

# Pathfinders

## CONSUMER PARTICIPATION

In mental health and other services:  
Evidence based strategies for the ways ahead



Consumer-collaborative social action research  
**By Allan Pinches**

Consumer Consultant for Mental Health  
Bachelor of Arts in Community Development (Victoria University)

**Fully comprehensive overview of consumer participation  
Challenges, problem-solving, and areas of potential  
18 key achievement areas -- 55 action strategies  
Keeping active consumers' work effective and sustainable**

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# **PATHFINDERS – Consumer participation in mental health and other services: Evidence based strategies for the ways ahead**

**Consumer-collaborative social action research report**

**by Allan Pinches,**

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# Summary statement

This research project aims to make substantial contribution to the evidence base and help inform discussion about the experiences, achievements, the challenges, problem solving processes, future strategies and key areas of potential for consumer participation programs in public mental health services in Victoria.

The report has a particular focus on the dedicated work and major contributions of the Consumer Consultants employed within Victoria's 22 clinical Area Mental Health Services and some related disability support, health and community services.

This comes at a time when many mental health services are looking to enhance consumer participation through many different strategies -- including the extension of employment of consumer consultants into Psychiatric Disability Rehabilitation and Support Services. (PDRS) Innovative consumer participation approaches developed in the mental health field are now also helping guide and inform similar consumer and community participation initiatives in general health and community services.

This consumer collaborative social action research project was carried out with the spirit of Participatory Action Research, (although its design had differences to PAR) and sought to reflect an innovative consumer-perspective/ service staff collaborative values base. The project came into being partly in answer to questions about information consumer consultants themselves wanted to know, to determine what progress had been made and how it could be extended.

The research seeks to identify many key achievements of consumer participation, explore many issues impinging on the success and effectiveness of this unique consumer advocacy approach, analyse and explore ways that barriers and constraints have been addressed, and to highlight some possible strategies to further strengthen and extend consumer participation in mental health services. The research is also expected to help guide the rapidly unfolding development of consumer participation across many areas of health and community services.

This report is a revised and somewhat augmented version of the research report from a project carried out in part fulfilment of the author's studies for his Bachelor of Arts in Community Development (Victoria University of Technology.) The author was also undertaking a concurrent placement at the Victorian Mental Illness Awareness Council. (VMIAC.)

Consumer Consultants are diverse and multi-skilled workers with personal experience of being consumers (or service users or patients) of mental health services in Victoria, who are employed to go "back into the system", with varying levels of support and acceptance of their role, to facilitate a range of consumer participation activities, aimed at enhancing consumer rights, empowerment, more say for clients in their own treatment, and consumer-led improvements in mental health services.

The project draws on an extensive literature review and of both formally published and consumer-generated materials; evidence from interviews and a workshop with Consumer Consultants; interviews with service provider managers and staff; and the deliberations of an expert Critical Reference Committee, in analysing evidence, and developing lines of discussion and possible strategies for the future.

Consumer participation is seen by the growing and worldwide consumer movement -- and a steadily emerging "critical mass" of service providers, health and community services leaders and policymakers -- as an important vehicle for consumer rights and empowerment, improvement of mental health services and more effective service delivery, more closely tailored to consumers' expressed needs and lived experiences, more integrated with a range of community resources, and assisting consumers in meeting the challenges and opportunities that go with greater participation in the wider society.

## Acknowledgements

The Researcher wishes to thank the other members of the Critical Reference Committee for their generous assistance, and the knowledge, wisdom and insight they brought to the project. Their support and encouragement made a made a vital difference.

### ***Members of the Critical Reference Committee:***

**Wanda Bennetts**, Consumer Consultant from an Area Mental Health Service

**Liz Carr** (then Metropolitan Advocate), Victorian Mental Illness Awareness Council (VMIAAC),

**Merinda Epstein**, Consumer Advocate/ Academic;

**Greg Miller**, then Coordinator of a Mental Health Program Training and Development Unit.

**Allan Pinches**, (the Researcher), in completion of his Bachelor of Art in Community Development at Victoria University of Technology and a Consumer Consultant for an Area Mental Health Service, and broad involvements in the sector.

**Sue Robertson**, Consumer Rep for a Consumer Advisory Panel at an Area Mental Health Service;

**Peter Sanders (Rev)**, co-ordinator, “Hope Springs” Rosanna Uniting Church support and pastoral care service for consumers and carers in the mental health field.

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## Thanks

Thanks are due to the Victorian Mental Illness Awareness Council for being the host agency for my VUT student placement and research project and particularly my agency supervisor, Liz Carr, who substantially supported this project and helped shape its development throughout the life of the project.

The Bachelor of Arts (Community Development) course at Victoria University of Technology and CD course at Kangan-Batman TAFE are a continuing source of learning, personal growth and inspiration for so many people who want to be active in seeking positive social change. May these courses go from strength to strength!

I want to thank all of my friends and associates who have supported me and encouraged me in my work and involvement with consumer participation, who have kept me going when the going was tough. Especially to my darling wife Sue who is my soulmate and fellow traveller in all of these endeavours and a source of insight and wisdom.

I would also like to pay special tribute to the memory of late Mr Maurie Pitfield, a pioneering CEO of the Richmond Fellowship of Victoria, my friend, a man of great determination and talent (as well as complexities and contradictions,) who was afire with “the Vision” more than two decades ago of community managed mental health services where consumers could change *themselves*, the *system* and maybe, in some ways, *the world*. I think many of us are now walking that road.

-Allan Pinches, Consumer Consultant for Mental Health, Bachelor of Arts in Community Development

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# INTRODUCTION:

## Key objectives of the research project

**This research project sets out to explore and help to develop a range of possible action strategies to strengthen and build upon the widely acknowledged success of many consumer participation programs and activities in mental health services in Victoria.**

It closely examines consumer participation programs and activities in Victoria's clinical mental health services with particular attention to the achievements and conditions operating in the Victorian Government-funded Consumer Consultants Program in Area Mental Health Services.

### ***-Consumer participation an important contributor to change***

Considerable evidence is identified in this report that these innovative consumer participation projects have had a marked influence on processes of systemic change and quality improvement in mental health services -- despite the "shoestring" resourcing and often difficult conditions under which these projects often take place.

