'People who have experience of using the system and who have done some thinking about this and know other people using the system can offer sensible advice about how to make it better. It's about being experts by experience.'

Executive Summary and Recommendations

This research explores the achievements and struggles of the mental health consumer movement across Australia in order to inform the development of consumer activities in one state, Tasmania. Using information collated from a literature review and one-to-one interviews with over 70 consumers and other stakeholders it maps consumer initiatives and activities nationally, describes the key themes and issues mental health consumers face both in Australia and overseas and presents some options for Tasmania.

The research demonstrates that both nationally and internationally the mental health consumer movement can claim a number of successes. Its two key aims – to transform mental health provision into a recovery-orientated service which is about wellness rather than illness and to ensure consumer participation is an accepted and routine part of service delivery and evaluation, policy and planning – are now accepted goals for those making decisions about mental health services. In Australia a recovery focus has become a cornerstone of mental health policy and mental health services are required to promote the participation of consumers at all levels. Twenty years ago consumers were excluded, their experiences of services were not valued and they were not involved in debate. Today the consumer movement is established, accepted and seen as being a good thing.

Across Australia the research found a complex jigsaw of consumer activities and participation mechanisms. These range from small consumer support and self-help groups and involvement in decisions about treatment through to developing a paid consumer workforce, consumer advocacy organisations and consumer-run services. The report identifies two major strategies: working within the system to promote cultural change and working outside the system in independent consumer organisations to advocate for systemic change and to role model alternative services. Each jurisdiction is different but most have witnessed a burgeoning of consumer initiatives on the ground accompanied by a push to develop state wide and national consumer run peaks and a consumer workforce. Victoria in particular is identified as demonstrating a positive model of mental health consumer involvement in public mental health services and in sustaining an independent consumer-run peak body.

However, the research also found that for many consumers and other stakeholders the consumer movement has not reached its full potential. Participation and advocacy activities are patchy, funding and resourcing are often inadequate and consumer run organisations and services struggle to survive. In many places there has been a failure to translate support for consumer initiatives and participation mechanisms into the financial resources and the capacity building required to make them work effectively. Some of the key issues for the movement identified in the literature review are about how best to promote a recovery agenda so that it becomes a reality for mental health consumers and how to progress the cultural change necessary to remove the barriers to effective participation in clinical services. There are also issues about the most effective way to develop a consumer workforce, the pros and cons of working with carers, the meaning of consumer leadership and representation and the establishment and sustainability of consumer-run organisations.

These issues are reflected in Tasmania where, despite having active and influential consumers, there have been low levels of consumer activity. The state now lags behind other jurisdictions. The main mechanism for consumer and carer participation has been TASCAG – an independent ministerial

advisory committee on mental health. In addition there have been two key consumer initiatives – a consumer consultancy project which began to develop a consumer workforce in the south of the state and the Tasmanian Mental Health Consumer Network which, for the past three years, has performed an important role in advocating for system improvement and improved community attitudes and worked to strengthen the mental health consumer community. There has also been a growth in small consumer support and self-help groups across the state. Nevertheless, despite these developments Tasmania's small and dispersed population and a lack of financial and other resources have mitigated against state wide consumer activity and involvement and raised concerns about the sustainability of consumer-run initiatives. This has resulted in an on-going debate about how best to promote the consumer voice so that it informs policy, planning and service delivery. It has also resulted in an acknowledgement that there are no easy solutions and that there are different perspectives about how these issues should be addressed.

The research clearly demonstrates that the difficulties faced by Tasmanian consumers are not unique, that many mental health consumers and indeed many community organisations and movements have shared these struggles and that, although there is no 'road map', there are valuable lessons to be learnt from experiences in other jurisdictions and internationally. The research makes three major recommendations in order to improve the situation in Tasmania. It recommends the establishment of an independent and sustainable consumer-run organisation, the building of a consumer workforce and the creation of an appropriate supporting infrastructure.

Recommendations

Recommendation 1: That the Department of Health and Human Services provide funding to establish a state wide mental health consumer run organisation in Tasmania.

Recommendation 2: That the Department of Health and Human Services support and facilitate the development of a consumer workforce in Tasmania in collaboration with mental health consumers.

Recommendation 3: That the Department of Health and Human Services use funding already allocated

through the *Bridging the Gap* report to immediately recruit three regional consumer liaison workers to oversee the implementation of participation mechanisms and to build the capacity of consumers and carers to participate and of mental health providers to facilitate that participation.

Recommendation 4: That both public mental health services and those operated by CSOs implement positive discrimination practices in recruitment to mental health programs towards those with a lived experience of mental health problems.

Recommendation 5: That the Department of Health and Human Services provide opportunities for the training of consumers in order to build the capacity of the consumer movement.

Recommendation 6: That the Department of Health and Human Services make the consumer perspective intrinsic to all aspects of the education and training of the mental health service workforce through using consumer educators.

Recommendation 7: That the University of Tasmania through the Pro Vice Chancellor, Centre for the Advancement of Learning and Teaching, ensures that the consumer perspective and the use of consumer educators is embedded in teaching related to mental health issues.

Recommendation 8: That the Department of Health and Human Services sponsor a dedicated mental health consumer research fellowship at the University of Tasmania.

Recommendation 9: That the Department of Health and Human Services ensure mechanisms are available to develop and nurture consumer support and self-help groups across the state.

Recommendation 10: That the Department of Health and Human Services strengthen consumer engagement with Tasmania's health and human service system by establishing a peak body to represent consumers and the community, to support engagement activities and to strengthen consumer networks and organisations.

Recommendation 11: That the Social Inclusion Commissioner advise the Premier to direct the Tasmanian Government's Social Inclusion Unit to explore the civic participation of marginalised groups as a goal of the Tasmanian Social Inclusion Strategy.

Recommendation 12: That the Department of Health and Human Services ensure that performance indicators and outcome measures are developed and monitored for any consumer participation mechanisms or consumer initiatives in both public mental health services and in CSO provision and that this is undertaken in partnership with consumers and carers.

Recommendation 13: That the Department of Health and Human Services ensure that a requirement to involve consumers and/or to employ consumer workers is built into the contractual requirements for CSOs providing mental health services.

Recommendation 14: That CSOs delivering mental health services ensure that the existence of consumer engagement mechanisms are a key quality indictor in their organisation.

1. Introduction

1.1 Background

People with mental illness have battled for the past two decades to have their voice heard and their experiences used to drive reform of the mental health system. As a result consumer participation in mental health services has now been championed internationally for well over ten years and in many countries, including Australia, it has become the cornerstone of mental health policy (Steward et al. 2008). Consumer[1] activities are seen as highly beneficial in offering opportunities to improve mental health services, tackle negative community attitudes, promote a better quality of life for consumers and assist in the recovery process. Indeed some would say that consumer activities are the key to transforming mental health services into a recovery-orientated service where wellness rather than responding solely to illness becomes the goal.

These perceived benefits have been endorsed in the Australian National Mental Health Strategy and there is now a clear requirement that mental health services should encourage the participation of consumers in the development, implementation, delivery and evaluation of services (Happell 2006). This has resulted in a range of activities from active participation at the micro level of individual decision making about treatment to more macro level involvement in service planning, evaluation, training and research. At one end of this spectrum are consumer driven and controlled advocacy services which offer leadership by and with people who share the experience of what it means to be a consumer. A number of jurisdictions in Australia now have independent mental health consumer organisations which are managed and governed by consumers and which oversee the development

of the mental health consumer community. At the other end of the spectrum are participation activities, controlled by non-consumer stakeholders, where opportunities are made available for consumers to become involved in areas ranging from individual treatment plans through to decisions about policy and services. One manifestation of this is the employment of consumer consultants within mental health services to provide a consumer perspective.

Yet despite this significant political encouragement in reality consumer participation and advocacy in mental health services remains patchy, limited and under-funded. These difficulties are not exclusive to Australia but are global where there are concerns that mental health consumer involvement has not developed to its full potential. A recent Australian Senate inquiry (Standing Committee on Community Affairs 2008) highlighted the lack of priority given to the consumer voice in formulating policy and implementing programs. The inquiry emphasised that, despite hundreds of initiatives and projects across Australia, support for consumer advocacy, training, peer support and consumer-run services had yet to translate into resources and the capacity building required to assist consumers in these roles.

Compared to the rest of Australia Tasmania has seen lower levels of consumer activity and, despite a number of active and influential consumers, the consumer movement has struggled to make an impact. Some of the work has been undertaken in an embryonic form by the Tasmanian Mental Health Consumer Network, an organisation of consumers, for consumers. However, despite the existence of the Network and the formulation of a Consumer and Carer Participation Framework (DHHS 2006), there remains a dearth of activity and an ongoing debate about how best

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1. Unless otherwise stated the term 'consumer' will be used throughout this report to mean consumers of mental health services.

to ensure that the consumer perspective is integrated into service development and delivery across the state.

This report contributes to that debate by examining the spectrum of consumer initiatives and experience both nationally and internationally, and exploring what lessons can be learnt for developing consumer initiatives in Tasmania.

1.2 Definitions

The terms consumer, consumer movement, consumer community, consumer participation and consumer advocacy are complex and multi-dimensional and require some clarity.

In Australia the most common term for someone who has used, is using or might use mental health services (and other health and human services) is a **consumer** (McInerney 2008). In some contexts it can be used to refer to both consumers and carers of those with mental illness. However in this report it refers solely to users of mental health services, not to carers. It is a useful term because it can be aligned with the wider consumer rights movement and accompanying expectations around rights and protection, being treated with respect and dignity, having regulations and standards and having an entitlement to redress for misrepresentation and poor quality services. However some question the use of a word which suggests choice and purchasing power and has connotations about taking rather than giving. For these reasons the terms service user, survivor, or patient/ex-patient are used in other countries. Advocates of the term survivor in the USA and some parts of Europe believe that it portrays a positive image of those who have had the strength to survive the mental health system.

The **mental health consumer movement**, also known as the user or survivor movement, is a diverse association of individuals and organisations, small local groups and national networks which campaigns for improved services and consumer-led alternatives. It developed during the 1970s and 1980s alongside the women's movement, disability movement and gay rights movement and internationally its catchphrase, like the disability movement, is 'nothing about us without us'. Some parts of the movement are anti-psychiatry so their objectives are to empower individuals through mutual support and create alternatives to the mental health service system. Others align themselves with the civil rights movement

and emphasise a role in lobbying for the right to be part of decision making processes. This results in activities initiated by organisations or citizens to promote the right to participate. The largest part of the movement is consumerist and would like to influence the mental health system by getting inside it through consumer participation and involvement mechanisms, on boards and advisory committees or by obtaining employment in the system. Some consumers question whether the movement has become stronger in recent years or whether it has lost its focus and been pulled too much towards the agenda of service providers. However, both nationally and internationally, there is a general agreement that there are a growing number of consumer groups involved in a diverse range of activities and that consumers are increasingly working with professionals.

The term **consumer community** is problematic when applied to what is a heterogeneous and diverse population. Firstly, unlike other illnesses like cancer, there is not necessarily a solidarity between consumers who may not have much in common apart from difficulties in accessing appropriate services. For instance, someone with depression may hold the same prejudices as the general population about psychosis or personality disorder. There can also be tensions between well and ill consumers where judgements are made about whether people are sick or debilitated enough to be called consumers. There are those who use the public mental health system and those who use private services, those who use hospital services and those who have only used community-based services. This makes setting up structures to work across the mental illness community problematic. Secondly, there are many more people with mental illness than those who have contact with the service system and some may not even be seeking services. Almost two thirds of those with mental illness (ABS 2008) do not see a professional and some may rely entirely on their family or self help groups. This raises the issue of how to engage people with mental illness who do not access services. The vast majority of consumers remain unorganised and unconnected which presents a major challenge to the consumer movement as well as an opportunity.

Consumer participation can mean different things to different people which has led to confusion. It is variously defined as either voluntary or paid participation by consumers in all aspects of mental health care in order to improve the quality of services. This includes involvement in individual treatment

plans through to local, regional and state planning and policy decision making. Types of participation or engagement have been represented as a ladder or hierarchy moving towards an ideal goal of full engagement. More recently engagement has been described as a continuum offering sets of choices for policy makers (Health Canada 2000) and shaped by the policy problem and the resources available.

Consumer advocacy is the mechanism used to empower consumers and provide a consumer voice. There are several different types (Meagher 2002a) ranging from self advocacy where an individual or a group speaks for itself, individual advocacy where an advocate represents the perspective of an individual through to system advocacy where advocacy activities are directed towards the systems and structures which create injustice and inequity.

1.3 The Prevalence of Mental Health Problems

There are problems in estimating the number of people with mental illness (Cameron & Flanagan 2004) particularly as many people do not access mental health services.

The latest estimates come from the National Survey of Mental Health and Wellbeing (ABS 2008). They show that one in five Australians aged 16-85 had a mental disorder in 2007 and almost half or 45% will have a mental disorder at some point in their life. At any one time serious mental illness affects 3% of the adult population and a further 17% will experience problems in the next 12 months. Anxiety disorders like post-traumatic stress disorder and panic disorder are the most common and affect 14% of people. Affective disorders like depression affect 6%. However only two out of every five Australians with a mental health problem access services. This means that the mental health community in Tasmania consists of approximately 60,000 people experiencing mild, moderate and severe disorders but with only about 24,000 people in touch with a mental health professional.

1.4 National Policy Framework

Since 1992 consumer (and carer) participation in mental health service development and delivery has been embedded in Australian policy frameworks at both a

federal and state level. These policy frameworks are:

- **1991 Mental Health: statement of rights and responsibilities** (NMHS 1991). This aimed to ensure that consumers, carers, advocates, service providers and the community were aware of their rights and responsibilities and confident in exercising them. It followed the adoption of the United Nations principles for the protection of persons with mental illness (United Nations 1991) and included the right of consumers to live in the community and contribute to and participate as far as possible in the development of mental health policy, the provision of mental health care and the representation of mental health consumer interests.

