric symptoms and other significant benefits. Studies in China, Spain, Scandinavia and Britain have demonstrated that family interventions are effective across different cultures. This is important in consideration of our own CALD communities. There is evidence also of benefits for clinicians – families become appreciative allies, not angry and frustrated people seen as difficult and dysfunctional. With the satisfaction that this brings, there is less staff burn-out, less absenteeism, fewer resignations and fewer problems with confidentiality.

The programs on which this research evidence is based share three important features:

- Family and carers, the consumer and the clinician work together
- The 'working together' is pro-active and structured over a period of at least 9 months
- Clinicians encourage and train families to develop appropriate skills for management of the illness

The Chief Psychiatrist's Guidelines call for family inclusion to be at the core of treatment programs, and a local study in 2003 recommended family intervention programs as beneficial and cost-effective (Appendix A, reference 14). There are a few examples of excellent work that is beginning to be done with families in Victoria - for instance in the Northwest, Northern and Grampians AMHSs. However, we know that in many services:

- Family and carers are largely excluded in favour of an individual alliance between the clinician and the consumer, sometimes even suffering from stigma demonstrated by staff.
- Rather than "working together", the inclusion of families is reactive: services respond to families only when there is a crisis. Early-in-episode intervention is almost impossible, even when families know that it is needed.
- Families are largely excluded from the discharge planning process, sometimes are not even informed of discharge, although they then have to provide ongoing care.
- Although families may be given some information and some support (rarely enough of either), there is no provision of training in skills required for optimum management of mental illness.

In spite of the overwhelming evidence supporting 'Family Work' and the development in Australia of best practice guidelines recommending family involvement, family work is not happening in any extensive way in this country. If similar evidence supported a new medication, a vast marketing campaign would ensure that the medication was used. Research results for family inclusion are as impressive as for medications, but there is no marketing apparatus to ensure that the research results are publicised.

As well as the need for education and training of the mental health workforce in working with families (see p 17), there is a need for organisational change within the specialist care services to accommodate these new ways of working. Barriers to implementation of family programs include outdated clinical attitudes to families as the cause of mental illness, poor methods of case-load management, lack of resources (management time and initial funding) to implement the change process, and lack of ongoing clinical supervision to ensure sustainability. There is now a substantial literature from clinical researchers in other countries where family work has been implemented, who have confronted and overcome such barriers (see Appendix A, references 10,11,12, 13).

The reform strategy should place strong emphasis on the importance of family involvement. It should call for implementation of family work programs in all services, making family inclusion an integral and mandatory component of treatment (unless, of course, a carer cannot be identified). This approach could be written into Goal 4.3 as a new numbered item under “*What we want to see*”. The item would then read *promote family/carer involvement (in partnership with consumer and clinicians) in individual treatment and care programs*. As we have proposed earlier, it should also be a feature of the vision and principles set down in Part A.

### **Consumer and carer participation in systemic development and reform**

We are pleased to see the focus on this topic on pages 84 and 85 of the consultation paper and agree with all the points made therein. Consumer and carer participation is strongly supported in “*Consumer and Carer Participation Policy*” (NCCF 2004, pages 6, 7 & 17), in “*Caring Together – an action plan*” (Vic Govt 2006, page 5) and by the review in May 2008 of the National Mental Health Standards.

The private sector has explained that it needs to explore further the issue of consumer and carer participation in service planning and delivery – much work needs to be done to improve the public-private interface in mental health services.

In spite of the official support for participation of consumers and carers in systemic development and planning, this is still not consistently and effectively practiced throughout the mental health system. In some cases it has been seen as an end in itself (“We can tick that off”) and not recognised as a key to improving the planning, delivery and evaluation of services.

To raise the profile of this important topic, we suggest that it should be treated as a central partnership program and presented as such in the reform strategy under Focus Area 7. We develop this proposition further in our notes on Focus Area 7.