This research project tends to confirm suggestions from consumers and a growing number of service providers that increasing the financial base and support systems for these projects would strengthen consumer participation and enhance its benefits.

An evidence backed rationale for increased funding and improved and expanded support systems for consumer participation projects in mental health seems to be finding increasing support among service provider managers and staff and consumer advocates, as well as a range of other services in the community.

Better resourcing and more comprehensively-developed support structures and processes for consumer participation projects, along with a deeper and more articulated level of engagement in various forums within services, would allow services to build upon the many demonstrated successes and emerging areas of potential from consumer participation.

This present research study makes an attempt help identify and make strategic recommendations about a new level of resourcing and support systems for consumer participation through reliable research and development processes and the building of a more solid evidence base for consumer participation, in terms of its effectiveness and potential as an influence for innovation and change in mental health and related fields, given the right circumstances.

### ***"Pathfinders" report: A new strategic overview of consumer participation***

This Consumer based Social Action Research Project provides a new strategic overview of Consumer Participation – responding to the consumer movement' challenging task of seeking growth, empowerment, strengthening consumer participation work, in ways which would be effective and remain congruent with our deeply-held values base which respects the direct experience and knowledge of consumers.

The study was partly taken on in response to an expressed need arising from workshops within a planning conference of about 30 Consumer Consultants at Moama in 2003, hosted by the consumer

peak body the Victorian Mental Illness Awareness Council (VMIAC.) The group discussions covered many achievements, challenges, problems, areas of potential in the work, and possible strategies to strengthen the work.

A number of prominent leaders in the consumer movement within the past few years have commented on a lack of consumer-based and comprehensive research about the achievements, range of activities, working dynamics, and possible strategies to strengthen and promote consumer participation projects. This current project was conceived from the perceived need for some organised process to help develop further steps in the debate, beyond producing yet more articles and papers about “how to do” consumer participation or “why it needs to happen” and to work together to “take stock of achievements” discuss many issues and chart many ways of consolidating and strengthening these projects and some future directions.

## **How this research project report offers a structured and easily navigated overview of consumer participation:**

**An overview and logical progression is offered here for exploring a range of issues. The qualitative social research was built up in a strategic and developmental manner, throughout the research project’s inquiry, analysis and writing phases.**

The major design elements are laid out in a progression which broadly includes:

- Documenting key achievements of Consumer Consultant/ consumer participation projects and activities in Victoria and at local mental health services within the past seven years – notwithstanding marked limitations of resources and support systems.
- Factors which helped and hindered consumer participation projects.
- Problems, barriers and constraints encountered.
- Investigation and analysis of the nature and possible causes of these situations, including apparent implications of policy, programmatic, political and economic factors.
- Suggestions from Consumer Consultants, service provider staff and managers, and others of how problems and barriers and constraints might be addressed or overcome.
- Suggested action strategies to strengthen and build on the achievements of consumer participation programs in clinical mental health services, with emphasis on matters of resourcing, support systems for consumer participation, and services’ cultural and systemic aspects.
- Emerging new applications for consumer participation and areas of potential in mental health services and other health and community services.
- Develop strategies to strengthen and progress the Consumer Consultancy and consumer participation;
- Implement the project in ways congruent with the deeply respectful, diverse and inclusive values base of the consumer/ survivor/ ex-patient movement, which many have maintained as our greatest collective strength and strongest resource

## **“Concrete” evidence and strategies emerging in relation to the achievements, challenges, and future potential consumer participation**

This broad-ranging qualitative social research project, -- which was more Participatory Action Research in its guiding philosophy or “spirit” than was possible to be achieved in practical terms --was designed in ways which sought to encourage and facilitate discussion and reflection about many important questions in relation to consumer participation.

It explores many achievements of Consumer Consultants programs, examines various barriers and constraints and factors for success; looks at methods of problems and solutions have been used; examines issues around resourcing, support systems, and ways of promoting systemic and cultural change within services; and puts draws together various possible action strategies for strengthening and growing consumer participation in health and community services.

### ***-Stresses, personal demands, and impacts upon Consumer Consultants***

**While the value and cost effectiveness of Consumer Consultants projects may be a legitimate factor for services to consider when evaluating consumer participation programs, as a knowledge resource and developmental “tool” for services to gain a better understanding of the expressed needs of people using mental health services – it is also important to recognise that many of these innovative and ingenious projects have been developed by dedicated and “overworked, underpaid” consumer workers, reps and volunteers, often with great personal sacrifice and stress.**

**A key message coming through this research seems to be that there are limits to how far this equation of self-sacrifice by Consumer Consultants, can be pushed and services could be argued to have a special responsibility to be aware of this—partly because of inherent power imbalances in the employment of consumers as change agents within a system which has a range of impacts on them and others, and the somewhat open-ended and “challenging” nature of the work.**

The research involved a wide-ranging exploration process which combined both inquiry and discussion. This led through many broad, complex and multi-faceted discussions, ongoing within consumer advocacy – a field where many principles and values familiar within social theory, such as power balances, or concepts of empowerment, or social justice or equity have a particularly relevance and immediacy.

### ***-Many examples given of consumer-led projects making a difference “on-the-ground”***

This research report contains a large component of first-hand and detailed accounts about the implementation of consumer participation projects and activities aimed at building mental health services which are more responsive to the expressed needs and lived experiences of consumers.

The unique and special role that Consumer Consultants can play in consumer participation is an innovative form of systemic consumer advocacy in itself, and can make a large difference in helping bring about “consumer-led” improvements mental health planning and development and in actual service delivery.

**The research should help consolidate the view that mental health and other health and community services have much to gain from the knowledge and strategies emerging from collaborative consumer participation projects. It seems to be amply demonstrated in this study that consumer participation projects can greatly facilitate development of better and more responsive service systems, more effective methods of treatment and care, and contribute to more positive service outcomes for all stakeholders.**

While much of the momentum of Consumer Consultants' work and consumer participation is clearly related to the growth of the mental health consumer movement, which is increasing in numbers and influence – but the sheer utility and applicability of the products of consumer participation in a programmatic and policy areas is also an important driver for this type of systemic consumer advocacy.