- Three **National Mental Health Plans**. The first Plan (Australian Health Ministers 1992) officially recognised consumers as having a vital role in the mental health services system and that consumer and carer input is essential if improvements in service delivery are to be achieved. This commitment was operationalised at national and state levels by establishing a committee of consumers and carers – the National Community Advisory Group on Mental Health (NCAGMH) and state and territory based CAGs. The Second National Mental Health Plan (Australian Health Ministers 1998) reinforced this commitment. However by the third Plan (Australian Health Ministers 2003), although consumer and carer participation at all levels in policy, planning and treatment was identified as 'the hallmark of a quality mental health system', the Plan also stated that 'participation in service planning and delivery across the spectrum of care from promotion and prevention to recovery has not yet been achieved' (p. 24). A fourth plan is currently being drafted.

- In 1997 the **National Standards for Mental Health Services** (Australian Health Ministers 1997) were published as the key mechanism for assuring quality in mental health services and with a commitment from all jurisdictions to implement them. The Standards include the requirement for mental health services to have policies and procedures relating to consumer and carer participation and to maximise their roles and involvement. Implementation involves in-depth review of services against the standards by an external accreditation body.

The **National Practice Standards for the Mental Health Workforce (**NMHETAG 2002) were published in 2002. These Standards specify how services should involve consumers as active participants in their own care and in planning and evaluation and one of their key underpinning principles is that mental health professionals should be educated by consumers.

- The **2006-2011 Council of Australian Governments National Action Plan on Mental Health** (COAG 2006) aimed to deliver a more seamless and connected care system. However, the Plan has been criticised for being a list of initiatives and programs rather than a vision for the future and for a lack of clarity about how it fits with the National Mental Health Plan. It is also criticised for not addressing how participation in state and service policy development and delivery should be addressed and for not prioritising a consumer and carer focus.

- **Participation policy frameworks across health and human services** parallel developments in the mental health sector and aim to place health consumers at the centre of health policy. A recent report (McInerney 2008) outlines some of these initiatives. The Australian Institute of Health Policy Studies is investigating current practice and developing new models for engagement in health policy. The Victorian Department of Human Services has produced a number of documents to promote participation as an essential principle of health development, community capacity building and development of social capital. The Australian Commission on Safety and Quality in Health Care is consulting on the development of a consumer engagement strategy and the Consumers' Health Forum of Australia is working to involve consumers in health policy at a national level.

- The recently established national **social inclusion agenda** is also pushing for meaningful participation for people with mental health problems. Social inclusion is seen as an essential component of recovery which should be fostered through ensuring consumers, their families and carers have ongoing input into service delivery and planning. In addition they should have access to services tailored to individual needs and practical assistance with reintegration and there should be an increasing awareness

of and a reduction in stigma in the community. In the UK consumers are beginning to articulate a model of social inclusion which does not mean fitting in and passing as normal but is about including the experience of madness as part of the social spectrum and recognising its positive aspects as well as the pain involved (Sayce 2000).

The **National Mental Health Reports** which monitor progress in mental health reform under the National Plans have identified that there have been substantial gains in consumer participation. The 2005 report (DoHA 2005) showed that the proportion of mental health organisations with a formal mechanism for consumer participation had increased from 53% in 1994 to 82% in 2003. Yet this also meant that 18% of mental health service organisations lacked a basic structural agreement for consumer and carer participation. It also found that the total expenditure on consumer and carer consultants was only a fraction of spending on wages in the mental health sector. The 2007 report (DoHA 2007) provided a summary of twelve years of reform in mental health services. It showed that there are pockets of good practice including an acceptance that consumer representatives should be remunerated and also included in all national planning groups. But progress has been uneven across jurisdictions and there is also an acknowledgement that there is a long way to go before satisfactory levels of consumer and carer participation are achieved. There is also confusion about how to transform theories of engagement into successful practice (McInerney 2008).

An inquiry into mental health services in Australia (Standing Committee on Community Affairs 2008) recommended that the Australian Government strengthen mental health consumer representation through funding consumer run organisations to provide independent advocacy at state, territory and Commonwealth levels. In particular it highlighted that awareness of the importance of consumer participation was not matched by funding and support to actually facilitate such involvement and that there were very few opportunities for consumers to develop the skills to be effective advocates.

1.5 Aims of the Research

This research aimed to formulate an evidence based model of effective consumer activity in order to progress the development

of the mental health consumer community in Tasmania. More specifically it aimed to piece together the complex tapestry of consumer activities and initiatives across Australia and internationally, explore how this jigsaw fits together and draw out the lessons for development in Tasmania. It entailed:

- conducting a literature search of interstate and overseas models of mental health consumer community development;

- conducting a broad based consultation with mental health consumers and other stakeholders across Australia and internationally; and

- outlining possibilities for the development of models of mental health consumer community development for Tasmania.

The research was initiated by the Tasmanian Mental Health Consumer Network (TMHCN) and undertaken by the Social Action and Research Centre (SARC) at Anglicare Tasmania in partnership with the TMHCN. The work took place over a six month period between October 2008 and April 2009. It was not anticipated that the research would provide all the answers but that it would offer guidance for developments to be pursued by both mental health consumers and providers.

1.6 Research Methods

Globally there is a wealth of information and experience about mental health consumer activities and a growing literature. The research was designed to be able to draw on these experiences, on the successes and failures and on the lessons that can be learnt from them to inform developments in Tasmania. To this end the research proceeded in three stages:

- **collation of literature and documentation** locally, nationally and internationally about developing mental health consumer communities. This entailed conducting a step-by-step search for material on mental health consumer activities and participation through the internet and a range of other information sources including libraries, databases, government documents, conference proceedings and the 'grey' literature produced by organisations but not necessarily formally published.

- **interviews with key informants** in Tasmania, other states and territories and overseas to explore experiences of developing the mental health consumer community and map both consumer engagement processes and consumer run initiatives. Key informants were identified using a snow-balling approach whereby interviewees were asked to nominate further useful contacts. This ensured that the researcher was able to speak with key figures in each jurisdiction and tap into a range of perspectives.

In order to collect information in a systematic way interviews were conducted using a semi-structured interview schedule covering the history of consumer development, successes and pitfalls, the current situation and future directions. Although some interviews were conducted face-to-face the majority were carried out on the telephone and took between twenty minutes to one hour. They included:
  - 7 interviews with informants generally recognised as consumer leaders in New Zealand, the UK and Canada;
  - 42 interviews with consumer leaders, consumer workers and other stakeholders with an interest in promoting consumer activity across Australia; and
  - 26 interviews with consumer leaders and other interested stakeholders in Tasmania. This included an open invitation to active and ex-active TMHCN members to participate. Where appropriate, remuneration was offered to mental health consumers for their participation in the research.

Some of the early telephone interviews were taped and transcribed. Subsequently comprehensive and often verbatim notes were taken and quotes from the interviews have been used to illustrate the text of the report.

- **engagement in concurrent development processes**. This entailed participant observation at consultation events and activities. It also entailed setting up communication mechanisms with development processes so that they were able to inform this research.

The research was guided by a research reference group with a fifty percent mental health consumer membership as well as representatives from Mental Health Services, mental health provider organisations and the Tasmanian Council of Social

Service (TasCOSS). Consumers included both those involved in the TMHCN and non-TMHCN consumers. The reference group met four times during the course of the research.

The TMHCN produced the original research proposal and assisted the project by making literature and TMHCN documentation available and by identifying some of the key informants.

1.7 Limitations of the Research

There were some factors which limited the extent of this research. Firstly the research took place at the same time as other consultation and development processes. These were:

- a statewide review of mental health consumer and carer participation led by Mental Health Services. This entailed a consultation process with consumers, carers, families, providers and other stakeholders through public consultations, consumer focus groups, a questionnaire survey and individual submissions; and
- the Consumer Organisation Project (see page 63) which entailed a number of TMHCN-run development forums to develop a business plan for a new Tasmanian consumer organisation and the formation of a small coordination team to drive the project forwards.

Given this environment there was a high risk of 'consultation fatigue' and it was imperative to make every effort to collaborate with, rather than duplicate, other consultation exercises. To this end the researcher attended the TMHCN and review consultation forums as well as establishing boundaries and information exchange mechanisms with the Review process. This included inputting some questions particularly relevant to consumer-run activity into the consultation process and the presence of the lead officer on the research reference group. It was also determined that this research should focus specifically on consumer-run activities rather than exploring the full consumer participation spectrum.

Secondly, the fact that the TMHCN was a partner in the research meant that the starting point for the research was not a neutral one. This meant that every attempt was made to consult with a wide range of informants to ensure a balanced and objective view.

Thirdly, it was not the purpose of the literature review to comprehensively describe all the literature relating to the consumer movement and participation activities. Rather emphasis was given to identifying relevant discussions and examples of activity which could help inform future developments in Tasmania. So although the research draws upon a range of information sources and published material it is not a definitive summary.

Fourthly, despite high levels of activity where consumers are actively engaged with contributing to service development the documentation of this activity can be poor. This means some reliance on oral testimonies from a small number of informants and on the judgement of the researcher to gauge the accuracy and reliability of sources and to construct some sense of historical developments and current realities. As a consequence there may be some gaps in illustrating the breadth and depth, impact and outcome of consumer developments in particular jurisdictions. However, the research has been able to reflect the major initiatives, themes and developments in the consumer world.

Lastly, this is a snapshot picture at one point in time. In a sector where resources are tight but where there is significant pressure at a policy level to promote development, activities and initiatives can change rapidly. This should be taken into account in using the information in this report.

2. The Consumer Movement: Themes and Issues

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This chapter combines an overview of the literature about the consumer movement and consumer participation activities with first hand accounts of key informants to create a picture of the major issues facing mental health consumers in their efforts to engage in the planning and delivery of mental health services and of services in trying to facilitate such engagement. It outlines what both existing research and consumer leaders themselves tell us about effective strategies and where developments and energies might be leading in the future.

Consumer involvement can be initiated by mental health services or by consumers with the former being the most common and where consumers are expected to contribute in a way which fits with bureaucratic boundaries (Gregory 2007). This chapter looks at the issues faced in developing consumer involvement mechanisms from both within and outside the mental health system. It covers the underlying theme of recovery as an organising principle for mental health reform and the drive towards consumer participation across the mental health sector including the issues of representation and leadership. It discusses particular strategies for consumer activity and involvement including consumer workers, consumers as educators and researchers, consumer organisations and working with carers. Finally it explores the literature on the effectiveness of consumer initiatives and participation mechanisms in influencing mental health provision.

2.1 Recovery

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Until relatively recently it was assumed that most individuals with severe mental illness would never be well again (Kruger 2000). However a recovery focus in all mental health services has now become a cornerstone of Australian mental health policy (Rickwood 2004) and one of the key organising principles for services internationally. The National Mental Health Plan 2003-2008 states that 'a recovery orientation should drive service delivery' (Australian Health Ministers 2003, p.11). The concept emerged from the consumer movement and has increasingly informed policy and service development. It identifies that the purpose of services should be recovery and self determination and that adopting these values profoundly changes the way people think about madness and mental health and requires a radical transformation of mental health services.

Recovery is defined in terms of outcomes: for example the ability to lead a satisfying life despite illness or symptoms. It does not necessarily mean a cure or clinical recovery but rather is about 'living well in the presence or absence of one's mental illness' (O'Hagan 2004). A paper providing an overview of the recovery literature (Casey 2008) identifies that it is underpinned by notions of hope and healing, positive identity, taking responsibility and control and choice and is a process or a journey which the individual undertakes. It is closely linked to the principles of consumer participation and empowerment where active consumers provide evidence to clinical workers that recovery is possible and are involved in decision making at all levels.

However, there are questions about how a recovery focus should be put into practice within services (Shepherd et al. 2008). Some research has been done to identify the perceptions of both case managers and of consumers about the key factors which contribute to recovery. The research identified these factors as collaborative treatment planning, strength based approaches, knowledge and acceptance, appropriate medication, spirituality and holistic support and the self monitoring of symptoms (Ellis & King 2003). Many of these

factors are now enshrined in policy and planning statements. Others have identified non-compulsory services, wide availability of talking therapies, consumer orientated outcome measures and an independent national agency to monitor quality (MHAC 2008) as being key to a recovery orientated service. Yet there are concerns about how far these ideals are reflected in workers' actual practice. Although services are increasingly defining and implementing specific strategies to support recovery this process can be impeded by scepticism and a lack of understanding about which factors impact on recovery. This means it is far from being standard practice in services. Worldwide there are now a number of initiatives to develop recovery competency frameworks for mental health workers in order to embed these skills into services.

At the same time concerns have also been expressed that recovery has been 'colonised' and diluted by professionals and managers so that services now say they are doing it but in reality they are not (O'Hagan 2004, Wellesley Institute 2009). It is also being used to support other policy agendas. For example, one informant in the UK suggested that recovery was being used to support welfare to work initiatives:

> *Recovery is getting a bad name. We never managed to establish it as a service user concept in England. It was coming from America, Australia and New Zealand and was not a home grown concept. The government are now trying to use the term recovery to get people back into work in a punitive sense, to prevent people being out of the workforce too long. This is received with great suspicion by people who have been long term unemployed for mental health reasons. They are worried they will have their benefits taken away. So there is now a suspicion about the idea of recovery happening. (Consumer leader, UK)*

2.2 Consumer Participation

There is a large body of literature about consumer participation both as it relates to mental health services and more broadly about methods of consumer engagement across the health and human services sector. This literature covers the rationale

for facilitating consumer involvement, definitions of what it is and what it should encompass, models of effective practice, its impact and outcomes and the barriers and obstacles. This has generated a number of 'how to do it' guides.

Essentially mental health consumer involvement is about the ways and means of creating a partnership between consumers and providers to improve the quality of care and outcomes for consumers and to provide a mechanism to ensure accountability and recovery orientated services (Meagher 2002a). Using the 'lived experience' of consumers is increasingly accepted as making a unique contribution to improving care and outcomes through modelling recovery, instilling hope and providing support and practical help (Doughty & Samson 2005). It can be seen as a democratic right, as a vehicle for positive systems change, and as a new way of doing things which offers a different perspective, insights into mental distress and alternative approaches. Participation by consumers in mental health services can be seen as even more crucial than in other health fields in order to counteract the reduction in civil rights experienced by those deemed legally incompetent to make decisions about their own health and who are treated involuntarily (Roper 2003).