### **The Carer Consultant program**

The consultation paper (pp. 84-5) correctly recognises Carer Consultants as playing an important role as system advocates. It indicates that consideration will be given to increased role clarification, stronger support and improved funding arrangements for Carer Consultants, and to broadening the model within all mental health services. Carers believe that development of the Carer Consultant program should be given a much stronger focus in the paper – it should be a key element of workforce considerations in Focus Area 6.

### **The diverse needs of carers**

Carer needs are acknowledged on page 86 of the discussion paper. We want to see emphasized here the need for information on mental illnesses; information on the mental health system and how to access it; information on the different roles of staff; information on medications prescribed; advice services; respite; peer support and contact with workers trained in carer needs.

CALD communities have particular needs in all these areas, but especially important is dissemination of appropriate information at all stages of contact with primary care providers and mental health professionals. Such material should be provided to CALD carers within established protocols at mental health services, incorporating follow-up to ensure that the information has been understood and successfully used. This is essential for continuity of care and particularly pertinent in regard to crossing the chasm that language barriers present.

Evidence indicates that carers, particularly carers of the mentally ill, have low health and well-being and are much more likely than the general population to experience depression and anxiety. Support for carers such as counselling, education, peer support and respite are beneficial and effective.

Caring is a lonely activity. Many carers report losing their circle of friends, and emphasize the value of peer support. Carer support groups, Carer Consultants, Carer Resource and Carer Support workers play vital roles in this area and should be strongly supported.

Respite is highly sought after and needed by carers. Gaps remain in respite provision for specific groups of carers. Carers of young people with mental health problems frequently report difficulty in accessing suitable respite options. Much funding for carer-specific respite services is now provided by the federal government rather than through the state mental health system. Although new resourcing for carer respite is welcome and necessary, there is a risk here that we are developing a dual service system that separates the needs of carers and consumers rather than working competently with all family members. For respite to be acceptable it must be meaningful for both carer and consumer and both must participate in any arrangements made. To achieve this, more intensive co-ordination between governments is necessary.

Aged persons often have additional issues including physical health problems, frailty and dementia, and could therefore be included in this section on Complex Clients.

Training in carer needs is required for workers in all mental health services, in the general health sector and in other community services.

Carers living in rural areas face particular issues and have particular needs. Many areas lack specialists and the services provided by visiting specialists are limited. Choice of clinicians is not possible which can be particularly difficult, for example when gender issues are a concern. Long distances and operating hours make access to services difficult for many carers.

### **Forensic clients**

This topic is concerned with one type of 'complex client', so the material presented under Goal 4.4 would be more appropriately placed in Focus Area 5.

## **FOCUS AREA 5 COMPLEX CLIENTS**

Once again a change to the title of this Focus Area is worth considering – “Clients with complex needs” would be better. This Focus Area recognizes the need to improve the co-ordination of services for people with complex needs, the vital role that stable housing plays in recovery, and the need to support the social inclusion of people with mental illness. As mentioned in our response to Focus Area 4, we would like the structure of the discussion paper to reflect the importance of these aspects of support to all groups of people with mental illness, not just those with more complex needs. While acknowledging that there are people who need much more intensive support than others, it may not be helpful or true to the principles expressed elsewhere in the paper to define a focus area around a group of people identified in this way.

### **Housing and support**

Housing was identified in a 2007 survey of carers of people with mental illness, consumers and mental health workers (Mental Illness Fellowship) as the mental health system’s most important issue requiring advocacy and change. Lack of housing clearly affects people with a mental illness but often also means that families are left trying to manage difficult circumstances with no suitable alternatives. For older carers, there can be considerable anxiety about the future of their family members when they themselves become frail or die. Resources need to be provided to assist in the planning and provision of accommodation and other supports to be engaged in the event that a primary carer becomes unable to continue in that role. This would provide a necessary back-up support system for consumers, as well as peace of mind for carers.

Access to suitable housing can be usefully viewed as an enabler or essential prerequisite for the success of mental health services. We welcome the discussion (pp 92-98) on this issue and reference to the analysis contained in the Boston Consulting Group’s report about the role that accommodation plays in allowing the mental health system to function.