The overall findings of the “Pathfinders” research were broadly able to confirm many points that came out in the Department of Human Services funded “Evaluation of Consumer Participation in Victoria’s Public Mental Health Services (Service Quality Australia, 1999) – but it was pleasing to note that considerable progress seems to have been made across the mental health service sector, with significant difficulties remaining in some areas.

In line with the Service Quality Australia evaluation, which was then three years into the consumer consultants program, services were along a continuum of engagement, understanding and support of consumer participation and the situation was “patchy” across the state in terms of achievements of stakeholders’ belief of what could be possible.

Service providers had debated in the times of the 1999 report about the nature and need of consumer participation from various perspectives, and questions of “why should we be doing consumer participation?” This research suggests that this gradually grew on campuses to “how can we support it?” “To what extent should we become ambassadors for this model?”

The 1999 document urged governments, services, consumers and all other stakeholders to work to strengthen the structures and processes for consumer participation, by a combination of evolving, growing, and building consumer participation programs and initiatives.

***-The benefits of consumer participation are clear – and informants hold that so are the strategic benefits that would flow from a boost in resources and support systems for consumer participation***

Informants in the research from among mental health consumers and service providers clearly believed that consumer participation has demonstrated a great ability and potential -- given appropriate resourcing, adequate support from service management and staff, and effective support systems for active Consumers -- to make progressively greater contributions to service development and improvement processes and service delivery.

It was unanimously maintained by consumer and service provider participants in this study that higher levels of funding to be allocated by State and Federal Governments for consumer participation activities would be desirable. Many parties, including some service providers also support the notion of local services putting their own resources into these projects.

***-Some senior managers strong supporters of consumer participation – including seeing the merit of arguments for better resourcing***

**Several senior managers and senior staff in the clinical mental health system who were interviewed for this research expressed unequivocal support for the achievements and growing range of applications for Consumer Consultancy and consumer participation.**

**A top-level executive in a mental health service network firmly stated the belief that consumer participation had “earned its stripes” in mental health service planning and development. The executive added that consumer participation was working to its utmost capacity already, and for more benefits to flow, consumer participation “deserves to be better resourced.”**

**Another high-level manager, from an Area Mental Health Service said: “I think the information we get from consumers really does really inform and re-shape some of the ways we’ve done things...” Asked by this researcher about whether resourcing should be improved, the manager replied: “I would hope that consumer consultancy and consumer participation is funded in a way that keeps up with the enormous developments that are happening.”**

Most Consumer Consultants who were interviewed or took part in the interviews and workshop discussion also placed a premium on issues of financial resourcing, arguing that this could have a large bearing on success or otherwise of projects.

As well as increased core funding, one possible solution suggested was for some of the costs of consumer participation activities could be “shared” by different parts of an organisation that benefit from the resource, such as a localised service within an Area Mental Health Service, which makes use of input to a project or development from the Consumer Consultant or other consumer reps. This and other ideas discussed by CCs and other stakeholders appear in more detail in the section on evidence and discussion. There is also a case study which highlights possible strategic ways of structuring financial aspects of project.

## **Six major suggested strategies for strengthening consumer participation:**

**Discussion by participants within interviews and a workshop, pointed to possible future growth and development in consumer participation which could provide for:**

- Through training and development create more opportunities for active consumers to go onto “pools” of consumers in their areas for committees, special projects and consultations, as skilled and fully informed contributors. Would require resources to carry out.
- Involve more consumers in consumer participation, using many different methods, and encourage a greater “diversity of voices” from across different groupings in society, some who are poorly represented now in both advocacy and service usage issues.
- Extending and enhancing consumer participation throughout the mental health service system, including being consumer consultants getting more “say” in clinical aspects of service development.

- Making consumer participation a “built-in” part of services rather than an “add on” -- more integral to the full range of service operations, including staff education and training, staff selection, and community education and development work.
- Exploring new and innovative forms and applications for consumer participation a substantially proven and very cost-effective knowledge resource for service planning and development.
- Possible “exporting” of Consumer Consultants/ consumer participation methods to other areas of health and community services, in various ways for social benefit and mutual advantages. This could also be a way of drawing in additional resources for consumer projects.

## **Major qualitative considerations emerging from the study:**

### ***-Consumer perspective as the “must have” factor in consumer advocacy***

Consumer advocates maintain that working from a consumer perspective is an indispensable element of any consumer participation activity. Accepted consumer movement wisdom points to a certain range and diversity in consumer perspectives from the standpoint of the knowledge and experiences of particular groupings and individuals – while at the same time there are many areas of commonality.

However, as several informants pointed out, the clear common denominator for consumer participation work is an absolute respect and concern for the lived experience of consumers.

The study draws from a rich contextual field of knowledge generously shared by informants to this study, and the ongoing consumer participation work going on in the field, it is clear that the current and prospective changes and developments in mental health services require pro-active, collaborative, and dedicated efforts by many people. Much of this is given good expression in the evidence and discussion section later in the document. It would be desirable to have in the field follow ups for information sharing, swapping-models or education for consumers and staff on various areas.

### ***-Money alone can't buy service improvement...service provider “attitudes” can be a make of break factor.***

It emerged that many of these Consumer Consultants were often more immediately concerned and affected by the many ways that the cultures and environments of mental health services could be a supporting factor for consumer participation efforts, or the source of difficult and frustrating barriers.

“Attitudes” of service provider staff and managers towards consumers and receptivity to change were seen by some stakeholders as an important factor influencing outcomes

Consumer consultants spoke about a wide range of experiences at their local Area Mental Health Services.

A sizable number of Consumer Consultant informants reported that they could in varying degrees work collaboratively with service providers to carry out projects, and develop through dialogue new understandings that help inform positive changes in key aspects of services.

It was often a question of whether services would listen to and recognise the value of consumer perspectives -- or constantly act in ways which frustrate the attempts of consumer consultants and reps to try to discuss often difficult issues and get changes made.

Other Consumer Consultants, an apparently smaller group -- who measured their situations in various different ways -- said that the local Area Mental Health Services where they worked remained apparently “resistant and entrenched” toward consumer perspectives, maintaining attitude barriers and “us and them” thinking, and sometimes taking a “pathologising” view of issues. Consumers spoke about exhaustedly feeling like they were hurling themselves “up against a brick wall.”