It is however still a challenge to define what is meant by involvement and what it would look like if it had been achieved. Nevertheless there is a consensus that when consumers are trained, paid and valued for their skills and expertise, have an active role in hospitals, community services and community service organisations (CSOs), have their ideas for change seriously considered and are involved in decision making structures the goal will have been reached. UK Mind[2] (Mind 2009) states that consumer involvement means:

- equal citizenship;
- dignity and respect in mental health services;
- full information on treatment and rights;
- involvement in treatment and care;
- independent advocacy in every area;
- broad participation through equal opportunities in employment and service delivery practices;
- involvement in planning, running and evaluating services;
- policies to ensure it is safe to get involved;
- the training of workers by consumers; and

2 UK Mind is a leading mental health charity in England and Wales which aims to influence policy, challenge discrimination and promote the development of quality services and inclusion.

- practical commitment and resources for consumer involvement.

In practical terms consumer participation in mental health services operates at four different levels (DHHS 2006); at the personal level through involvement in care and treatment plans, the level of local services, the level of policy and the service system and the government level to improve provision state wide and nationally. At each level there are a range of mechanisms to facilitate involvement ranging from information provision and one-off consultations, opinion polls and questionnaires through to consumer representation on decision making bodies. Indeed in some jurisdictions the mental health system now routinely has consumers as salaried staff, consultants on policy, researchers and management committee members. This means that the lived experience is now operating at many levels from active participation in treatment upwards (Gregory 2007) and that consumers can be engaged in different ways to suit their level of interest. This spectrum of involvement has been described as a ladder of power sharing where at the highest level consumers are sharing decision making responsibility with policy makers. It is conceived as embracing three distinct conceptions of consumer involvement – as recipients, subjects of consultation and agents in control (Peck et al. 2002). To date activities, certainly in Australia but also globally, have focused on consultation rather than influence, partnership or control and there remains a general lack of genuine opportunities to participate at both a treatment level and in the broader system. Consumers have also raised concerns that although consumer participation in service planning and delivery attracts more attention one of the most useful ways to implement it is for consumers to be involved in the development of their own treatment plans and respected for their illness, their knowledge and their lived experience (Pinches 2003).

Three of the most common models of participation (Kroschel 2002, 2005) have been identified as:

- representatives on committees;
- involvement in short term projects without the establishment of a consumer participation infrastructure; and
- consumer groups developed through mental health service support.

The first is the most widespread and supported by national and state strategies. It is one of the easiest to implement which makes it the most feasible in terms of gaining the support of providers. However, it is also service controlled. The last model is, for many consumers, the most sustainable and productive model and allows consumers to set their own participation agenda. However, there is also a consensus that diversity is required:

....

Consumers need several different avenues in order to tell their story, open groups where they can come and go when they feel well enough to engage and give their opinion, opportunities at service level and strategic levels to engage. The idea that one group, diverse and experienced as it may be can be the one point of reference is just not broad enough to realistically give a picture of what's happening in mental health. They might be the point of engagement around particular things but you would need to engage in a broader and more open strategy. (Consumer leader, SA)

....

2.2.1 Community service organisations (CSOs)

Much of the literature about models of consumer participation focuses on public mental health services. However, CSOs have an increasing role in the delivery of mental health services and this is likely to expand as more services are contracted out. Although there may be an assumption that because they work at ground level and may have a history of being led by consumers and/or carers they are consumer aware and clear about consumer rights and participation mechanisms this is not necessarily the case. Yet the research did find many examples of good practice in CSOs where consumers held positions on boards and committees, where quality frameworks were designed to be inclusive of the lived experience and where there were initiatives to develop consumer worker roles and peer education. Informants reported a growing awareness of the need to have well developed roles, policies and mechanisms for consumers to participate in supported accommodation and day programs. As one informant said:

Some NGOs have really embraced consumer involvement and built it fundamentally into their core principles of operation. They offer ground breaking models of how to reengineer and redesign services to authentically take into account the consumer perspective and involvement. (Stakeholder, WA)

In one jurisdiction the peak body for the mental health non-government sector has developed a consumer caucus to promote involvement in strategic decision making:

When the Mental Health Coalition formed it established a consumer and carer caucus which was more than a consumer advisory body. It was a link to our Board of Management. The caucus nominates two consumers and two carers to sit on the Board and to raise the profile of issues with policy and service development. It really gives the potential for consumers to be involved in the organisation's policy development and other program areas. This is a unique model for any peak body in Australia but it does require ongoing attention and support. (Stakeholder, ACT)

Despite significant levels of consumer activity in CSOs these models have not been reviewed and are rarely evaluated.

2.2.2 Barriers to consumer participation

Whatever model of participation is being used and whatever the rhetoric in policy and practice frameworks good practice consumer involvement in mental health is still essentially a minority activity (Tait & Lester 2005) and a range of obstacles are encountered which have been well documented in the literature nationally and internationally. The key barriers are:

- **lack of commitment to adequate resourcing** where consumer views are regarded as the icing on the cake rather than the cake itself and there is little practical support for consumers in terms of remuneration, training and welcoming environments (Bertram 2002). This is seen as the key reason for failure; for example when consumer participation is named up as a 'money neutral priority'.

- **negative stereotyping of consumers** as incompetent, unreasonable and illogical, uninformed and potentially violent and where their views are considered to be a reflection of their psychopathology (Meagher 2002a).

- **professional attitudes and resistance** where people are understood according to their symptoms, where there is a lack of awareness about what can be gained from the consumer perspective and where experiences are seen as personal stories rather than having wider implications (Edan 2006).

- **a gap** between the requirement for participation at the political level and the lack of mandates on how processes or mechanisms should be facilitated. This leaves too much room for local interpretation and results in the absence of systemic approaches to facilitate participation.

- **developing a consistent response across a diffuse sector.** There are questions about how to promote consumer participation across a diverse sector which encompasses public and private services, GPs working autonomously and CSOs providing a range of community services.

- **lack of consumer confidence** where consumers suffer from self-doubt and a lack of faith in their ability to exert control or represent others and have difficulties in 'coming out' and taking on the risks of personal exposure.

- **professional control of participation structures** which are geared in favour of full time professionals. This can result in tokenism when there is little infrastructure to facilitate involvement, no training or support and no real transference of power.

- **conflicts within the consumer movement** which impairs the ability to present a united voice. Some consumers have described a crisis of integrity and ethics in the movement (Meagher 2002b).

These barriers mean that although consumers may be involved in the system and working in mental health settings their involvement is marginal because the status quo has not been challenged. Some have described a backlash

from professionals with consumer competence being challenged when participation gets close to the area of treatment which is traditionally the unquestioned domain of professionals (Roper 2003). As one consumer said:

> *Sometimes we are just there as tokens. That's the feeling. Consumer reps are there and consumer consultants just so they can tick a box to say they've had consumer representation. That's why a lot of positions aren't paid and you only get paid travel sometimes or you don't get sitting fees. The leader of the mental health team said we can't have consumers on the Board because they don't understand how we work. My reaction is we don't have to. All we have to do is be an expert in our area which is being a consumer. If they wanted financial advice they wouldn't expect a worker to know how they ran their budget, it would be an expert on finance. (Consumer leader, SA)*

Another consumer described how this had manifested as political correctness where a T-shirt designed by consumers and with the logo 'batty is beautiful' had been censored by professionals for reinforcing negative stereotypes (Happell 2008).

To overcome these barriers requires action to change cultures and attitudes, reverse low expectations, deal with the practical aspects and embark on education, training and awareness-raising.

2.3 The Consumer Workforce

There are increasing opportunities for those with 'lived experience' to go back into the mental health system as paid consumer workers performing a variety of roles. The three main roles are as:

- paid consumer consultants or advisors engaged in systemic advocacy work;
- paid peer support workers providing support, befriending, role modelling and hope for recovery to both consumers and the mental health workforce; and
- consumer representatives participating in advisory and decision making forums and paid sitting fees.

These roles can be established and integrated within traditional mental health services, in CSOs or in consumer-run organisations. There are also limited opportunities to work as consumer service auditors and mental health surveyors involved in surveying mental health services under the National Standards.

Internationally the value of consumer roles in mental health services has been widely accepted (Hansen 2003). They are seen as mechanisms for the transformation of mental health services towards a recovery orientation, as a vehicle for cultural change and as providing much needed employment opportunities for people with mental illness who suffer disproportionately from structural exclusion from employment (Bertram 2002). They can facilitate consumer participation activities, enhance the visibility of the consumer voice at both the individual treatment and service delivery end and provide general support and mentoring to other consumers.

In Australia five jurisdictions now employ consumer consultants, some also have paid peer support workers and all use consumer representatives. Many see these workers as an entirely new service located within traditional mental health services and an integral part of developing quality recovery-orientated services. The picture can be confusing because consumer workers are called different things in different places. There are 16 different job titles for employed consumers in Australia alone which means that little can be assumed about the role from the job title.

However research has also documented numerous problems in establishing consumer positions and sustaining them. They have evolved in an ad hoc fashion with an absence of guidelines or clarity about aims and functions and often minimal support and resourcing (Hansen 2003). There is a lack of standard training for consumer workers, confusion about roles, titles and expectations and no development of career pathways (Steward et al. 2008). An analysis of the situation in one jurisdiction (Watson 2007) found confusion between consumer positions and the mental health workforce generally with no recognition of the distinct role of the consumer, no appropriate award structure and no accredited training. In another state consumer consultants employed by area mental health services suffered from low rates of pay, lack of support and training, high workloads and high stress levels. This results in a high

turnover of personnel (Pinches 2004, 2005). They are employed part-time for a few hours a week or month as cheap, unskilled welfare workers and with no industrial protection (Edan 2006) and they are often seen as add-ons to mental health services without the same entitlements as other employees.

> *You are piggy in the middle all the time. You are neither staff nor consumer. Staff won't treat you as staff because you're a consumer. You are isolated and on your own. It's a very, very hard role. We have a workforce who already have a disability and we're asking them to work in a hard and isolated role without much support. We will have a lot of burnout and staff turnover. We have people employed under different awards and there are at least four or five different descriptions of what a consumer worker's role may be in any given area. Also there is no accredited training and it's been highlighted that consumer workers must have a minimal set of standard training before they hit the wards or they will fail, burn out, get sick. They need to be well prepared and know exactly what it is they are doing. Not even the line managers or area directors really know what the consumer worker's job is. There is therefore no real management or guidelines. It seems to be whatever your area health service deems it to be. (Consumer leader, NSW)*

There are also difficulties associated with the blending and overlap of consumer advocacy and peer support roles.

> *The position was supposed to be systems advocacy. Obviously you can't get away from doing a bit of peer support but some positions have turned into nothing but a peer support role. We should be changing the system and identifying the barriers and making a better quality of life for the consumers. The touchy feely peer support stuff is good and it's wanted but that wasn't what consumer consultants were supposed to be doing. Some are going into the units and that's all they're doing, sitting talking to consumers all day long and not doing any advocacy at all. (Consumer leader, Qld)*

The issue of training and qualifications has become paramount and led to debate about formal qualifications, the benefits this brings in terms of improved self esteem, credibility and a reduction in stigma and how qualifications should be balanced with lived experience and skills learnt on the job. In the absence of any accredited training for consumer workers the only option can be to qualify as mental health workers and this can result in role confusion and an impact on wellness (Watson 2007). This picture has been further confused by recommendations from the Mental Health Council of Australia that consumers should be encouraged and assisted to become part of the mental health workforce:

> *There are national recommendations that consumers should be part of the new mental health workforce or substitute workforce but without any proper distinction between a consumer workforce and other workforce issues. People are disappearing from the workforce and we have people with mental illness looking for work and all these vacancies. How can we plug the hole? We put them in as substitute mental health workers. This approach was put forward for an award for best practice in mental health and consumer participation policy is used as the justification. That is a big error. (Consumer leader, NSW).*

This kind of approach has promoted a trend for some consumer workers to become quasi mental health workers but without a clinical caseload. There are concerns that they are in situations where there are two lines of accountability and divided loyalties to service managers and to consumers. This creates difficulties in trying to maintain personal and professional integrity with both groups. As one consumer said:

> *They had become subsumed by the system. They were sitting in on clinical reviews and having access to confidential information without the consent of consumers. The worst violations of rights by consumer workers are the breaches of health privacy rights. (Consumer leader, ACT)*

This of course raises broader questions about how far being employed by the system traps consumer workers in reactive roles rather than being able to set agendas or do systemic advocacy. As one consumer said 'there are difficulties in being an advocate in the service trying to initiate change and also protecting your own job'. Some would like to see consumer workers being employed by consumer-run organisations rather than the mental health sector.

....

> *Most of the consumer workforce don't last more than ten years. They are put in positions to advocate against the people who fund them and there are many conflicts between the expectations and role and ethics of the consumer. It creates difficulties and can leave people in pieces. It happens all over Australia. (Consumer leader, NSW)*

....

> *My biggest wish is that [the consumer organisation] take over running consumer workers with the area health services so they don't get gagged. There have been situations where you report back and you get threatened by staff because you're the whistle blower. If you bat for the consumer it feels you are then biting the hand that feeds you and you think will I have a job next week? (Consumer leader, NSW)*

....

There are questions about how best to support an emerging consumer workforce and ensure that employees are resourced and well paid. Many consumers would like to see clear job descriptions, a common understanding of the role, adequate preparation, ongoing support and supervision and the development of accredited training for workers supported by a code of ethnics and minimum performance standards (Steward et al. 2008). They wanted the consumer workforce seen collectively as a separate discipline – for instance like nursing – with external supervision and mentoring or apprenticeship accompanied by guidelines for employers to reduce inconsistencies and map career pathways. They also wanted to see 'real jobs with real qualifications required and real expectations'. As one consumer said each 25 bed in-patient unit with an attached case management service requires one three day per week consumer consultant at a minimum.