### **Housing and support models and supply**

Debate about housing often focuses on which housing types and models should be developed and resourced for people with mental health problems. There is good evidence from Victoria, New South Wales and Queensland that has been helpful in identifying the features of successful models.

Given that successful models are available, the shortage of housing can be seen as a problem of resourcing and political will (B. Ilsley, New Paradigm 2007). There is some evidence from the USA and now Western Australia (AHURI) that dramatic cost offsets result from provision of housing and support – fewer demands are made on mental health, drug and alcohol, homeless, general health and correction services. Housing for people with mental health problems should therefore be dealt with by a whole-of-government approach rather than only within housing departments.

Many advocates have concerns about the temptation to build larger facilities because of the economies of scale, seeing this as a backward step towards institutionalization.

### **Community housing**

The Victorian State 2007-08 budget announcement to increase community-housing spending by \$300 million was warmly received. There has been concern, however, that government policies that require housing associations to grow housing stock may be counterproductive for people on very low incomes – a category that includes many people with psychiatric disabilities – because of their inability to pay higher rents. Growth strategies may also limit the choice of residents to live with the people they want to and to have space for family members. For these reasons, we agree very strongly with the need expressed on p. 96 to set housing targets for people with mental health problems.

## **Employment**

As discussed on p. 108, employment can be a key pathway to a person's recovery from mental illness and can have many benefits. The disadvantages of economic exclusion should not be underestimated, and the level of workforce participation for people with psychiatric disability is unacceptably low in Australia (National Mental Health and Disability Employment Strategy Discussion Paper 2008). The recent decision by the Commonwealth government to separate the seeking of employment from review of benefits is welcome. As described on p. 109, employment support services are 'generally based on a funding model that encourages throughput, rather than sustained assistance over the longer term'. Services could significantly enhance their efficacy by not only helping consumers find employment, but also assisting with issues surrounding job retention. Issues of retention and the income support implications of becoming unwell are of particular importance to people with episodic conditions such as mental illness. The state has a role here, and there is a need for mental health services and employment support services to work more closely together. Research by Geoff Waghorn and others has shown that consumer choice is a key determinant to successful outcomes. It is hoped that a proposed system outcome framework would inform improvements in this area.

## THE ENABLING STRATEGIES

To achieve the reforms that we all want, we need to give attention to the things that will make it happen – workforce development, cultural change, accountability, education and training, leadership, partnerships and research. These enablers are important across all sectors of the mental health system as well as in other community services.

### FOCUS AREA 6 WORKFORCE

#### Training for working with families

We note with pleasure the fifth dot point on p. 111 of the consultation paper: *“The Victorian Government wants to achieve a sustainable specialist mental health workforce that ... works in partnership with consumers, families and other carers ... to maximise client outcomes”*. This is a logical extension of the statements on page 84 on the benefits of partnerships with carers, of the arguments we have presented above and of the evidence base outlined in Appendix A. The abilities and culture of the workforce are key elements in achieving this goal. On p. 85 we read: *“Consumer and carer involvement in treatment planning can be improved through staff education and strengthening accountability through the use of outcome measures and quality frameworks”*. However, in this Focus Area 6, there is no further reference to working with families and other carers, only some brief comments on the need for consumers and carers to play an active role in undergraduate and postgraduate worker training, and for consumer and carer perspectives to be fed back to workers. Family work should be a key consideration as the following ideas are developed:

- New models of mental health service delivery and new ways of working
- Creation of new workforce roles ...for people with consumer and/or carer experience
- A culture ...responsive to evidence-based practice and client need
- Ongoing education and training to update worker knowledge and best practice
- Incentive-based learning

To promote the formation of partnerships with carers, there is an urgent need for education and training of the mental health workforce in how to work with family and other carers. This should be a significant component of the educational curricula at undergraduate and post-graduate levels for all relevant disciplines and of ongoing professional development. Carers should be involved in the education and training of all mental health professionals, so that their ‘lived experience’ is understood and appreciated. Excellent training programs have been developed in the UK and America and local versions have been developed in Victoria. Two models of working with families that have been developed from the evidence-base and training manuals are available: *“Building Family Skills Together”* (North West Area Mental Health Service, Centre for Psycho-Social Research and Bouverie Centre) and *“Multiple Family Groups”* (Inner West Area Mental Health Service) - see Appendix A, references 7 & 8.