A more subtle but still difficult situation was where consumers perceived that services seemed to be “saying all the right things” but were short on meaningful action – sometimes opting for quick fixes, tick - the - box checklists and “tokenistic” displays of consumer participation through Public Relations exercises, and ever more pamphlets.

Themes of this kind, and examples where the work achieved far more through partnership and shared visions, are elaborated upon in the evidence and discussion section later in the document. Many of the trends discussed were more encouraging, with evidence of noticeable change within the system.

### ***-Service provider support, goodwill and collaboration a beneficial element***

It was acknowledged by consumer informants that the achievements of Consumer Consultants and their groups of consumer reps would not be possible without the support, goodwill, consumer-awareness and collaboration in these projects by service provider managers and key staff. There are many service provider supporters and “allies” of consumer participation, who understand the meaning and significance of consumer perspectives, and who have encouraged many consumers in this work and been champions for consumer participation as a process for positive change.

There are also many newly developed and emerging areas of cross-over of consumer participation knowledge from the mental health field into areas of general health and community services. The principles of consumer, carer and community participation, are also becoming more widely adopted across the spectrum of health and community services -- and the pioneering work of mental health consumers and service providers in this regard is a shared point of pride.

### ***-Consumer participation can stimulate and open up a range of “wider debates”***

In Victoria, as with other States and at the Federal Government level, financial restraint remains a major defining characteristic of economic policy. And the same financial considerations also have a major influence on the extent to which is it possible for mental health services and other health and community services to be implemented in accordance with policies annunciating a values base consistent with a social model of health, but not funded in a way that such approaches to achieve their potential. Currently various aspects of healthcare do have prominence in the social and political agenda but the media debates often concentrate on “crisis” scenarios, often overlook the hard work by many stakeholders in the mental health field to improve the service system, and financial arguments are simplified beyond usefulness.

However while the prevailing “realities” about policy and funding settings are of crucial importance, this research project deals with much more than matters of funding or even matters of policy and programmatic imperatives.

From a broader view, this document in part provides a detailed overview of a fascinating journey of discovery in the mental health field, where many active consumers are serving as often very skilful “Pathfinders” towards new ways of seeing things and doing things in mental health services. These new “learnings” in terms of method and content in Consumer Consultancy, are also proving to have

ready applications a wide range of health and community services, and indeed consumer participation is an area of growing interest, and even excitement, across many service types.

This research project can also help to showcase some of the best and most innovative thinking and action taking place in mental health consumer participation today, with many words quoted directly from many of its leading exponent Consumer Consultants, some of whom are involved with academic and community based work.

***-The “life” of the project kept getting better as more people realised the huge, even daunting, potential for consumer participation.***

The qualitative research project was aimed at working collaboratively and developmentally with a range of Consumer Consultants and a number of very experienced Consumer Consultants/ Advocates, together with some service provider staff, in exploring ways to enhance consumer participation in mental health service planning, development, training, recruitment, training and education, delivery, and evaluation.

This research project involved an intensive and solutions-focused literature review, various policy and programmatic investigations, semi-structured interviews with a range of stakeholders including Consumer Consultants, service managers and key staff, and analysis by an expert Critical Reference Group, the research project aims to help create a more substantial evidence base about what factors are most conducive to strong and effective consumer participation projects, and how these might be translated into practice.

The research project has drawn upon a range of data and sources of analysis and conceptual development, including: a range of solutions-focused documentary sources; semi-structured interviews with various key players in consumer participation, including interviews with a number of Consumer Consultants; interviews with a number of service providers; a workshop session for interested Consumer Consultants, as an add-on to the cycle of VMIAC Consumer Consultants meetings; and the special analysis and deliberations of an expert Critical Reference Group, whose consumer and service provider members had extensive knowledge, experience, vision, conceptual skills.

This research project and report will hopefully provide a rich source of valuable information about many aspects of consumer participation in mental health and how this unique human services activity translates into the lives of mental health consumers, service staff, managers, policy makers, carers, community service providers, and the wider society.

But it also is designed to make a substantial contribution to the evidence base of consumer participation – in terms solid and tangible enough to back up real time submissions and negotiations for additional funding and provision for development of better support systems for this work.

# Key research questions:

**The research explored the following questions and sought to explore a range of action strategies to strengthen consumer participation projects and activities in clinical mental health services in Victoria.**

- What have been some of the positive achievements and emerging potentials of consumer participation programs and activities in clinical mental health services in Victoria, notwithstanding limitations of resources that have been made available?
- How have resourcing limitations contributed to problems and constraints in consumer participation programs and activities in mental health services in Victoria?
- What personal costs and difficulties do consumers face in trying to carry out this difficult role?
- To ask a question somewhat colourfully: “How do Consumer Consultants manage to do “The Impossible,” in a System widely-acknowledge as slow to change, with very scant resources – and how come they are actually having quite a lot of success?” Is it really a case of extraordinarily dedicated people doing extraordinary things?
- What additional resources and what enhancements to support structures and processes for consumer participation would be needed to give service users a stronger voice in mental health service improvement and public policy?
- What are some possible sources of additional funding for consumer participation and advocacy and are some possible avenues for future collaborative partnerships?
- What might a well-resourced consumer participation system for Victoria look like, both centrally and locally? What practical strategies and directions can be developed for the future?

A detailed explanation of how these research questions were translated into the semi-structured interviews, utilising a logical progression formulated by the researcher in close consultation with the Critical Reference Committee, is set out within the Methodology Matters section.

# Situation overview of consumer participation in Victoria's clinical mental health services:

**The State-funded employment of Consumer Consultants within Victoria's 22 Area Mental Health Services, across the regions, is the major "spearhead" for consumer participation programs and activities in clinical mental health services.**

The State-wide Consumer Consultants Program was implemented in Victoria in 1996, under Federal and State mental health policy frameworks which put consumer participation high on the agenda. The initiative was at first funded as a one year project but three years into the program was granted recurrent funding.

A smaller number of Consumer Consultants work in Psychiatric Disability Support and Rehabilitation Services and specialist clinical services and agencies, which have only recently been promised specific funding to develop these roles in a future budget.