This is certainly happening in New Zealand where peer support and consumer advisor services are run variously by consumers, district health boards and CSOs. A literature review undertaken to inform the development of a consumer workforce within mental health services found that successful services shared a clear philosophy, guidelines to separate peer work from traditional support roles, a good recruitment process, training consistent with the role and an effective supervision structure (Mind & Body Consultants 2008). There is now a push in New Zealand to establish national guidelines for consumer roles, build a culture of acceptance, reduce the stigma and discrimination they face and develop a training framework (Hansen 2003).

In Australia the Department of Health and Ageing (DoHA) has recently initiated a scoping study to look at the formal training available for consumer leaders, peer support workers and consumer consultants and to recognise them more formally as a profession with the mental health sector requiring specialist training. The study aims to explore how to develop a nationally consistent approach to better engage consumers in the mental health workforce, set national standards for consumer workers and develop accredited courses for consumer consultants and peer support workers. There are also moves to formalise and better support consumer representatives. The Consumer Affairs Advisory Council (CAAC 2002) published principles for the appointment of consumer representatives stating that it should be on merit, targeted at those with expertise in consumer affairs and linked to relevant consumer organisations.

....

> *The whole system needs to adjust to having well consumers involved in positions – representative or paid – when they might at any other time be using that system themselves as unwell consumers. Consumer representation provides a mechanism for showing that people can be well enough to participate. As a lot of clinicians only see people when they're crook it's about undoing the fear and stigma. (Consumer advocate, WA)*

....

One of the key functions of developing a consumer workforce is to initiate the cultural change required in services. This can also be promoted by encouraging consumers to become part of the professional mental health workforce through using

positive discrimination and flexible working arrangements in the recruitment of staff to mental health programs. People who have used mental health services and who now hold reasonably paid employment both inspire other consumers and provide evidence to staff of what can be achieved. This challenges the 'them and us' culture and the low expectations held by so many mental health professionals and works to reinforce social inclusion. Work undertaken in the UK (Seebohm & Grove 2006) provided a practical demonstration of how mental health trusts could lead by example in employing mental health consumers in the National Health Service (NHS) workforce while at the same time improving the working lives and job retention for all staff.

2.4 Consumers and Carers

Australia is unusual in having a number of initiatives which involve consumers and carers working together around a common agenda. Elsewhere consumers and carers have remained separate although they might come together to take up particular issues or campaigns. Commonly their agendas are seen as different; for example carers might want access to information or compulsory treatment to keep their relatives safe and ensure access to services while consumers might not want them to have access to information and feel that compulsory treatment severely impacts on their rights as citizens.

Working together in Australia was promoted by the first National Mental Health Plan in the early 1990s when there was a push to establish consumer and carer advisory groups in all jurisdictions. In 2002 the National Mental Health Consumer and Carers Forum was also established to provide a focus for joint work around national issues.

Some jurisdictions have continued to support structures where consumers and carers work together with joint agendas. In some cases this is due to preference while in others it is more a question of feasibility particularly when resources are too tight to be able to build separate structures. Informants described few differences of opinion and mechanisms which allowed separate platforms when required.

If you don't have a group made up of consumers and carers and it's just consumers it tends to fall over. A carer is a consumer of the service and we champion the cause of consumers

so we work in partnership quite well. As long as there are not more carers than consumers it works. If there weren't any carers in my group it would fold. If consumers are doing a lot of work they can put themselves under too much stress. (Carer leader, SA)

We are not advanced enough in our philosophy. Maybe there will be a split sometime in the future but I don't think we have the luxury here and we don't even have the forum for really having that discussion. (Consumer leader, Qld)

Other jurisdictions have maintained separate development. Carers are seen to dominate any mixed group and although sometimes it was mutually beneficial at other times it was seen to be destructive and had led to passionate discussion. As one consumer said 'not having carers involved helps a lot. That's just another extra layer of angst which we don't need'.

We decided that even though we are on the same journey there are some areas that are different, in the same orchard but two different trees. I have met consumers where there are major issues with family that can exacerbate the mental illness. In some other states it's quite successful. Here the carers have gone ahead in leaps and bounds, they are a very professional organisation. I am envious. But it has been difficult to prevent carers making remarks that are offensive to the consumers. (Consumer leader, WA)

In New Zealand there is a basic cry that the primary stakeholder is the consumer because if the consumer wasn't there none of the other stakeholders would exist and the distinction between carers and consumers interests is very well accepted. There is a little more collaboration going on now partly because of the clarity around the differences and because consumers feel in a strong enough position that they won't lose power. But what lies underneath this battle is an assumption of disability and that mental illness will be disabling. To try and

*get consumer initiatives started in a system
still working within this conventional paradigm
is very difficult. (Consumer leader, NZ)*

2.5 Representation and Leadership

A common consumer participation strategy is to foster, support and remunerate consumer representatives to sit in decision making forums and provide a consumer perspective. This raises issues, usually among service providers but also among consumers, of how representative these active and involved consumers are of the broader and diverse mental health community (Happell & Roper 2006). Typically representatives do not represent an organisation or interest group but are unconnected individuals who rely on their own experiences. This means that it can be difficult for them to get beyond their personal view to represent the broader, generalised views of consumers or marginalised groups especially if they have had no training. In addition there is also a view that active consumers or consumer groups are unlikely to represent ordinary consumers. This raises questions about how to collate the broad views of the consumer community while avoiding the risk of sectional interests. These concerns have, as Mind UK[3] identified, led to an endless search for the elusive typical user representative and to questions about who the ordinary consumer is: are they the most incapacitated or those who have been made better by treatment? Suggestions that those who advocate are not typical and therefore not representative is the 'catch 22' of consumer participation where consumer views are welcomed but not from those who are confident enough to give them. These issues are identified at the macro level of consumer participation engaged in systems reform rather than at the micro level of participation in individual treatment plans, where the issue of representation is not relevant as care is individually based (Lloyd & King 2003).

As one consumer said this emphasis on a requirement for representativeness means that instead of the consumer role being about introducing a consumer perspective, someone will always ask who you represent (Meagher 2002a). This is not a question asked of professionals and there is no known process to canvass the views of the broader profession. It means that professionals can make unrealistic

3. See note 2 on page 11

demands but without offering the resources for consumers to develop the capacity to become representative.

Research (Crawford & Rutter 2004) sought to determine how far the views of an established mental health consumer group were representative of the broader community of consumers through comparing the rating given to the importance of specific priorities for service developments. The results were similar although the consumer group placed a higher importance on the priorities generally than other consumers. The research concluded that the assumption that the views of active consumers are out of step with others should be questioned and that in fact it was a discriminatory position which served to silence activism and diminish the importance of what consumers were saying. It also undermined the legitimacy of consumer roles and introduced an inherent contradiction in employing someone to provide a consumer perspective and then dismissing it as sectional or anecdotal.

This search for representativeness in consumer participation activities is leading, particularly in New Zealand, to a move towards the notion of consumer leadership where consumers participate as individual recipients and leaders. As one Australian consumer said:

We are now ditching the term representative completely. It's a stupid term and you can never represent people. It takes you down a dead end. So we are talking about consumer leadership and we are moving on to thinking in quite different ways than what we were thinking ten years ago. (Consumer leader, Victoria)

Our current policy talks about consumer leadership. In New Zealand we got a little bit tired of consumer participation. We felt that was about being invited to someone else's table according to their agenda and culture and roles. We felt if we talked about leadership then we would have our own table or at least a shared table. (Consumer leader, NZ)

A recent literature review and consultation about consumer leadership across the health sector (Victorian Quality Council 2007) found that it is organic and arises from a

community of interest like a consumer organisation or network. Its promotion and development relies on effective consumer participation mechanisms where it can grow and gain sustained support. These mechanisms can include having consumer representatives or consultants at all levels, including at a senior management level, to create an enabling environment and an investment in education, training, mentoring and support. The review outlined key leadership characteristics as having a strategic direction or vision, the ability to energise others and provide a role model, good communication, negotiation and relationship building and conflict resolution skills. The review concluded that the most effective strategies for developing leadership capability in the health system are formal learning, peer support and mentoring programs accompanied by guidelines for supporting consumer leadership in the health system.

Interestingly there is now a move in New Zealand to professionalise the representative role by employing representatives. The question then becomes how professional representatives or consumer leaders keep in touch with the broader constituency of mental health consumers. This points to having solid and credible consultation mechanisms:

Mind and Body Consultants[4] in New Zealand do consumer representation but they have a number of employed consultants which creates a professional body. It is a different model with advantages and disadvantages. Are the representatives actually representative? Being a consultative body really is the key to doing a good job and a legitimate job rather than being representative. The argument then is that the representatives could be a more professionalised group and an employed group as long as the consultative processes are well established and sound. (Consumer leader, ACT)

It requires that consumers are clear about their links to mental health constituencies and proactive in representing disenfranchised groups to ensure a range of consumer views are heard. This requires the development of sophisticated and ongoing consultation mechanisms.

What happens with representative structures is they go to the government and they say, 'you are just the strongest voice and just giving us your agenda. How do you know it's what those other people out there are thinking? We need to develop a survey capacity and you can do that through technology easily via emails and websites. So in order to do advocacy we need to really get them good information and instead of going along with a few ideas from a committee it would be great to have a way of surveying consumer opinion very quickly. (Consumer leader, NZ)

Mad people are not a constituency whose interests can be represented like a political system. It is better to say that people who have experience of using the system and who have done some thinking about this and know other people using the system can offer sensible advice about how to make it better. So it's about being experts by experience rather than representatives by mandate. This is a significant factor in development because it lays the groundwork for people in consumer positions having the same responsibility to be competent and deliver the goods as anyone else. (Consumer leader, NZ)

There are of course real issues about how far consumer participation mechanisms and consumer run organisations deal with diversity. It can be difficult to tap into the views of Aboriginal[5] and culturally and linguistically diverse (CALD) groups, rural populations, older people and young people, all of whom may suffer particular disadvantage and have special issues and needs. For example, experiences of stigma can be compounded in rural environments (McColl 2007) by lack of services, isolation, confidentiality concerns and cultural differences.

In the Chinese community they don't want to discuss mental illness. It's seen as hereditary and will affect marriage prospects and family fortunes. It is not accepted by many circles

4. See page 53 for a description of the work of Mind and Body Consultants.

5 In this document Aboriginal refers to Aboriginal and Torres Strait Islander people.

and they look down on you as crazy. Mental health in many CALD groups is not defined by the consumer but is a family matter and more of a community issue rather than just personal. (Consumer leader, NSW)

Organisations do describe working with a range of agencies and individuals to ensure the views of these groups are heard.

We sit on committees with Aboriginal people and know that if you need some specialist advice you can contact each other. We do have some Indigenous people who are quite involved as reps. When we go to in-patient facilities we see everybody, different ethnic backgrounds, Aboriginals are not exempt from problems. (Consumer leader, Victoria)

2.6 Consumers as Educators, Researchers and Evaluators

A core problem in increasing the involvement of consumers is the stigma and discrimination[6] they face in the mental health system and the professional resistance to involvement activities which is a symptom of that. A major goal of the consumer movement has always been to change staff attitudes using the mantra of 'treat us well and we will get better sooner'. In response to this consumers are increasingly acquiring a role as educators and trainers (Pinches 2003) and there is a push to make the consumer perspective intrinsic to all aspects of education and training (NMHETAG 2002). There are now examples of good practice where this has become a reality (Edan 2006) and where valuing the lived experience is an integral part of training.

It seems to work. A systematic review of the evidence of the impact of consumer run initiatives (Doughty & Samson 2005) did show that using consumers as trainers enhanced effectiveness and that post-training attitudes were more positive (see page 28). Delivering personal stories can impact on the values and attitudes of mental

6. Increasingly consumers have rejected the word stigma as it attaches to the individual and implies something is wrong with them. Discrimination is being adopted as a stronger term which also has useful parallels with the anti-discrimination legislation sought by those in the disability movement.

health clinicians. A number of consumers and consumer organisations are now engaged in this work across Australia.

We have been going to the medical schools to those who will end up being the future doctors. There has been work with current mental health service staff in various sessions and on a project called Consumers as Tutors which involved being engaged in training for staff. Mental Health ACT has got to the point where a lot of the training they provide invites consumers to participate so they end up playing an important role in educating staff that are also attending the training. So there are things happening on a more informal basis. We also did a couple of narrative sessions which brought consumers and mental health professionals together to talk about things like stigma or the doctor/patient relationship. Participants felt they have really opened minds and helped move on to a more open and equal relationship. (Consumer leader, ACT)

There are questions about how to build an enduring system where consumers are routinely involved in the development and presentation of training to clinicians.

Mental health services have nurse education units with nurses as educators. We want a consumer education worker in my directorate with input into the education program and curricula development. This should not be about story telling. It is much more complex than that and should be based on a philosophy of social change from a critical consumer perspective. So it's not about being critical of the service but about developing services and reaching a situation where clinical staff always question what they are doing from a consumer perspective. (Consumer leader, Victoria)

There is also a trend towards consumer led research and consumer clinician research partnerships (Beresford 2002) although it is not routine in services and consumer-controlled research projects are still relatively rare in Australia. It is

challenging for clinicians to engage with the consumer perspective and there is often a lack of opportunities for consumers to have hands-on experience of research methods. Pinches describes a shift from non-patient researchers to patient researchers and the resourcing of consumers to evaluate services themselves (Pinches 2005). He identifies active consumers as 'pathfinders' who are providing new ways of seeing and doing things.

Consumers are increasingly involved in devising consumer-orientated outcome measures. Performance measures which use the recovery paradigm to improve clinical practice and policy development would have real benefits for consumers. This requires working in partnership with consumer consultants and advocates. There is also a move to establish consumer perspective research and teaching in universities.