It may be thought possible to encompass these ideas within Goal 6.3, but we would be concerned then that its relative importance would be lost. We propose that a new Goal should be set down in Focus Area 6: “Promoting the practice of working in partnership with families and other carers through education, training, incentives and accountability”. The goal could be further pursued by the creation of new workforce roles that focus on family work (in addition to the vitally important Carer Consultants). One suggestion has been made by an expert in this field – establish a position of Director of Family Services or add Family Work to a selected clinician’s portfolio. This director could develop, implement and oversee family programs, lead and supervise family work, monitor the delivery of family services, identify and train clinicians to concentrate on families, work with family advocacy organisations and carer support groups, and participate in continuing education activities.

#### Carer Consultants

Carer Consultants have made an immensely valuable contribution to the quality of services provided in the Victorian mental health sector. They have two essential roles, separate but inter-

related: (1) to provide direct support to carers and (2) to work collaboratively with other staff to help them understand and respond to the needs of the whole family, including the consumer. The first role informs the second. The second will involve participation in planning and quality committees and the like within their services.

We strongly support the important dot-points made on pp. 84 and 85 of the consultation paper on building the capacity of the Consumer and Carer Consultants to be more effective system advocates, and we urge the government to progress these matters. A good first step would be to move this discussion to Focus Area 7, recognising the importance of Carer Consultants in the workforce.

We would like to see the necessary improvements in the Carer Consultant program more forcefully proposed. The following matters need attention:

- It is quite inappropriate for the program to be funded from the Carer Support Brokerage Fund. Core funding should be established immediately.
- The role of Carer Consultants is defined differently in different services. A firm position description should be set down, mandating the two roles described above.
- There is no agreed award base for employment of Carer Consultants. The government should liaise with the appropriate union and the Carer Consultant Network Victoria (CCNV) to agree on a suitable award, remuneration and career structure.
- There are far too few Carer Consultants in the services, often covering large numbers of clients across ridiculously large geographical areas. A significant increase in Carer Consultant numbers is required. Requests for more Carer Consultants may not come from the services themselves. Carer Consultants have been so “thin on the ground”, and as such, their extraordinary value to services is not universally appreciated. In fact, many clinicians do not respect their views, are still threatened by their presence and do not understand what they can achieve.
- Some services choose not to employ a Carer Consultant and some employ them with impossibly low work-hours. Appointment of a prescribed minimum number of Carer Consultants should be mandatory for each service. Funding should be available for this purpose only.
- There is no training program for Carer Consultants. The government, working with training providers, CCNV and our Network, should set up a such a program and fund it as required.
- CCNV operates without support, providing information distribution, networking and peer support among Carer Consultants – essential for workers who are often alone in their services and widely dispersed geographically. The government should support this effort by requiring services to permit attendance at CCNV meetings within working hours and by covering CCNV’s basic operating costs – this could be conveniently achieved by an auspicing arrangement with this Carers Network. We are currently working on a Memorandum of Understanding to cement relationships between the two Networks.

### **Supporting the existing workforce**

The paper acknowledges the need to address issues of pay parity for similarly qualified workers in different parts of the system, as well as the need to “support the PDRSS workforce to reinforce its status as an equal partner in mental health service provision” (p. 116). The paper also asks how the PDRSS and clinical parts of the specialist care system can be encouraged to work together (p. 79). History and culture play a part here and some recent alliance initiatives have made valuable inroads towards reaching common understandings. Inequalities in pay, entitlements and professional development are also a barrier to establishing an equal relationship. Until this issue is addressed, problems will remain. The state government does have a role to play here in determining service pricing, establishing service agreements and advocating to the Commonwealth government.