While consumer participation is a widely known practice within mental health services and is a genuinely innovative method of advocacy and service improvement, there is quite a well established set of policy and legislative provisions for it, going back to about the late 70s.

## ***-Innovative approaches from the "wellspring" of the acclaimed "U & I" project***

The program was partly based on the innovative and world-acclaimed "Understanding and Involvement Project (with the beautiful acronym "U & I") which pioneered the model of employing Staff/ Consumer Consultants in a consumer-controlled evaluation of an inpatient unit at the former Royal Park Psychiatric Hospital from 1989 to 1996. It is with inspiration from the "U & I" model, developed by researcher Yoland Wadsworth, Consumer Consultant and academic Merinda Epstein and a team of more than 30 Consumer Consultants, that this present research project has been designed to be implemented from an approach which aims to be "consumer perspective/ staff-collaborative."

The U & I Project (in fact a series of linked projects) was auspiced by the Victorian Mental Illness Awareness Council (VMIAC) the peak consumer body in the State. The VMIAC remains a champion of consumer participation in mental health services and provides much ongoing practical support towards its implementation, including consumer networking and education activities.

This takes place along side the VMIAC's important consumer advocacy work which includes:

- Maintaining and consolidating a strong and viable state-wide consumer network with about 80 local "active participant" groups.
- Individual advocacy for consumers encountering problems within mental health clinical and disability support services.

- Actively engaging in “big picture” systemic/ or group advocacy, policy development and public debate mental health issues; fostering consumer peer support efforts; and,
- Supporting consumer education and skill development, peer support, community access, and a range of community education/ awareness raising activities.

### ***-The consumer/ survivor/ ex-patient movement and awareness campaigns***

Consumer participation and advocacy appears to have made a key contribution to many contemporary changes in the mental health field, and is part of a much more broadly based movement to promote good mental health because of the benefits that would flow to the social and economic wellbeing.

A catch cry which has been used in awareness campaigns such as the annual Mental Health Week, is: “Mental Health: What Do You Know?” and “Mental health is everyone’s business -- Let’s talk about it.” There are equally important messages about how people with mental health problems should be treated in a socially just, inclusive and sustainable Australia. There are also messages about the economic costs of mental illness, in terms of lost productivity and cost of health care and support services, and huge downstream costs in human and financial terms if people’s needs are neglected. Recent newspaper opinion polls have tended to rate mental health more highly as an issue of public concern.

Some important landmarks in consumer participation in mental health services have included:

- Australian Mental Health Consumer Network, as a national “consumer voice” established in the mid 1990s and granted funding in recent years -- now building in capacity and strength.
- Vincent’s Peer Support consumer initiative at Albert Park, established in the mid 1990s and failing to get re-funded in 1997, becoming defunct. Unique project provided training and direct services in consumer peer support.
- Publication in 1998 of the landmark Commonwealth funded consumer and carer participation training package “The Kit – A guide for the advocacy we choose to do.” This had involved input from scores of consumer and carer representatives and remains the comprehensive guide for consumer participation in Australia.
- The consumer-run “Our Lives, Our Choices” conference in Adelaide, claimed to be the first major consumer run conference in Australia in the late 1990s.
- BBQs for Consumer participation in Melbourne in 2000, the brainchild of David Buller, at the time a worker from Eastern Region Mental Health Association (ERMHA.)
- Consumer participation in Australian and New Zealand College of Psychiatrists revised treatment guidelines on Schizophrenia, in early 2000s.
- Psych Activism and Training (PAT) initiative for Consumers as Educators of service staff, convened by Cath Roper. Consumer Academic, Centre for Psychiatric Nursing Research and Practice, Melbourne University, since 2001.
- VMIAC Consumer Consultant training and development monthly sessions, in recent years.

## ***-Mental health issues slowly climbing higher in the public agenda***

In the broader social context, it can be argued that while matters related to mental illness are inter-linked with virtually all areas of government policy, there has been a historical lack of political interest in a field not seen as a “vote winner,” possibly due to public ignorance, stigma and misinformation about mental illness and the previous lack of “voice” for consumers, their families, friends and supporters.

However in the past Decade State and Federal Governments have given mental health a higher place on the policy agenda, including consumer and carer participation, which were prominent features of the far-reaching and widely supported National Mental Health Strategy # I and # II.

There are also policy and legislative provisions for consumer participation within the

- National Standards for Mental Health Services.
- Victorian Mental Health Plan, Framework for Service Delivery of 1994.
- Victorian Guidelines for Consumer Participation of 1996, and the now-recurrent funding for employment of Consumer Consultants in Victoria’s 22 Area Mental Health Services.
- The Victorian Mental Health Act of 1986 also contains references to consumers having the right to participate in development of their treatment plans.
- Some sections of the Act also appear to extend these principles to having a say in the running of services.

While the lack of understanding, fears and stigma about mental illness are still widespread in the community, compounded by the tendency of parts of the media towards unhelpful stereotyping, there is some evidence that community awareness campaigns, and some more positive and increased media engagement with the social and economic significance of mental health issues, and a higher priority given mental health in the public agenda, are gradually bringing positive changes in public attitudes about the importance of mental health as a social good needing to be maintained and enhanced.

# *Progress indicators for mental health consumer participation:*

**The research highlights the many achievements and the often highly innovative work of consumer participation programs and activities in clinical mental health services in Victoria, largely made possible by the hard work and often considerable personal sacrifice of Consumer Consultants and other consumer advocates or reps, and their organisations and supporters.**

**The research evidence gathered from various stakeholders and many written sources in service provider and consumer literature tends to confirm that consumer participation is a significant and effective tool for positive change in mental health services.**

**A significant finding of the research project – reverberating throughout the accounts given by most informants – is that even with marked limitations in resources for consumer participation activities, a great deal of service improvement and innovation is being brought about in many local clinical mental health service systems.**

**Furthermore, the “wave” of consumer participation during the past decade may well have been a more extensive and influential source of service system improvement than any one stakeholder would be in a position to know.**

**Much of this success can be attributed to the extremely dedicated work of many Consumer Consultants – and the consumer reps and service providers they work in partnership with, and much willingness to “listen” and keep “open to possibilities”, practice honest critical analysis, pursue creative thinking, and use innovative problem solving approaches.**

The importance and usefulness of taking into account consumer perspectives – and also the views of carers and community groups – within processes of service planning, development, evaluation, delivery, training – and more growing consumer involvement in staff recruitment -- has been widely recognised and embraced by management and staff in mental health services, both clinical services and community-based services. Community managed mental health services are increasingly now run along “corporative” lines as often large Non-Government Organisations (NGOs) and now known at least in Victoria as Psychiatric Disability Rehabilitation and Support services. (PDRSs.)