> *One of the big things that's happened in the last five years is this moving towards consumer studies as a discipline and thinking how to place the discourse somewhere where it can make a huge difference. We would like a consumer research unit attached to a university which would act rather like an Aboriginal educational research unit. It would be there to support consumers through university because people with mental health problems drop out or they are sick. It would collect the grey literature because so much of what we've written doesn't get into Medline where you would go about finding literature on mental health. And it could act as a way of nurturing PhD students writing about consumer experiences. We want to challenge methodologies like what is knowledge in this area. (Consumer leader, Victoria)*

Involvement in the evaluation of services has been promoted through the requirement to have consumers as part of the teams reviewing services against the National Standards for Mental Health Services. While one of the accrediting bodies reports difficulties in recruiting and maintaining a pool of consumer reviewers, the other has trained consumer surveyors and coordinates this workforce centrally. It has also set up annual surveyor training and support mechanisms entailing quarterly telephone conferences to establish an informal support network (ACHS 2007).

2.7 Mental Health Consumer Organisations

There are many different kinds of consumer groups and organisations. Firstly, there are local consumer support groups which are about sharing experiences, social contact and activities. They may target people with a particular disorder like eating difficulties or depression, and operate as mutual support and self help groups where members gain support from others living with the condition to promote recovery. They are small, commonly facilitated by volunteers and run by committees which may just be consumers but can also include carers and professionals.

Secondly, there are larger consumer groups which may or may not offer mutual support but also perform a range of other functions like information provision, individual or systemic advocacy, educating mental health professionals, establishing new consumer support groups and auspicing consumer projects or research. Some have also established web based groups and forums which provide support, information, debate and opportunities to feed back service experiences. They are largely run by consumers for consumers.

Thirdly, there are consumer run service provider groups which are driven by a desire to create alternatives to traditional mental health services at a grass roots level and to push for a recovery orientation. They may support patients in professionally-led services and provide drop-ins or alternatives to hospital admission as well as personal support and advocacy. Lastly, there are consumer-run businesses which can provide a range of employment opportunities for consumers outside the mental health sector.

Some classify these groups as 'consumer developed initiatives' (or CDIs) which is a broad phrase to describe any activities organised by consumers to provide mutual support or change society's perception of mental health consumers. They are seen as providing a range of benefits including a support base, a sense of hope, opportunities for decision making, choice and the development of new skills and creating a cadre of knowledgeable consumers and leaders to press for change. They have increased in visibility and importance in the mental health systems of many countries in recent years and in the US, for example, now outnumber traditional mental

health providers by a considerable margin (Goldstrom et al. 2006). They are also seen as central to the development of a consumer workforce (Orwin & Burdett 2009).

Yet they also suffer from a range of problems in getting established and sustaining themselves and are constrained by both the resources available and the culture and understandings of mental health providers and systems. Research to pool the experiences and knowledge of consumer developed initiatives (Mowbray et al. 1997) describes their ideas, principles, guidelines and practices and the issues, challenges and barriers they face. These include a lack of support and funding, difficulties in dealing with internal conflicts and tensions, high burn out rates and a lack of stable workers to provide leadership and maintain organisational survival. Overall the research identifies the absence of a road map or established wisdom about how to avoid difficulties or resolve them and no mechanisms to share and accumulate knowledge as significant gaps.

2.7.1 Getting Started

The difficulties consumer organisations face in establishing themselves is well documented although they are not significantly different to the difficulties faced by many new community organisations. This research gathered a wealth of material on the experiences of setting up and sustaining consumer organisations both from the literature and from the first hand accounts of consumers. They all undergo a difficult struggle to exist, survive and be effective and, as one consumer said, the common experience is organisational crisis which is almost inevitable (Meagher 2002a). The factors contributing to this are a lack of adequate structures to maintain a shared purpose and direction, dominating charismatic leaders who can disempower others and lead to factions and breakdown and the difficulties reactive, activist groups have in sustaining a purpose and motivation. In terms of establishing organisations research informants spoke about three things – the shortfalls in capacity in the consumer community, the difficulties of gaining and maintaining independence and difficulties in defining a purpose.

Building a mental health consumer organisation can be more difficult than setting up other kinds of CSOs because of a lack of capacity within the consumer community:

Usually the community can generate a non-government organisation because it has lots of its own citizens with personal resources: a lawyer who is prepared to give some time, an accountant, a person who has a computer. But often the mental health consumer groups do not have a depth of resources that collectively individuals can throw into that process. This is what has to be argued with government, that a mental health consumer organisation needs to be seeded and funded in a different way for its growth. It is also a painful and reluctant process to identify as a mental health consumer and often those that do are those who have had it all taken from them, their identity, their professional identity and family identity. The people who do identify as mental health consumers are often those who have long standing illness, impoverishment and disadvantage. Add all of that together and it isn't the best foundation for pulling together twelve people to make an organisation. (Consumer advocate, WA)

These issues can make it particularly difficult to present a credible front to potential funders and of course organisational stability is usually dependant on attracting adequate funding. Many organisations find themselves working in a voluntary capacity for a number of years and relying on their own resources and volunteer effort. If they are successful in applying for funding it is often for short term projects rather than core funding which creates difficulties for organisations in building their infrastructure.

What set us onto a more stable framework was the funding by DoHA. We are providing peer support services through a national peer support line and we are also funded for a Hospital-to-Home Team. This gave us two offices, a meeting and training room. But we have no core funding, it's only for projects and through fundraising. I'm out of a job next year if this project is not refunded. (Consumer leader, NSW)

One way of seeding a consumer organisation is to establish auspicing arrangements with a larger organisation which can provide accommodation, mentoring and support in the early days. A number of organisations who participated in the research had experienced auspicing. It had worked for some and not for others depending on the nature of the relationship with the auspicing organisation and clarity about what that relationship entailed.

....

We became incorporated and we got a small grant and established an office but there were difficult periods. Building up an organisation and structures is always a challenge and there were times when the network was auspiced by the local [Council of Social Service]. We had one part time coordinator a few hours a week and there was more than one instance when that person became unwell and there were difficulties just running it and keeping up with requirements and living up to a contract. There were times when it was fairly close to collapsing. (Consumer leader, ACT)

....

Organisations reported difficulties with auspicing arrangements, particularly when they were auspiced by organisations in the mental health sector. It meant that they were unable to escape the role of client or patient and the accompanying discrimination that this entailed.

....

It usually doesn't work. There is some literature and a lot of discussion from around the world that this type of arrangement does not usually work well. Occasionally it does and that's probably due to clarity around the relationship and a CEO who is not full of levels of prejudice because that is what we've got to face in the mental health sector. (Consumer leader, NZ)

....

It is very important to stay away from the mental health sector. Consumer run organisations do not get the understanding from mental health services. The clinical services are too ingrained in their practices to understand. They find it too risky, unsafe, they can't actually see that there is another

level of working. It's really advisable to look at non mental health providers to support as auspicers or as an umbrella to make it easier to get contracts. If you work with a well established organisation getting contracts is easier. (Consumer leader, NZ)

....

This meant that the goal is often to become an independent, incorporated consumer-run organisation.

....

I have always seen that in having legitimacy and being a maturer organisation one has to be incorporated. I felt incorporation was a measure of independence and a demonstration that it's a stand alone organisation. To a degree it added credibility to the organisation and it certainly acted as a spur for a number of others to become incorporated. (Consumer leader, Qld)

....

Although most consumer organisations are established initially to provide a voice for consumers and/or to offer support, in order to attract funding they need to be able to carefully define what kind of service or service mix they can realistically offer. It means choosing between a range of options from individual to systemic advocacy, support and recreational activities, education and awareness raising, information provision or consultancy. Some focus on systemic advocacy, others might find a balance between individual advocacy and broader lobbying and campaigning work.

....

Consultation is a key element in the work we do and it did grow organically with a desire to go and represent and be involved directly at different levels and there was a willingness from ACT Health to involve consumers. The government sees the consumer representative program as the key service and most of our contract revolves around that but there is also an element of awareness raising and education of consumers and the broader community and policy work. We are a systemic advocacy organisation so we try not to get too involved in individual advocacy. It would be logical to be involved with it and consistent with the aims and goals of the network but at the

same time it's a very different dimension of work and individual advocacy is provided elsewhere. (Consumer leader, ACT)

It's the individual advocacy that informs us about what is missing systemically. We do the individual advocacy, keep data on it and then we have group advocacy. We establish consumer groups in the areas in which people live, visit them on a monthly basis, have a meeting over a barbeque about how are you going, what are your issues? Those two activities inform us about the systemic issues. For example we know patients' rights is a systemic issue right across this state, so is women's safety, seclusion practices, the culture. We can say in this state what the major issues of concern are because we are out there visiting people in in-patient facilities, in the towns, listening to them, not telling them what the issues are but getting them to tell us. (Consumer leader, Victoria)

It is of course important to be delivering a service that people want and need and some organisations have had difficulties in defining a role that meets the desire to advocate and strengthen the voice of consumers in a way that attracts and involves a broad range of consumers:

We have an attitude that we are service providers. Every year we used to hold a meeting with consumers where we said you tell us what you want us to do. The services we deliver are the ones that they have identified as wanting. Other places don't do that. You get a small core and they don't do an analysis of what consumers need. They develop a service they want to deliver and that is comfortable for them. (Consumer leader, Victoria)

Some organisations may come together to promote a particular issue but when they achieve that goal have to restructure and define another purpose otherwise they cease to exist. It also means that success in one area can boost confidence and build the capacity of organisations to move on into bigger and broader fields.

It started out in the late 1990s with a group of people coming together after a workshop. We wanted a place to call our own that respected us in a different way to what we experience from mental health services. So the initial drive was to establish something based around the club house model. The Rainbow was established so there was a sense that we had achieved what we initially came for but also that as consumers getting together we can actually achieve things. From there it developed a broader perspective to have an input into the development of mental health services. (Consumer leader, ACT)

Lastly, a common problem faced by many organisations is the expectations of others about what they can or cannot achieve.

Mental health services here would like to have the group run before it can crawl and really it needs to evolve at its own pace. They want it running training for consumers, placing consumers on committees and supporting them in that work. All of that requires quite a solid structure and to be able to deliver a service means you have to have your house in order. It will take some time. (Consumer advocate, WA)

2.7.2 Governance and staffing

Governance structures vary but usually entail a management committee or board of trustees. Commonly consumer organisations require that all committee members are consumers and a number of research participants described the difficulties they had in building stable committees of consumers to govern organisations:

One of the problems at the beginning was how to develop any kind of governance structure for consumer involvement that was consumer led because a lot of the consumers who came into the system were dealing with their mental health problems and not a lot of them

necessarily had management or community governance experience. We had trouble recruiting people that were able to sustain their efforts for a range of different reasons. You have people at different stages of their own mental health and some may never be able to contribute a great deal, maybe their opinion now and again. So a lot falls on one or two shoulders. (Consumer leader, WA)

Getting a stable consumer board is quite an art in itself, one which will be there for the long haul and can create that stability. We have the capacity to have nine members on the board but we have never had the full nine. (Consumer leader, NSW)

This has led to exploring ways of building the capacity of consumers to participate through building up the membership. In 2007 the Health Issues Centre in Victoria undertook a project to determine the skills, knowledge and needs of mental health consumers and then to provide education and training to meet these needs and to support trainees to negotiate the mental health system. 'Self stigma' is an issue for most people with lived experience and is the result of internalising the negative messages and behaviour received from others. The project found that many consumers required support with their self-esteem and in dealing with stigma before they could participate. The Centre also conducts annual training to support consumer involvement in health care generally and many participants in the training have mental health issues.

At another level training is also required to equip consumers to participate equally with providers by acquiring skills in meeting procedures, public speaking, submission writing and advocacy. As one consumer said 'it's training people in the fundamentals of how a system works. It's an apprenticeship'.

If you can get a membership core then the job is to educate people to a point where they take over. It allows you to train people up. We watch that person grow and over the years they end up becoming the president of your organisation. There's a lot of education of consumers to be done to the point where they

are confident enough to say things but not in a way that will alienate anybody. This has to be done well and by other consumers and they have to be funded. (Consumer leader, Victoria)

There has also been a more profound questioning of the appropriateness of committee structures for consumer-run organisations.

In some ways the traditional consumer organisation is really based on an old trade union structure. You have your representatives, they come together and make decisions. That is not a very 21st century structure. Who are you representing? And there isn't always a body to represent because there aren't local structures. So I think that model is dead, it's disastrous. I would like to be able to do away with all that stuff and just have a group of people who may be governed through a company or a trust but who have accountability. (Consumer leader, NZ)

Many organisations are committed to employing only consumers. This can mean they have flexible arrangements to manage and accommodate illness. It can also mean recruiting from a very small pool of people with the appropriate skills, including relationship building which was seen as essential.

One of the reasons why this place has survived so well is because I have a management background. People are often appointed to be managers who have no education around these matters at all. I'm not talking about balancing a budget, I'm talking about managing people. Also people have become unwell from time to time. We have flexible working rules. Ninety nine per cent have never taken advantage of that flexibility. One per cent have and I've nipped it in the bud. (Consumer leader, Victoria)

If you can go into any meeting and make the people around you feel good you're much better off. That is the fundamental responsibility of consumers if they want to do this work. But too many have an operational

style that is vitriolic and abusive. I don't consider it okay to have a string of corpses that end up back in hospital because of the consumer movement. (Consumer leader, WA)

Some research informants felt that the requirement to employ only consumers should be revisited and that having the skills required should be the priority rather than the status as a consumer.

The shift was the realisation that it was necessary to run the office as a professional entity and that it might require employing someone who is not a consumer to do that. It's about employing people for their skills rather than because they need a job. There was the experience of having a person from the group and the person simply not having the skills to do the job properly and at other times becoming unwell and suddenly the whole thing falls down. (Consumer leader, ACT)

Those experienced at employing staff all emphasised the vital importance of skilled recruitment to consumer positions.

I learnt very, very quickly that you should select on merit, not because the job would be good for someone but because they would be good for the job. It will be good for them but you give it to them because they can do it and that can never ever be stressed too much. We actually demand an incredibly high standard from our staff and they are more professional than the professionals. They get monthly external supervision and they use it. The amount of supervision workers need is more than people who don't carry the scars of mental illness. The business model is important because you have to employ competent people because you have to deliver against contracts. (Consumer leader, NZ)

2.7.3 Dealing with conflict

Conflicts and tensions are common experiences for community organisations including mental health consumer organisations and some voiced the opinion that 'too many consumers with too many egos' had resulted in a fragmented consumer movement across Australia. As one consumer said 'I don't know of many consumer organisations that don't threaten to self destruct every now and again, it's par for the course'. These difficulties have been attributed to a lack of effective and appropriate leadership and to 'disempowered individuals becoming empowered and then not knowing how to wield that power for the benefit of others'. Informants described situations where a core group of consumers had effective control of an organisation and became increasingly intolerant of others who did not share their views.