### **Culture change**

Culture change will be necessary if working with families is to be practised consistently. Research evidence shows that clinical attitudes can be changed and confidence in working with

the family and the consumer together can be achieved. Working with families provides an excellent opportunity for incentive-based learning. Staff members find intrinsic rewards in the greatly improved relationships with both families and consumers. A further incentive can be developed in formal accreditation for clinicians who undergo training in and implement family work.

To improve accessibility and outcomes for consumers and carers in CALD communities, all staff should have training in cultural sensitivities. In some services, there needs to be a significant shift in the manner in which CALD families are treated.

### **Leadership**

We agree with the need for strong leadership to forge new collaborations and develop new integrated service delivery models (Goal 6.4). For this to be successful, cross-sector linkages will need detailed attention. Carers already find it difficult to navigate through the complexities of the system and access the services they need. There is concern that the system envisaged will make this even more of a problem.

Leadership will be of major importance to ensure that information systems are regularly updated and accessible to staff and the community with particular attention to the needs of rural and CALD communities. Leadership will also be important in ensuring that Case Managers are skilled and knowledgeable about mental health and community services so that they are able to effectively operate across the interfaces and facilitate access to appropriate services.

Leadership will also be integral in ensuring Carer and Consumer Action Plans are implemented and that staff are trained in working with families as well as being sensitive to the need to do so. This would certainly be a responsibility of a Director of Family Services – a new position suggested earlier in this section.

## FOCUS AREA 7 PARTNERSHIPS

### **Consumer and carer participation in systemic development and reform**

As stated in our discussions of Specialist Care and Workforce areas, the participation of consumers and carers has been widely acknowledged as vitally important in the planning and development of mental health services. Nevertheless, this practice has not been uniformly adopted. This Victorian strategy document presents a wonderful opportunity to restate this message and to commit to its universal implementation.

We propose that this essential partnership be covered by a new Goal in Focus Area 7 – “Establishing a partnership at all levels between government, providers, consumers and carers for planning, development, delivery and evaluation of mental health services”. Only by identifying this as a central partnership can one establish its importance throughout the sector, from ministerial committees to local service steering committees. It should not be restricted as in the consultation paper to being part of a Goal within Specialist Care. The excellent comments on consumer and carer participation on pp. 84-85 of the consultation paper can be transferred to this new partnership goal.

Participation of consumers and carers is an important “enabler” – it will improve the way services are planned, delivered and evaluated. It is not an end in itself. It should occur throughout the public mental health system - at the statewide level in the top DHS committees and round tables on mental health, in regional bodies and in all types of service providers. If it does not start at the top, it will not filter down.

National Mental Health Standards, quality improvement programs and accreditation processes should be used to monitor the implementation of consumer and carer participation. There must be serious accountability, with significant consequences for non-compliance.

Policies at state level support consumer and carer participation, but those at regional/Network and AMHS levels are inconsistent at this stage. This must be corrected. In the PDRS services, where carer participation is even less well developed than in the Area MHSs, encouragement and incentives are needed. In the private sector, again encouragement and incentives are needed; collaboration with RANZCP and the College of GPs on their policies should be productive.

Within services, Carer Steering Committees (comprising senior clinicians, Carer Consultants and carers, and reporting to the Quality Committee and the Executive) have proved effective. Local AMHS-level Consumer and Carer Advisory Groups, working with the Area Manager and Senior Clinicians, can identify issues needing improvement and work collaboratively to solve them. Such initiatives can be usefully supported at Network/regional level by a combined Advisory Group comprising Carer Consultants, Consumer Consultants and clinicians. There are good examples that demonstrate the value of these approaches at North West AMHS and the North Western Mental Health network.

Training and support for clinical staff in working collaboratively with consumers and carers is essential. Training and support for consumers and carers is also required to assist them in making strong contributions.