The mental health consumer advocacy field is one constantly concerned with many moral and ethical dilemmas, and is a field where subtleties matter. In solutions-focused thinking advocates must navigate through complex “maze” of barriers, constraints, attitudes, service cultures, political realities of the day, and dominance of medical model of psychiatry, historical “hangovers” regarding concepts of madness, and social stigma, problems, and disadvantages faced by consumers, especially now that services are geared to an “often - idealised - but - seldom - realised” mission of “treatment in the community.” All of these factors need to be taken into account in seeking to understand the workings of consumer participation projects and activities.

# Achievements of consumer participation in MH field so far...

**Many improvements in mental health services have been set in motion in local Area Mental Health Services, based on advice and policy development coming out of various methods of consumer participation. There have been many achievements, some quite significant in their scope and others quite small but meaningful -- typically achieved within a range of often stringent problems and constraints.**

Consumer Consultants, and Advocates, and service provider managers and key staff, spoke about Consumer Consultants/ consumer participation projects having contributed to growing and emerging range of changes and developments across Victoria's mental health services -- to varying degrees in different areas.

Some clear indicators of progress participants have identified and discussed in the course of the research include the following:

- Enhanced levels of consumer and service awareness and observance of consumers' rights.
- Changing service environments toward **more "consumer friendly" practices**, attempting to highlight ways to "factor in" consumer perspectives throughout all aspects of mental health service delivery.
- Significant and welcome improvements noted by long-serving advocates and by key staff, in the **communication styles and attitudes – quite often now perceived as more respectful and affirmative** -- in dealing with clients and addressing their expressed needs.
- **Information provision practices by staff in services are described as having dramatically improved** across most of Victoria's mental health services -- in ways which helped to facilitate better utilisation of services by consumers, reduce consumer fears and uncertainty, minimise potential conflicts and which sought to favour approaches of explanation and cooperation, instead of coercion.
- Debate having shifted in many local mental services **from "why do" consumer participation to "how shall we do" consumer participation.**
- **Consumer participation is becoming in many local service systems an accepted and expected part** of any activity related to service planning and development. More of a "built-in" part of services and less of an "add-on."
- More **emphasis on health promotion, crisis-prevention, community linkages**, more focus on consumers' "real-life" issues, fostering family and social connections, and working towards consumers aspirations for fuller participating in the community, rather than just "coping."
- Services in many areas **trying harder to respond to consumer, carer and community diversity**, within modes of service delivery, feedback and complaints mechanisms, and consumer participation activities.

- A growing orientation in many services **towards a consumer-collaborative “reform agenda,”** and a willingness to learn and change by listening to and responding to consumer, carer, and community views, complaints or suggestions.
- A growing and increasingly diverse range of **major innovative projects with a consumer focus** are opening up, within a more “activated” mental health service landscape.
- Consumers gradually having more involvement with their own treatment planning and decision making, and enhanced choices.
- Action intensifying across a more defined “field” of identified problem areas, gaps, and unmet needs.
- Methods of consumer participation becoming more structured, coordinated, and integrated within service systems.
- Complaints systems and culture becomes superseded by a **newly emerging culture of making comments, suggestions, requests with a greater degree of expectation,** and an encouragement of open communication between consumers and service provider staff.
- Many service provider **staff becoming encouraged and energised by consumer participation,** the creation of more attractive “shared learning” working environments where staff can more fully exercise and enhance their skills.
- Consumer participation increasingly evolving and becoming **recognised as a creative tool in service development,** with great potential, when used collaboratively and in genuine partnership.
- More “windows” gradually opening to extend consumer participation into service’ discussions about clinical issues.
- Adversarial approaches to advocacy and demands for “basic consumer rights” are becoming de-emphasised in consumer advocacy overall, as these areas are tending to be improved/ addressed and other more developmental priorities emerge. When rights issues are at the forefront more recently, they often seem to be a mechanism invoked to remove obstacles or get additional progress in dealing with some wider aspects of services. These factors still do vary greatly between services and localities, with different issues more prominent in different areas.

These themes and issues discussed by participants are elaborated further in the Evidence and Discussion section later in this document.

Answers were sought throughout the research process to the fairly obvious question: With these signs of progress, how much more could be achieved through consumer participation if resourcing and support systems were to be enhanced?

# BARRIERS and CONSTRAINTS: Consumer Consultants often face hard work, “uphill battles”, difficulties with service cultures/ attitudes/ concepts, limited resources and inadequate support systems.

**Considerable evidence emerged from the research indicating that limited resourcing is a major factor preventing many of these projects from reaching their full, (and supporters of consumer participation would argue) *deserved* potential.**

There are also widespread accounts of Consumer Consultants trying to maintain large outputs of work, within an already complex and demanding role, with limited resources, putting in large amounts of extra voluntary time, in some cases striving to personally “bridge” service gaps, and often facing costs to their own health and wellbeing.

There has been a very high attrition rate (estimated by this researcher at more than 90 per cent) in these jobs since 1996, with only a “handful” of Consumer Consultants from the first entrants to these State funded CC jobs in that year, still working in their roles. This Researcher is one of these “survivors”, but has personally experienced significant difficulties in health and wellbeing at times, as well as challenges and enjoyment.

The research was particularly attuned to finding out more about the experiences of a range of Consumer Consultants and advocates.

Many Consumer Consultants report a mixture of “highs and lows” with the role, but often spoke of satisfaction, strengthened sense of purpose and being part of a movement for positive change in mental health services, which would ultimately lead to better health and life options for consumers.