We have individuals who have a lot of long standing involvement but have taken a lot of power and aren't particularly ethical in the way they operate. It's very difficult to get rid of people who have set up empires and who have their own issues which they project into their role and who don't have supervision. They are not acting with a strong sense of self reflection and are often unethical. They bully others out of the way. (Consumer leader, NSW)

We've had a great deal of difficulty with this issue of leadership because when you have a group of people who have been marginalised and experienced a lot of powerlessness you need particular types of leaders. Some of the consumer leaders haven't quite got that and in fact if you spend a lot of time in the mental health system you might have learnt a few things about leadership which won't be useful to you. Leaders are about helping people reach and live their values which is a very different philosophy to traditional mental health services. (Consumer leader, NZ)

Informants saw ways of addressing these issues as strictly enforcing policies, procedures and codes of conduct to eradicate bullying and abusive behaviour

and having organisational structures which ensured accountability. This can be a lengthy process but means that organisations can develop a culture of respect where everyone is heard and treated with dignity.

> *We remove bullying from the management of these organisations by strengthening the processes and insisting on processes no matter what. Processes are our safest bet. There should be no bullying and everybody should be treated with respect. Often people are very gifted, very knowledgeable and excellent representatives but the problem is they don't allow for the empowerment of anybody else. One of the core values of a consumer organisation is that people must be enabled to have a voice. (Consumer leader, NSW)*

Informants also identified the need to clearly separate the policy and strategic direction role from the administration and day-to-day management role.

> *With organisational structures, we need to divide the roles very cleanly and divide the administration and accountability role from the policy and direction role. Those two roles need to be equal and accountable to one another with the chair or president as a third party – a triumvirate. They should meet regularly, discuss the business and advise each other respectfully and be informed from the membership through the chair and the policy person. The membership as a whole, through strategic meetings and consultations, should be the people who make the directional decisions in discussion with the person managing the administrative and policy area. Everyone should have checks on everyone else that the processes are being followed. The real mistake is that people get to represent the organisation but the other members never hear anything about it. (Consumer leader, NSW)*

2.7.4 Factors for Success

What determines whether a consumer-run organisation is successful or not in attracting funding, sustaining itself and providing an effective service? There are a complex array of factors but key informants variously identified the commitment of the group, a culture of learning, training for members and support from a range of sources. They also identified having capable and skilled staff and professionally delivered and credible services, having good consultation mechanisms, the capacity to build productive working relationships with all stakeholders and having independence as important for survival.

> *It comes down to the dedication and commitment of the consumers involved. Funding does help and it does create more stability in an organisation. We have a very good culture of learning and we've received a lot of training over the years before incorporation. We also have the support of different people and the inaugural Board set up a reference group of interested individuals to advise and support the Board. So whilst there weren't non consumers on the Board they had access to a group of non consumers to help support and advise them. That's worked and they have always been there on tap for us. It's also about the Board being proactive in meeting challenges and they have to be informed. If there are staff positions you must make sure the selection is full of integrity and that information doesn't sit with one person. (Consumer leader, NSW)*

> *The professionalisation of what we do has something to do with it and being focused on coming across as a professional body. There has also been a lot of support from the executive level of the public mental health service and on a broader level across Australia there has been a move towards more consumer participation. A lot has been achieved in terms of establishing the network and its consumer representative program as a credible player in the mental health sector in terms of being valued by other players for its expertise and input. (Consumer leader, ACT)*

Having a receptive environment and particularly having a champion within the mental health sector was seen as essential by some informants:

> *You have to have a champion within the health service who has some clout, who will listen to you and understand and to whom you can make points without them taking it personally. Without a champion when you criticise services they behave as if you're attacking them and get very defensive. (Consumer leader, SA)*

There is a growing literature on the unique needs of consumer organisations and the development of programs to assist them to build capacity (Wituk et al. 2008). In the US there is a well established network of technical assistance through centres providing on site training and skill building in business management, leadership, communication and networking. Australia has recently seen the establishment of its first technical assistance centre, Our Consumer Place (see page 45), in Victoria and it is hoped that this will become a national resource. However like many other countries including New Zealand most consumer organisations have to find their own way and although funders may provide the financial resources they do little to develop the capacity of organisations (Orwin & Burdett 2009). This situation could benefit from in-depth study of successful and unsuccessful consumer enterprises and the cost factors involved in order to propose a suitable funding formula which recognises their particular needs.

2.8 Measuring the Impact

What is the impact of consumer participation and consumer run initiatives? If the aim is to move towards a better recovery-orientated mental health system how successful have they been? The evidence base is scarce and there is little literature on the effects or how widespread they are (Crawford et al. 2002). Although initiatives and organisations which receive public funds may be involved in independent evaluations of their work most studies are descriptive and there is no Australia-wide comparative study. People commonly say they are doing an effective job and having an impact but without the evidence base to prove it. As one consumer said 'consumers are adverse to evaluative research about themselves and there is an attitude of I'm a consumer therefore I know what I'm doing'.

However what evidence there is indicates positive outcomes. Findings from research into consumer initiatives (Nelson et al. 2006) suggests that they can assist individuals with social support, empowerment, increased wellbeing, enhanced quality of life and reduced use of services. These outcomes can be achieved at a fraction of the cost of professional community programs. At the same time system level activism can result in changes in perceptions held by the public and professionals about the value of the consumer perspective and consumer run organisations and concrete change to service delivery, planning and funding.

A study designed to explore the effects of involvement (Simpson 2002) explored databases between 1966 and 2001 for systematic reviews of randomised controlled trials and other comparative studies. The research found five trials and a number of other studies where half considered that consumer involvement in managing treatment led to more satisfaction and less hospitalisation. The study found that providers trained by consumers had more positive attitudes to the lived experience. It also found that patients registered lower levels of satisfaction with services if they had been interviewed by consumers rather than non-consumers.

A systematic review was carried out in New Zealand (Doughty & Samson 2005) to identify the international evidence for the effectiveness of consumer-run activities compared to those run by mental health services. Consumer-run was defined as having self governance by consumers and consumer staffing and supervision, control of program policy and responsibility for program implementation. The review identified 26 primary data papers and two systematic reviews. Overall the research showed very positive outcomes for clients of consumer-run services including higher satisfaction with services, general wellbeing and quality of life. Although some studies did not show a significant difference between user-run and service-run activities, no studies reported any harm to users or that consumer-run services were in any way less effective. Despite these findings currently consumer run services worldwide receive very limited funding from mental health budgets.

Consumers themselves have raised concerns about whether consumer involvement, especially where the agenda is centrally controlled, actually detracts from improving

services and the quality of life. If consumer involvement mechanisms are tokenistic and do not necessarily impact on decisions and when there are insufficient resources for consumer priorities to be implemented is involvement a good use of consumers' time and energy?

Some evidence also comes from outside mental health services, from the broader health sector. The Australian Government funded a project to review international and Australian evidence supporting consumer participation in generic health care (DoHA 2001). It concluded that participation in decision making at an individual treatment level results in improvements and access to good information helps decision making, supports people to manage their own health and results in more accessible and effective health services and a reduction in health inequalities. It also suggested that participation activities should use a range of methods.

What is required is systematic and comprehensive evaluations of processes and outcomes. The Cochrane Consumers and Communication Group[7] is currently designing a number of reviews to find existing evidence for any positive or negative effects of consumer involvement in mental health service evaluation research, in consumer employment as providers of mental health services and in involving mental health consumers as trainers for professionals working in adult mental health services.

2.9 Future Directions

Key informants were asked how they would like to see consumer initiatives developing in the future. They identified broad changes in the environment which would impact on the consumer movement as well as developments in particular areas and a vision where consumer engagement becomes an integral part of practice in equal partnerships with practitioners. In line with international trends there will be a shift of mental health services into the community, into mental health promotion and prevention and into the development of partnerships and coalitions. This requires consumers to develop credibility and respect with professionals, agreement about

7 The Cochrane Collaboration is an international not-for-profit independent organisation dedicated to making up-to-date, accurate information available about the effects of healthcare worldwide. The Consumers and Communication Review Group coordinates the preparation and production of systematic reviews of interventions which affect consumers' interactions with healthcare professionals, services and researchers.

what support is required, equality in status and a more united front. It also requires changing staff attitudes and staff culture.

Rather than using the language of participation and involvement we need to talk about partnerships. You have a better platform than if you talk about participation which is much more passive and about an agenda that has been set. Partnerships are the way of the future. It is a government imperative so there are ways in which it could be colonised. (Consumer leader, NSW)

These moves will be accompanied by a professionalisation of the consumer role with formalised representative roles, standardised peer support services, consumer-run and controlled services and a growth of consumer businesses. There were visions of an expansion in the consumer workforce, more specific roles in the education and training of clinicians, further inroads into consumer-controlled research and education programs for consumers to get them back on track in the education system. This will need to be accompanied by skills development so consumers can become more effective and by the establishment of technical assistance centres to assist in setting up and sustaining consumer organisations.

They will be funding us to provide information or services. We won't be given money just to run groups but to produce goods or offer workers or take on contracts. That has been the pattern worldwide. We are getting far more professional than we were 20 years ago and governments won't be funding us just to sit round and have talk-fests about advocacy. (Consumer leader, NSW)

As one consumer in New Zealand operating a consumer-run crisis intervention service said:

Having been involved for a long time, we made the decision that we would actually try and do something rather than just talking. We got fed up telling people what we wanted. We just started doing it. If we don't like the services and they're not listening let's set up an

alternative. It is really difficult to be accepted by the clinical-thinking funders that there is more needed to get people back on track than clinical services. It is really important to get people together who can start role modelling. That is how we got things funded, by showing them what could be done and starting off very small, showing them there was the ability and there were good results. (Consumer leader, NZ)

Some informants wanted to see a much more strategic approach and a closer alignment with other rights movements, with human rights organisations and particularly with the disability rights movement. They identified many shared issues, particularly in dealing with patriarchal systems and power imbalances, in moving towards a more rights based agenda, in focusing on the social rather than the medical model and in having strong organisational frameworks. However, internationally there have been difficulties in working collaboratively. Some consumers question whether mental illness is a disability which implies a long term unchangeable condition. At the same time there is a lot of 'sanism' in the disability movement. And taking on both a patriarchal disability service structure and the mental health establishment is a big challenge.

The differences between disability and mental health are quite hard to negotiate. A lot of people with mental illness don't see themselves as disabled and don't see the advantage of campaigning on joint things around discrimination. Disability organisations don't always get mental health and don't want to be seen as mentally defective. All of us need a bigger picture and need to realise what the disability movement has done and how this could help us. We need to work out what we would gain if we called ourselves disabled and what would we lose. We just lack strategic thinking in the user movement. (Consumer leader, UK).

Consumers should be working with human rights organisations. The responsibility of the consumer movement is to try and make sure

that consumers on the ground are aware of their human rights and to make sure people are treated properly. It is the one thing which makes a difference. (Consumer leader, UK)

2.10 In Summary

This chapter has illustrated the diversity of views, experiences and approaches in how best to engage with and use the lived experience of consumers to ensure that it informs a change in the way we think about mental health services. A key dilemma in this debate is whether, as consumers, it is better to work within services or remain independent from them. Informants illustrated both perspectives. Being employed within the system can offer distinct advantages in 'subverting from within' and having direct access to decision making forums. As two consumers employed at senior management and executive level said:

Initially I felt we should be employed outside the service in independent organisations. Now I have completely changed. When individual advocacy is the prime function you should be employed outside the service, peer support requires its own support structure or educating clinical staff where different skills are required. But if you work outside an organisation you are accused of not understanding the system. (Consumer leader, Victoria)

Some people said you can't possibly be an advocate if you're in the system but the job that I do is to subvert from within. I've been here two years now and I'm finding that I actually provide a lot of resources to staff. They say I am really interested in doing care planning and recovery plans or I want to know more about consumer participation but I don't know how. So there is not so much a resistance as really not knowing how to do things. Being in house staff are more inclined to access me. From the outside trying to get in you get blocked off. I think I am able to say a lot more in the service than people

might have thought. There is real value in being at this level. (Consumer leader, WA)

There are also those who feel it is best to remain outside and that it is too easy to become subsumed by the system. Building consumer organisations which can provide autonomous and independent consumer services should be the goal.

Consumer participation has been imposed on services so if you're a service which is not committed to it what you do is hire a consumer who you know will never be able to do the job. We have a few of them. Some start to identify with the service and then become apologists for it. They want to be colleagues with their colleagues and they have become colleagues of the clinicians. (Consumer leader, Victoria)

However many informants saw the advantages of both approaches and wanted to see models which combined the most positive aspects of working inside and outside traditional mental health services. As one informant in a consumer run organisation in New Zealand said:

The drawback is that we are outside the tent and our consumer advisers are external to the organisation. Elsewhere in NZ the district health board has set up peer support teams in the service itself with the intention of influencing the service culture whilst providing support services. They are more comfortable with someone they employ because they can control them. But how can one poor peer support worker in an in-patient unit change a culture with 150 years of history behind it? But it might have a greater impact on culture change than us as we are outside it maintaining our purity. (Consumer leader, NZ)

3. Mental Health Consumer Activity across Australia

This chapter maps the complex jigsaw of consumer activities and participation mechanisms across Australia and the structures at national level which draw these activities together. It has been collated from information provided by consumers and other stakeholders in all states and territories and from a range of policy, research and other material about particular initiatives. It highlights examples of good practice and particularly interesting and innovative approaches (which are boxed) and draws some comparisons between jurisdictions in terms of the history of consumer development and its current presentation.