Consumer Consultants and Carer Consultants clearly have an important role in systemic planning and development. We support mandatory employment of Carer Consultants across CAMHS, aged, adult and specialist statewide services, recognising that they act as catalysts for carer participation as well as for carer involvement in treatment and care at an individual level. They are an essential part of this Victorian reform strategy.

For further background in this area, refer to Chapter 5 “Involving Carers” in reference 15 of Appendix A – it presents the strategy, training and evaluation established by the Somerset Partnership NHS and Social Care Trust in the United Kingdom.

Finally, we urge the Victorian Government to show leadership by arranging real participation of consumers and carers in the further development of this reform strategy and in subsequent preparation of action plans by DHS and the various mental health services.

### **Accountability for instituting family/carer focussed mental health systems:**

We note that page 85 states, that "*Outcome measures will be included in the proposed mental health outcome framework to formally assess progress in achieving a consumer-centred and carer-sensitive system of mental health care*". Table 5, page 127 includes client focus and carer sensitivity as a performance measure. These references give a level of reassurance, however we suggest using the term "family/carer-focused" rather than "carer-sensitive". The word 'sensitive' is not sufficient and does not incorporate the active involvement and participation of families/carers.

The following comments relate to goal 7.3, pages 125 – 127. To assess progress in achieving family/carer-focussed systems of mental health care, where families/carers are involvement in individual treatment and care and able participate effectively in service development, it will be important to delineate responsibilities for implementing these systems and to establish appropriate accountability measures.

Outcome measures are only part of the picture in assessing a consumer and carer focused mental health system. Issues such as whether clients were treated with respect, whether consumers and carers were listened to and given information, and whether carers were involved in treatment and planning decisions, cannot be adequately addressed solely through the use of aggregated outcome measures.

The *Consumer and Carer Experience of Care and Support Initiative* (the C&C Experience) offers a model of best practice for participation in mental health service development and a focus that is different than, yet complementary to, outcome measures. It generates leadership among consumers and carers in collaborating with clinicians in quality improvement, the focus is on the experience of the service as opposed to the abilities of the client, and the information provides support to Consumer and Carer Consultants in their ongoing roles as educators in consumer and carer perspectives.

The piloting of the *Mental Health Experience Co-Design* (MH-ECo) project in 2008/9 builds on the findings from the *C&C Experience* project. Based on cutting edge approaches in design in healthcare, it offers the mechanisms through which services can build partnerships with consumers and carers to facilitate qualitative change. Both the *C&C Experience* and the *MH-Eco* initiatives provide pathways for participation and change which should be integrated into any Mental Health Outcomes Framework and adopted by services across the State.

### **Family/carer partnership in overseeing and implementing outcome measurement:**

The green paper discusses the need for an overarching framework (page 126), it suggests that an interdepartmental committee may be established to oversee the development of the new mental health strategy and suggests the formation of a small number of high level statewide partnerships groups may be formed to drive continued strategic policy and accountability, (page 130). It is important to ensure that carers and consumers are directly represented on all of these groups to ensure that real carer/consumer partnership and participation occurs. Carers and consumers need to be at the same tables as other stakeholders to ensure that reform happens 'with us' and not 'for us' or 'to us'.

The Network also advocates for a separate Carer and Consumer group to operate across all mental health sectors to assist in driving and reviewing the implementation of the Carer and Consumer Action Plans. Partners in such a group could include the Mental Health Carers Network, VMIAC and the Bouverie Centre.

## Research and Evaluation

The following comments relate to goal 7.4. Page 129 mentions that research should actively involve a range of stakeholders, including consumers. Carers have been omitted at this point and should be included. Page 129 also lists possible ways to achieve desired outcomes. We suggest including the centre for expertise for consumers and carers to provide mental health and mainstream services with access to technical expertise, education, research, training and evidence-based practice (referred to on page 85) in this list. We believe the recently established fledgling Research and Evaluation Units developed by VMIAC and the Mental Health Carers Network could be developed strengthened and to fulfill these purposes.