**There is considerable support and some would say a growing “critical mass” of support, commitment and goodwill toward consumer participation among many service provider managers and staff and some genuine attempts to work in partnership and collaboration with consumers – as well as some quite entrenched pockets of doubts, resistance and “hangovers” from the institutional attitudes and approaches in some areas.**

**It is true also to say that mental health services may find themselves often preoccupied with coping with day - to - day crises of an overloaded service system faced with burgeoning demands for services and limitations on resources.**

Exhortations to “work smarter” in ways that do not necessarily have to cost more may be correct, but it would seem to be another matter to make operational this principle.

Staff, managers, and consumers alike are experiencing great pressures in the re-configured world of post-deinstitutionalisation mental health services.

The policy of mental health deinstitutionalisation and mainstreaming, was endorsed by the landmark Burdekin Inquiry report (Human Rights and Equal Opportunity Commission, 1993) as being a good policy direction on the proviso that these changes needed to be backed up by adequate community support systems and proper levels of funding, if benefit of people with mental illness and the society. The Inquiry went on to examine a wide range of evidence of shortcomings in the new system.

Organisations representing every type of stakeholder to the mental health field, from consumer and carer peak bodies, to non-government organisations, doctors groups and senior health managers have consistently and publicly maintained that Australia's mental health services and relevant community resources are severely under-funded for the massive job they have to do.

### ***-Issues “at large” in broader service systems and related community services***

Consumer Consultants in gathering feedback and discussing issues with consumers have been able to hear about and witness close-up many significant problems affecting consumers, and consistently speak out and try to contribute to greater awareness and policy and systemic management responses regarding difficulties faced by the mental health service system itself – such as:

- Severe shortages of acute inpatient beds, and case management services at clinics.
- Case Managers juggling what they say are “impossible” caseloads and many consumers who would benefit from case management may not be assessed as eligible for a variety of reasons.
- A perceived lack of “meaningful” rehabilitation services that genuinely promote and empower consumers to have fuller participation in society, including social, economic, and political involvement. PDRS services in Victoria are currently subject to client load “ceilings” due to funding restrictions, and in Adelaide and Western Australia these services are threatened with extinction, for inexplicable reasons.
- Severe shortages of housing and support services, and a pervading lack of private and public housing options for consumers, with many in inappropriate accommodation or being homeless. This often results in a lack of accommodation places to refer people to.
- Lack of capacity within the wider service system to cater to the needs of clients with difficult/conflictual family situations and multiple and complex needs.
- Difficulty addressing serious physical health risk factors and high and disproportionate incidence of serious physical illness and related high rates of premature deaths in consumers.
- Social disadvantage and discrimination in society because of stigma about mental illness; poverty; isolation; drug and alcohol problems; nutritional deficiency; major barriers to employment; difficulty accessing education opportunities; trouble getting access to “generic community services”, and many other issues.
- Many service provider staff in the mental health have expressed concern that the sector is a much misunderstood and under-recognised among health and community services, and the

wider society, and that staff often experience something like the stigma around matters of mental illness that consumers have to live with -- although in the current changing and competitive employment market the growth of jobs in mental health and related services may have brought the newly found respectability that might go with “growth industry” status.

***-Consumer consultants also take a close-up look at localised service gaps and problems***

Consumer Consultants indicated that consumers taking part in various feedback processes, like surveys or forums, have often spoken about a range of commonly experienced problems and frustrations of using mental health services that the Consumer Consultants can often validate by personal experience.

These included:

- Perceived negative or judgemental attitudes towards consumers among some staff, and some consumers feeling their humanity, individuality, and potential somehow subsumed to an illness identity.
- Desire for a more treatment and support alternatives -- and psychosocial, holistic and “whole life” approaches – instead of the domination of the medical model of psychiatry, with its emphasis on medication.
- Consumers say side-effects of medications can be disabling and unpleasant.
- Lack of choices of treatment and consumers sometimes being compelled to take medications regardless of their wishes.
- Sustained discontentment over the over-stretched and inaccessible services, often seen as more crisis driven than preventative.
- Complaints of poor methods of communication and information provision by staff.
- Difficulty “finding the way through the maze” in trying to get help for mental health problems, find suitable community supports, difficulty accessing services, waiting lists and lack of “meaningful” rehabilitation programs.
- Few links being offered by services to “real world” social and economic participation for people pursuing recovery from mental illness – such as actively exploring options, educational pathways, employment and training programs; socialising and relationships; leisure, play and ordinary holidays; dealing with officials, etc.
- And many other issues, often involving a sense of injustice, claims of having been harmed instead of helped, robbed of hope instead of encouraged and supported, “made worse” by treatment, and being desperate for “real” help from someone who would listen.

# RECOMMENDED ACTION STRATEGIES:

## **Baseline recommendations and evidence-based action strategies for the strengthening and further development of consumer participation in mental health and other services:**

***-Some important and operational strategies being pursued through the peak VMIAC consumer organisation, aimed at strengthening consumer participation programs and the work of Consumer Consultants.***

A major point of reference for this research project was the reported discussion, outcomes and subsequent reflections of participants from the first annual Victorian Mental Illness Awareness Council (VMIAC) Consumer Consultants' Conference, in Moama at the Victoria-NSW border region, in March 2003.

This landmark event was attended by more than 30 delegates.

The directions which emerged from Moama provide an important underpinning set of key approaches to build upon -- and other possible strategies, including many developed and featured in discussions within this present study can be harmonised with these broader approaches.

The Moama conference sought to take stock of achievements, and methods and processes influencing outcomes, and to comprehensively plan for the future, including actions and resources needed to make it possible.

Many discussions and developmental workshops were held about problems and limitations of consumer participation programs and activities, as well as the sharing of stories of success and emerging areas of great potential.