3.1 The National Picture

National bodies can be important in providing a voice at the federal level, in setting national agendas, in promoting the consumer movement and in supporting developments locally. Without these structures there may be a lot of activity in individual jurisdictions but no mechanisms for bringing it together into a united voice. However, the ability to develop national structures is constrained by two issues. Firstly because the consumer movement has developed in a patchy and fragmented way across Australia there are questions about what infrastructure there is for any national bodies or coalitions to work with. Secondly while national organisations try to influence policy at the national level in reality most developments take place at a state or territory level. This means that it can be difficult to define concrete national agendas and to see positive outcomes spring from them.

Although there has been a growth in national advocacy organisations providing a voice for people with particular disorders, like SANE and the Schizophrenia Fellowship Council of Australia, the first all-embracing consumer and carer national body was the National Community Advisory Group on Mental Health (NCAGMH). This was established in the 1990s through the first National Mental Health Strategy as an influential committee of consumers and carers with representatives from each jurisdiction and its own secretariat, reporting to the Commonwealth Minister for Health. There was a parallel commitment at the state and territory level to establish CAGs of consumers and carers and give them direct input into policy discussions about mental health reform. It meant that for the first time consumers and carers were involved on every relevant federal committee and it led to the development of partnerships between mental health services and consumers and carers (Craze 2004). NCAGMH was disbanded in 1998 when the Mental Health Council of Australia (MHCA) was established.

In recent times the national scene has been dominated by four key bodies.

Australian Mental Health Consumers Network (AMHCN)

This was founded in 1996 as the only national consumer organisation for people with mental illness in Australia. It was an independent, incorporated body consisting of two delegates from each state and territory and aimed to provide a national voice in mental health service planning. It secured funding from the DoHA Mental Health Reform Branch to establish an office, a secretariat and a profile. During its life it organised conferences and events, issued a regular newsletter, initiated campaigns and was represented on government working parties, consultations and organisations at a national level. It also carried out a scoping study for the DoHA to explore workforce opportunities for consumers and the feasibility of establishing a national education and training strategy in consumer advocacy work.

AMHCN was defunded in 2008 due to concerns about its governance. There is an ongoing debate about developing a suitable successor to AMHCN and how to build on organised consumer activity in each jurisdiction to develop a new national peak consumer organisation.

National Mental Health Consumer and Carer Forum (NMHCCF[8])

This was established in 2002 with federal funding and is the only mechanism for bringing consumers and carers together at a national level. It aims to promote national partnerships at all levels, increase both participation opportunities and the capacity of consumers and carers to participate and provide a unified voice on consumer and carer issues. It also aims to identify best practice in participation and agree on national priorities for action in line with the National Mental Health Plan. The NMHCCF has one consumer and one carer representative from each jurisdiction and from national consumer and carer organisations. It operates under the auspices of the Mental Health Council of Australia (MHCA), meets four times a year and runs working groups to progress individual projects.

In 2004 the NMHCCF reviewed existing models of consumer and carer participation throughout Australia with a view to recommending the most practical working model at a national level (Craze 2004). It also published a guide for consumer and carer participation policy (NCCF 2004) which can be adopted by any organisation and which lays out the core best practice principles for defining the role, selection and employment of consumer and carer representatives. As well as setting up a website it is currently developing policy to improve its representative base, reviewing its strategic plan and identifying key priority areas. These include work around privacy and information sharing, seclusion and restraint and welfare to work.

Mental Health Council of Australia (MHCA)

This was set up in 1998 to provide representation from consumers, carers and providers at a national level. At the time many concerns were expressed that this would dilute the consumer voice because of domination by professional groups. It is now one of the first ports of call for those wanting mental health sector input at a national level, including consumer and carer input. As well as helping to establish the NMHCCF MHCA have been funded by DoHA to:

....

8 Previously known as the National Consumers and Carers Forum (NCCF).

- support consumers and carers in surveying mental health services under the National Standards. The Standards require all public mental health services to conduct a survey by an external accreditation agency to review implementation of the Standards. MHCA organised a national training workshop in 2003 for consumer and carer surveyors and set up the Network of Consumer and Carer Surveyors to provide a national database of surveyors, a website, a quarterly newsletter, telephone contact, informal mentoring and an annual workshop.

- develop and trial mentoring and training opportunities for consumers and carers to strengthen their ability to promote issues and concerns at a national level. In 2007 this resulted in the development of:
  - the National Register of Mental Health Consumer and Carer Representatives. This involved selecting 50 consumers and carers from around Australia to attend a two-day workshop focusing on developing representation skills. It also provides ongoing training, support and access to representation opportunities.
  - the Mentoring for the Future Program. This gave opportunities to five consumers and five carers to participate in intensive training and mentoring to enhance their advocacy and leadership skills over a 10 month period. In August 2007 they travelled to the US and Canada to participate in the International Initiative for Mental Health Leadership (see page 51) exchange program. In addition they automatically become members of the Register and are linked with leaders with advocacy experience from other sectors for one-to-one mentoring.

Private Mental Health Consumer and Carer Network

Private mental health services account for approximately 16% of mental health beds and 43 hospitals across Australia. The Network was set up in 2002 with $13,000 annual funding from the Australian Medical Association, private health providers, the DoHA and the Royal Australian and New Zealand College of Psychiatrists. It has a committee in each state and in the ACT and aims to facilitate the sharing of experiences and concerns in order to lobby at a national level. The Network meets twice a year and communicates through a strong email network. There is no committee in the Northern Territory because it does not have any private hospitals.

The Network describes consumer participation mechanisms in the private sector as poor and attributes this to the absence of any mandate to establish them and the absence of accreditation processes requiring in-depth reviews against the National Standards as in the public sector. Some hospitals have consumer and carer advisory committees but they rarely have input into service design and delivery. There are also a small number of consumer consultants (six) working in private facilities and based in just two states. Tasmania is unique in having a consumer representative on a private hospital board. The Network is pushing for better involvement mechanisms in private hospitals.

Other significant national initiatives

These are:

- **The Kit**. This was a community development initiative which grew out of the National Mental Health Strategy and which, in 1998, resulted in the production of a comprehensive resource kit for consumers of mental health services and their families and carers (DoHFS 1998). It aimed to enhance advocacy activity through increasing knowledge and strengthening skills within the mental health community sector. MHCA was involved in disseminating The Kit and developing an infrastructure to enable its implementation. Five training modules were produced and consumers trained to deliver them. However, a subsequent evaluation found that although the resource had been disseminated Australia-wide there had been little training in how to use it in any of the jurisdictions. The Kit remains highly regarded in the mental health sector.

- **Australian Network for Promotion and Early Intervention for Mental Health (Auseinet).** This is a web resource which aims to inform, educate and promote good practice. It provides access to a comprehensive clearinghouse on best practice models, publications, a newsletter and links. These include access to consumer participation models and debates.

- **Consumers Health Forum of Australia**. This is a national body working to promote the consumer perspective and interests and to provide a voice for all health consumers. Although it does not have a mental health stream it does provide a useful source of information about models and issues in developing consumer participation across the health sector.

- **TheMHS Conferences** are held annually to create a learning network for improving mental health services in Australasia. They aim to promote collaborative research, practice, policy making and education as well as the active involvement and inclusion of all mental health stakeholders. They also advocate for and promote leadership in the mental health field and have an important role as vehicles for empowering and skilling up consumers.

Consumer representatives continue to sit on relevant federal committees and working groups. These include the recently established National Advisory Council on Mental Health set up to provide independent and confidential advice and expertise to Government on mental health issues as well as the advisory group developing the National Mental Health and Disability Employment Strategy.

3.2 Australian Capital Territory (ACT)

The ACT has a strong mental health consumer movement. Its size, both geographically and in population terms, and the close working relationships which have developed between organisations has fostered a strong consumer organisation which has quickly gained credibility and support across the sector. It also has a consumer and carer participation framework developed through a highly regarded, inclusive and open consultation process driven by the ACT Health Policy Unit where participants felt they had the opportunity to fully influence the process. The framework was launched in June 2007.

ACT Mental Health Consumer Network (ACTMHCN)

ACTMHCN began in 1997 with a drive to set up a place where consumers could feel safe. This resulted in the establishment of the Rainbow, based on the clubhouse model[9] and offering a consumer space for sharing experiences and resources. This success motivated a push to set up a more advocacy focused organisation and the Network was formed. It incorporated in 1999 and acquired a small health promotion grant of $5,000 per annum to set up an office with a part-time

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9 The clubhouse model of psychosocial rehabilitation was set up in 1948 as a self-help organisation and is now an international movement providing non-clinical community based programs to assist people with mental illness to reclaim their lives. There are now over 300 clubhouses in 24 countries. Provision is focused on strengths and abilities not illness and members and staff work side-by-side to manage all operations.

coordinator. It was initially housed with the Mental Health Foundation and there were difficult times and challenges when the coordinator was unwell and the organisation came close to collapse. For a while the Network was auspiced by ACTCOSS which provided staff mentoring, support and financial management. A new influx of members and ongoing funding increases from ACT Health allowed it to regain its independence in 2004 and establish a sound and credible organisational structure with a strong volunteer base.

ACTMHCN currently have a management committee of eleven consumers, a full time executive officer, two part-time administrative staff and a growing membership of 140 people. It aims to improve mental health services by providing systemic advocacy through regular consumer forums and consultative mechanisms to share information and identify common policy themes. Its key service is running the consumer representative program and most of the annual ACT Health grant of $260,000 is devoted to this work. The program provides one gateway for requests for consumer representatives. There is a rigorous nomination and selection process for the representative pool and ACTMHCN also provides training, ongoing support, accountability and the development of consumer policy positions. Following a New Zealand model (see page 53) there is now some debate within ACTMHCN about having employed representatives and creating a professional body backed by a sound consultative process.

Network informants describe a maturing of the organisation with the recent acquisition of additional funding to employ two more part-time staff to oversee the consumer representative program and develop more policy capacity. It would also like to invigorate its education program in medical schools and with mental health staff. This would support more informal work where mental health services have begun to routinely invite consumers to participate in training activities. The ACTMHCN has been facilitating narrative sessions to bring consumers and professionals together in power-free environments and it hopes to expand this area in future. The Network is now highly regarded in the sector although the downside of this is an increasing workload with limited resources.

There has been little emphasis on developing a consumer workforce in the ACT although two consumer consultants have been employed by the mental health agency for the past decade. When they were first employed they tried to do everything; systemic and individual advocacy as well as peer support. However, over the years their role has gained clarity and its core is seen as being systemic advocacy. They participate in policy forums and at an executive level in mental health services and are involved in educating staff and visiting community mental services to speak to consumers.

Like a number of other jurisdictions there is currently little paid peer support in ACT although it is suggested that ACT Health may be interested in funding a peer support pilot program. ACTMHCN is also interested in setting up peer support but without funding this would have to be on a voluntary basis. This raises concerns that using volunteers detracts from the possibilities of paid employment. The Mental Health Foundation currently operates a peer support program with seven peer support workers who are reimbursed at $40 per hour and are trained, de-briefed and given clinical supervision. Funding for the program has come through health promotion but the Foundation is hopeful that ACT Health will pick it up as they regularly express interest in this area.

ACT Consumer and Carer Caucus

This was established by the Community Mental Health Coalition – the peak body for the mental health sector – and represents a unique model for ensuring consumer and carer participation in a peak mental health sector body. It was conceived as more than a consumer advisory body and has a link to the Board of Management whereby the Caucus nominates two carers and two consumers to sit on the board, raise policy and service development issues and be involved in the strategic direction of the organisation. It has been an important body in policy and planning issues and in bringing consumers and carers together and has run effectively for a number of years. It is now being reviewed by an independent consultant to reinvigorate it, improve the participation structures and ensure meaningful involvement. This will also entail exploring ways of funding a coordinator position for the Caucus.

The ACT branch of Mental Illness Education Australia – the Mental Illness Education Group – works to raise awareness of mental health issues, reduce stigma and discrimination, encourage health seeking behaviour and promote the recovery message using the personal story rather than the collective experience. It educates the Canberra community about mental illness through presentations by consumer volunteers, websites, theatre projects and community consultations. The core business is the school education program which uses consumer and carer volunteers telling their personal stories. Volunteers go through a rigorous training and then attend practice sessions to observe until they are confident enough to join in. The Group is now also working with community programs tailored towards particular audiences as well as the police, mental health providers, bus drivers and prison workers. Consumers have a strong role in governing and running the organisation and 80% of the board are consumers. They are not seeking registered training organisation status and wish to remain a small organisation.

3.3 New South Wales (NSW)

NSW presents a diverse picture with a number of different centres of activity. Although there is currently no state wide framework for mental health consumer engagement there are now moves to develop one.

There is one state wide CAG which is engaged in systemic advocacy and CAGs operating at a local level which have become activity focused. Although some have become consumer-only groups including NSWCAG, many have retained the consumer and carer focus. For example, Mid-Western Consumers and Carers Advisory Group is an incorporated organisation which manages the O'Brien Centre in the grounds of Bloomfield Hospital. The Centre is open one day a week and provides a safe and supportive social environment offering a range of activities and acting as a stepping stone to the community.

NSW Consumer Advisory Group – Mental Health Inc (NSWCAG)

This is a statewide incorporated organisation providing an ongoing mechanism for consumer participation in mental health policy, service development and evaluation. It is governed by a board with a 50% consumer membership and a staff of one full-time executive officer, a part-time policy officer and two part-time administrative officers. It has gone through many changes and challenges over the years but is now seen by NSW Health as the peak body and has developed a good working relationship with mental health services. It receives $246,000 per annum from the Mental Health, Drug and Alcohol Office, the Centre for Mental Health and NSW Health with additional project funding. Although it represents the interests of both consumers and carers, given the existence of a strong carer organisation, the main focus has become the consumer perspective.

NSWCAG has a website, a weekly e-news, a quarterly newsletter and a mailing list of over 1,000 consumers, carers and other stakeholders. It maintains a pool of consumer representatives and has become a one-stop-shop for finding a consumer representative. It has produced a DVD on stigma and in 2007 worked with the research unit at Rozelle Hospital and consumer consultants to develop and trial four workshops for consumer workers and carers about helping people with co-morbidity issues. This was funded through a NSW Health Innovation Scholarship. In future it hopes to consolidate its role as the peak mental health consumer body in NSW, develop more formalised links with existing consumer networks and explore training gaps for consumers and consumer workers.