Research needs to be undertaken to explore best practice in carer/consumer participation in system development, and to generate data on the efficacy of consumer/carer participation in systemic planning and development. *The MH-ECO* project and its predecessor, the *C&C Experience* project, jointly piloted by the Carers' Network and the VMIAC, will be useful in illustrating consumer and carers' experiences of services and in offering mechanisms for services to become more responsive to those experiences.

During the course of these projects, the relationships established between DHS, the Carers Network and VMIAC, have demonstrated the capacity of these organisations to provide the skill and leadership required to bring the voices of consumers and carers to the research table.

While these organisations are steadily building strategic partnerships with academics at Melbourne University, La Trobe, and other institutions, the Department would be well-served to recognise and support this growth in leadership within the sector. In order to fulfil both the fifth and ninth overarching principles for change, "consumer (and carer) centred approach" and "evidence-based practice", the perspectives of consumers and carers in determining research objectives and evaluating services must be strengthened.

This can best occur by creating clear linkages between any proposed Centre for Mental Health Intervention Research with a Consumer and Carer based research and training centre. In this context, the Network is very keen to explore further the idea flagged on p. 85 of a centre of expertise for consumers and carers to provide mental health and mainstream services with access to technical expertise, education, research, training and evidence-based practice.

## APPENDIX A WORKING WITH FAMILIES – THE EVIDENCE BASE

Powerful evidence (from over 40 randomized controlled trials carried out over 30 years) supports the inclusion of family and other carers in the treatment and care of their unwell relative. These studies meet the 'gold standard' for research; meta-analyses of these studies are included in references 1,2,3,4,5. The significant evidence is:

- reduction in relapse rates (up to 20%) – resulting in a reduced number of hospitalisations
- better medication compliance
- reduced psychiatric symptoms

Many research studies show other significant outcomes, such as:

- improved social functioning
- increased employment rates
- increased involvement in community
- reduction in the burden experienced by family carers
- improved relationships between family members, including with the consumer
- cost effectiveness

Studies in China, Spain, Scandinavia and Britain have demonstrated that family interventions are effective across different cultures. This is important for consideration of our own CALD communities.

For new models of mental health service delivery and new ways of working that translate the research findings into routine clinical practice, there are two major requirements:

### 1. Education and ongoing training of the mental health workforce

There are now excellent and effective training programs that have been developed in the UK and America. Programs that started in Australia have been largely unsupported, and have not developed to any great extent. Two models of working with families that have developed from the evidence-base and for which training manuals (refs 7,8) are available are:

- Behavioural Family therapy. This model has been adapted and is being implemented as 'Building Family Skills Together,' in conjunction with North West Area Mental Health Service, the Centre for Psycho-Social Research and the Bouverie Centre.
- Multiple Family Groups. A research project was implemented through the Inner West Area Mental health Service, and the results of this work have been published (ref 9). Multiple family groups have been commenced in two other AMHS.

### 2. Organisational change that can accommodate these new ways of working

There is now substantial literature from clinical researchers in other countries where family work has been implemented, who have confronted and overcome the barriers to this implementation (refs 10,11,12, 13). In brief, the major barriers have been:

- changing outdated clinical attitudes to families as the cause of mental illness
- implementing better methods of case-load management
- finding resources, both in terms of funding and in terms of management support, culture change carriers and the time needed in the beginning to implement the change process
- finding ways to ensure sustainability; this has happened primarily through ongoing clinical supervision to build confidence and expertise.

Working with families provides an excellent opportunity for incentive-based learning. Again the literature reports that staff find intrinsic rewards in the work itself because they are 'thanked' by families, rather than having to cope with families that are angry, frustrated, and therefore seen as difficult and 'dysfunctional.' Less burn-out, less absenteeism, and fewer resignations have

also been reported. Including the family is much more satisfying in that families are now 'allies', and not 'enemies.' Clinicians find many of the problems they work with (worrying about issues to do with confidentiality is the classical problem) disappear when families are part of the treatment and care team. Cost effectiveness of these interventions has been reported in several cases, including in Australia (ref 14). There is good coverage of many aspects of family work in a recent book (ref 15).

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