Like other jurisdictions there is a vigorous debate about the role of the 52 part-time consumer consultants employed by area mental health services in NSW. This debate has centred around the lack of role clarity and consistency in job titles, inappropriate awards and a lack of training and consistent guidelines. Because of the autonomy given to area mental health services to implement the role some areas have developed more strongly than others. For example, the Mental Health Consumer Participation Coordinator at St Vincent's Hospital works 20 hours per week and is involved in sitting on committees, running issues workshops, community development and setting up a Recovery Working Group. This contrasts with other areas where there are serious concerns

6. Conclusions and Recommendations

6.1 Summary

This research shows that across Australia and despite policy commitments at both a federal and state/territory level there is still a long way to go in order to achieve a satisfactory level of consumer participation. Increasingly the structural or formal arrangements are in place, there are guarantees in many documents and reports and pockets of good practice. There is also an acceptance that consumer representatives should be remunerated, that consumers should be included in planning groups and that there is a valuable role for a consumer workforce and independent consumer-run organisations. Yet, at the same time, the resourcing and support to fully endorse these trends has not been available and has led to a fragmented and stop-start approach. There is now a situation where, although the system officially endorses consumer participation, at the same time it often resists and denies the value of it, defunds it and prematurely ends initiatives. Tasmania reflects this national experience and indeed is falling behind other jurisdictions in both the range and level of consumer activity which it supports. However, opinions about how to proceed are diverse.

Evidence from both national and international sources suggests that models effective in driving the process of cultural change and recovery-orientated mental health reform require both independent advocates outside the mental health system as well as opportunities for people to be consumer advocates within the system. Ideally, and following experiences in New Zealand and elsewhere, it also involves the development of consumer-run services. Evidence suggests that the process of establishing an effective model can be hard, will take time and involves ensuring solid foundations, the setting of priorities and a staged approach. These are lessons which have been learnt locally through the recent work of the TMHCN.

6.2 Recommendations

Overall the consumer movement requires financial and organisational support if its contribution to mental health reform is to be fully developed and utilised. Given that promoting the involvement of consumers is a key priority for Mental Health Services in Tasmania this should be demonstrated through a commitment to ensure that there are a range of opportunities for the consumer voice to be heard.

In order to progress the development of consumer activity in Tasmania this report makes a number of recommendations which have emerged from the research.

6.2.1 Establishing a consumer-run organisation

The research shows that having an independent consumer-run organisation providing systemic advocacy and operating outside mental health services has significant benefits. These include providing a support base for consumers, fostering a sense of hope and inspiration and creating a cadre of knowledgeable consumers and leaders who can press for change. Three jurisdictions – ACT, Victoria and NSW – already have such an organisation and other states are now pressing to develop one. Such an organisation in Tasmania would be a strategic investment by the Department of Health and Human Services. It would strength the capacity of the Tasmanian community, particularly health and human services, to respond to the concerns of mental health consumers. It would improve policy development, provide effective systemic advocacy and an informed voice. It would also provide the opportunity to create a database of mental health consumer experiences and mechanisms for providing information and support to consumers across the state.

The key elements of this organisation are:

- an office base and paid employees with the ability to tour the state, market the organisation and have face-to-face contact with consumer groups, mental health organisations and individual consumers;
- a governing body providing strategic direction and support;
- consultation mechanisms to collate consumers' experiences and views of services and feed them into policy and decision making structures; and
- an interactive website and hard copy newsletter to link, inform and support consumers state wide.

This fits with discussions which have already taken place in the Consumer Organisation Project. It also opens the way for any consumer organisation to acquire a wider remit in the longer term. This might entail supporting a consumer representative program (like the ACT Mental Health Consumer Network), providing consumer educators to work in clinical and non-clinical settings, developing consumer-run services (like the peer support provided by the Consumer Activity Network in NSW) or undertaking community development work to nurture and support new consumer groups (like VMIAC in Victoria).

Although the consumer movement is characterised by an extraordinary resilience in the face of setbacks the research has demonstrated that the development of consumer organisations across Australia has been halting due to a range of factors including funding. Consumer organisations are subject to the pressures all growing community organisations face as well as the possibility of cyclical illness among staff, volunteers and the governing body. It is also clear that inadequate funding for a Tasmanian organisation will undermine its capacity and sustainability. Funding levels must be adequate to attract and retain appropriately skilled staff to positions which will require community development, communications, community sector policy and programme expertise.

This research does not recommend a specific funding allocation for such an organisation. However, experiences in other jurisdictions and a growing literature demonstrate that a mental health consumer organisation may need to be seeded and funded in a different way to other community organisations. Not only do funders have to provide adequate financial resources but they also need to ensure opportunities for developing the capacity of the organisation so that it

is not set up to fail. It requires a funding formula which recognises these particular needs which is clearly defined and agreed through a Service Agreement with annual performance and reporting requirements. Funding must be adequate for core functions which include the maintenance of communications mechanisms with the membership, state-wide coverage and policy development. It should be noted that industry sectoral peaks in Tasmania with governing bodies, professionally trained staff and a membership base receive funding of around $150,000 for core functions.

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Recommendation 1: That the Department of Health and Human Services provide funding to establish a state wide mental health consumer run organisation with the above elements in Tasmania.

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The research has clearly shown that if incorporation as an independent body is not immediate, auspicing outside the mental health sector should be considered. This avoids a situation where consumers have difficulties in escaping the role of 'patient' or 'client' and the accompanying discrimination that this can entail.

6.2.2 Developing a consumer workforce

The research has demonstrated that both in Australia and internationally the value of consumer roles in mental health services has been widely accepted. Consumer workers are seen as mechanisms for the transformation of services towards a recovery orientation, as vehicles for cultural change and for inspiring hope and as providing much needed employment opportunities for people with mental health problems. They can facilitate consumer participation activities and provide general support and mentoring to other consumers. Ideally consumer workers should be integrated into mental health services at several levels:

- as peer support workers in clinical and non-clinical environments to provide support and 'befriending';
- as consumer consultants, advisors or advocates in local services to oversee feedback processes and provide systemic advocacy;
- as consumer representatives to participate in decision making forums;

- as consumer educators in mental
  health workforce training; and
- in management positions to develop and co-
  ordinate consumer participation mechanisms
  at a regional or state wide level.

Lessons learnt from other jurisdictions point to a necessity for clarity about consumer workforce roles and responsibilities and a need to ensure appropriate remuneration, employment conditions, training, support and career pathways. There is also a recognition that developing a consumer workforce can take time and will need to have both short term and longer term goals. A starting point might be the piloting of consumer consultancy and/or peer support positions in Mental Health Services which are rigorously monitored and evaluated.

Recommendation 2: That the Department of Health and Human Services support and facilitate the development of a consumer workforce in Tasmania in collaboration with mental health consumers.

The *Bridging the Gap* report (DHHS 2004) made funding available for four consumer and family/carer advisory positions – a senior consumer and carer consultant and three regional posts. The regional posts remain unfilled. This report recommends recruiting to these posts as soon as possible to create 'consumer/carer liaison positions'. These positions would ensure engagement systems are in place and operational, organise consultation mechanisms, provide consumers with information about their rights and foster the development of consumer support groups. This would be carried out in collaboration with any new consumer-run organisation and with CSOs. Again given the difficulties consumer workers have experienced in other jurisdictions these posts need to be accompanied by an appropriate supporting infrastructure.

Recommendation 3: That the Department of Health and Human Services use funding already allocated through the Bridging the Gap report to immediately recruit three regional consumer liaison workers to oversee the implementation of participation mechanisms and to build the capacity of consumers and carers to participate and of mental health providers to facilitate that participation.

One of the key reasons for developing a consumer workforce is to initiate the cultural change required to forge a recovery orientated service. This can also be promoted by encouraging consumers to become part of the professional mental health workforce through using positive discrimination and flexible working arrangements in the recruitment of staff to mental health programs. People who have used mental health services who are 'experts by experience' and who now hold paid employment both inspire other consumers and provide evidence to staff of what can be achieved. This challenges the 'them and us' culture and the low expectations held by so many mental health professionals and works to reinforce social inclusion. It can also assist with easing shortfalls in recruitment to the workforce by expanding the recruitment pool.

Recommendation 4: That both public mental health services and those operated by CSOs implement positive discrimination practices in recruitment to mental health programs towards those with a lived experience of mental health problems.

6.2.3 Capacity building

Establishing a consumer-run organisation and developing a consumer workforce requires firm foundations and implementing the basic building blocks of consumer participation and empowerment. This means setting up mechanisms to:
- ensure the involvement of consumers in care planning and treatment at an individual level;
- provide information about mental health services state wide. (This process has begun with the development of a booklet for consumers, carers and family members);
- support the development of consumer support and self-help groups across the state;
- provide training for consumers to better negotiate the mental health service system, to build self esteem, to acquire the specialist skills required to fill peer support, consumer consultancy, consumer representative and

consumer educator roles and to boost expertise in the governance of consumer-run organisations; and

- provide training for clinical and non-clinical staff to understand the benefits of consumer involvement and raise awareness of the consumer experience.

Recommendation 5: That the Department of Health and Human Services provide opportunities for the training of consumers in order to build the capacity of the consumer movement.

Research demonstrates that the attitudes of staff are one of the major blocks to participation activities. It also shows that using consumers as trainers and educators enhances effectiveness and leads to more positive post-training attitudes towards consumers and involvement activities. However, although consumers are involved in the training and education of the mental health workforce in Tasmania there is no consistent approach which ensures that a consumer perspective is embedded in in-service training programs, in vocational and educational programs and at a tertiary level at the University of Tasmania.

Recommendation 6: That the Department of Health and Human Services make the consumer perspective intrinsic to all aspects of the education and training of the mental health service workforce through using consumer educators.

Recommendation 7: That the University of Tasmania through the Pro Vice Chancellor, Centre for the Advancement of Learning and Teaching, ensures that the consumer perspective and the use of consumer educators is embedded in teaching related to mental health issues.

As well as the need to establish consumer perspective teaching, there is also a need to establish more consumer perspective research.

Recommendation 8: That the Department of Health and Human Services sponsor a dedicated mental health consumer research fellowship at the University of Tasmania.

Both this research and the Review of Consumer and Carer Participation conducted by Mental Health Services has shown that many consumers want support and self-help groups where they can gain mutual support and acceptance from others, promote recovery and engage in social activities. There are currently a number of such groups across the state operating independently as well as being supported by Mental Health Services and by CSOs. However there is also a significant unmet demand for these groups.

Recommendation 9: That the Department of Health and Human Services ensure mechanisms are available to develop and nurture consumer support and self-help groups across the state.

Unlike some jurisdictions Tasmania has no peak representative body for consumers in the health system. Elsewhere these have operated as mechanisms for capacity building in the mental health consumer community, for example, the Health Consumers Alliance in South Australia and the Health Consumers Council in Western Australia. They have provided support for mental health consumers, offered training to promote the ability of consumers to become active, built a health consumer leadership and in some instances auspiced specific mental health consumer activities. A peak body in Tasmania should provide a range of advocacy and information services for consumers as well as a focal point for training initiatives and leadership building.

However, current proposals for such a body in Tasmania suggest that the consumer peak would represent the interests of clients of health and human services potentially broadening its remit to include a wide diversity of interests (such as clients of homelessness services, public housing tenants, ex-prisoners and so on). Representing such a breadth of concerns would clearly be difficult and would require strong linkages with a membership of effective consumer organisations.

Recommendation 10: That the Department of Health and Human Services strengthen consumer engagement with Tasmania's health and human service system by establishing a peak body to represent consumers and the community, to support engagement activities and to strengthen consumer networks and organisations.

The Social Inclusion Unit is currently developing a social inclusion strategy for Tasmania which will outline a set of guiding principles. Anglicare has already, in its submission to the consultation process on the strategy (Anglicare 2009) advocated for a human rights framework and for local and service user accountability whereby any strategy must ensure a voice for people at the local level. Although many people with mental illness fully participate in the community, there are a proportion who experience severe disadvantage and exclusion and whose voices are not heard. This is particularly true of those with severe mental illness.

Recommendation 11: That the Social Inclusion Commissioner advise the Premier to direct the Tasmanian Government's Social Inclusion Unit to explore the civic participation of marginalised groups as a goal of the Tasmanian Social Inclusion Strategy.

This recommendation supports that made by the TMHCN in their submission for mechanisms to support the civic participation for people with a mental illness (TMHCN 2009).

6.2.4 Oversight, monitoring and evaluation

Across Australia the evidence base for mental health consumer participation and consumer-run initiatives is sparse. What evidence there is is overwhelmingly positive, but there is also a need to ensure both routine monitoring and systematic and comprehensive evaluation. Whatever initiatives or mechanisms are established in Tasmania it is imperative that their processes, impact and outcomes are measured. As well as public mental health services provided by the state there

are now an increasing and diverse range of community mental health services delivered by CSOs. This means that CSOs must also be involved in any monitoring and evaluation exercises.

The National Standards for Mental Health Services require services to have policies and procedures relating to consumer and carer participation. These are reviewed by external accreditation bodies. However despite this requirement there is a lack of mandates on how processes or mechanisms should be facilitated. This leaves room for local interpretation and fosters an environment where responses are ad hoc and unsystematic.

Recommendation 12: That the Department of Health and Human Services ensure that performance indicators and outcome measures are developed and monitored for any consumer participation mechanisms or consumer initiatives in both public mental health services and in CSO provision and that this is undertaken in partnership with consumers and carers.

Recommendation 13: That the Department of Health and Human Services ensure that a requirement to involve consumers and/ or to employ consumer workers is built into the contractual requirements for CSOs providing mental health services.

Recommendation 14: That CSOs delivering mental health services ensure that the existence of consumer engagement mechanisms are a key quality indictor in their organisation.

Experts by Experience: Strengthening the mental health consumer voice in Tasmania