**A reading of official reporting of the conference, notes generated by some participants, and later discussion with some delegates and VMIAC staff, there were two recurring themes in the discussions about problems and possible solutions within Consumer Consultant facilitated consumer participation programs:**

- 1. More financial resources for consumer participation programs; and,**
- 2. Improved and extended support structures and processes to provide essential support, backup and capacity building for the work of Consumer Consultants and others working on consumer participation activities. (VMIAC, 2003)**

***-Some areas for further development and capacity building for consumer participation, suggested at Moama, and subsequently further developed and elaborated upon by informants to this present study, include:***

- More resources to increase the capacity of the Victorian Mental Illness Awareness Council (VMIAC) to support consumer participation programs – partly by creating stronger “nucleus” of support structures and processes.
- A **consumer information library and clearing house for the VMIAC** and the peak mental health consumer advocacy body in Victoria..
- New methods for networking and information sharing for Consumer Consultants and reps, including various uses of technology.
- Training and education programs for Consumer Consultants, advocates and reps.
- Consumers receiving training and opportunities to work as Educators and Trainers of mental health service provider staff, in structured, fully integrated and coordinated ways.
- Promote opportunities for consumer based research and development projects.
- Develop many ways for the **VMIAC and consumer consultants to keep hearing the voices of consumers** and promote the involvement of many more consumers in “the journey” of consumer participation.
- Additional financial resources be made available within local service systems for sitting fees, opportunities for training and development of Consumer Reps, and time allocation for staff involvement in various roles.
- Increasing the resources of VMIAC and other relevant consumer-collaborative organisations to be able to work pro-actively, develop more detailed submissions in policy debates, and gain a stronger voice on behalf of consumers in “big picture” systemic and policy issues.

Many possible directions and strategies can be developed from evidence highlighted and analysed in this research.

Some informants to this study have suggested that additional financial resources could come from philanthropic trusts, fundraising or corporate sponsorships, as well as specific governments “project” funding. This was agreed by Consumer Consultants and service providers alike to be an option more suited to one-off projects, rather than ongoing programs of consumer participation, which needed adequate and recurrent funding.

Government funding bodies (principally Victoria’s Department of Human Services) are already urging mental health services to look beyond government grants and use some of their own resources for any enhancements to consumer participation, arguing that it as it becomes more of a core activity within the service system, internal budgeting and local arrangements throughout organisations could take up some of the cost – in effect paying a charge internally -- to be able to locally use the “resource” of consumer participation maintained by the organisation.

Based on existing consumer practices in various Area Mental Health Services, Consumer Consultants may facilitate and provide direction and training to a central pool of consumers/ advisors in a local Consumer Advisory Group, who could be delegated out to other committees, forums, consultations etc in the service and beyond. From a bureaucratic dimension, this could be interpreted at a service

level "variation on the theme" of a "Purchaser-Provider Split funding method so characteristic of the prevailing "corporatised" policy environment. These or similar approaches do seem to assume the existence of a fairly well-established and sophisticated grouping of Consumer Reps, who would be well trained and have access to good quality information. Because these are quite stringent requirements such elements may take a long time to implement and be widely accepted.

The research found that some more progressive mental health services are already starting to dedicate some of their own resources to consumer participation, with local services factoring in local services the modest cost of sessional fees for consumer reps right from the start of local project committees, focus groups, or in the new practice of consumer participation in staff selection panels at a particular Area Mental Health Service.

Many consumers across a wide area still have difficult experiences within mental health services and the community, and often have a sense of powerlessness and frustration. Consumers as a group have a lack of access to resources and a lack of opportunities for developing collective responses, and this can gravitate against consumers having a clear "voice" in the mental health services system, the community and the wider political agendas.

And there many groups of consumers from diverse backgrounds who are further marginalised in terms of access to mental health services and community facilities, and consequently tend to get less chances for consumer participation.

A more networked approach to consumer participation could reasonably be expected to be one of the most meaningful outcomes of increased resources and enhanced support systems for consumer participation. More well-resourced and co-ordinated approaches should make it possible, with determination and effort, to extend the benefits of consumer participation with more marginalised groups of consumers, who have due to various circumstances had difficulty getting their voices heard and needs recognised in service planning and development. (National Resource Centre for Consumer Participation in Health, 2001)

## **Suggested action strategies emerging from the Research towards the strengthening, support and further development of the work of Consumer Consultants:**

### ***-Improving the establishment working, support and remuneration conditions for Consumer Consultants, for greater effectiveness and sustainability***

- Some work has been suggested to explore and implement various ways of **improving the Consumer Consultant job design** and seeking better conditions, more funding/ resources, and **improved support systems for consumer consultancy**.
- **Employment of more Consumer Consultants, including the** need to organise recruitments, training and deployment within the mental health service system.
- Desirable to **improved pay and conditions for Consumer Consultants** and for employing services to encourage and support CCs and their colleagues to work within reasonable limits. Flexible work schedules, working in pairs or "virtual partnering," possible job-sharing, locum worker availability, peer support, access to training, availability of professional supervision/ mentoring, can all make a difference.

- **Higher basic allocations of working hours** for Consumer Consultant employment were suggested, along with standard award-based pay rates, career paths, and perhaps ratio of a number of Consumer Consultants per X number of service consumers.
- Consumers, service providers, policy makers and supporting community groups to **campaign for the elimination of “poverty traps”** affecting Consumer Consultants who often because of various circumstances need to partly rely on Centrelink pensions or benefits, and seek an end to similar problems for consumers generally.
- Recognition and provisions made in relation to special difficulties and conditions that apply to **Consumer Consultants in rural and remote areas** and increased funding to cover additional costs.
- Some Consumer Consultants said it would be desirable for the **Department of Human Services to maintain a closer contact with Consumer Consultants**, with more backup support, resourcing and consistency of approach.
- More access to high quality information and being kept “in the loop,” given the “real story.”
- More effective methods for more direct means of accessing/ communicating with service consumers need to be devised in many areas.
- **Access to administrative support services** such as transcription, typing, filing, desktop publishing, mailing etc should be made available for Consumer Consultants – to avoid using up their limited time doing “generic” tasks that take them away from their specialised consumer based knowledge and expertise for which they were employed in the first place.
- Some **admin support work and supplementary office tasks** could be fulfilled by consumer reps working with CCs, and for these people to be paid at sessional rates for their work.
- Consumer Consultants be encouraged to **help link consumer reps into resources in the community**, such as training opportunities, access to reconditioned computers, provide background reading materials, support and mentor their development, inform them of opportunities, and help guide their efforts to be effective. This needs to be an acknowledged part of the Consumer Consultant’s role, and part of their time allocation and performance criteria.
- Need for many further **strategic planning discussions** among Consumer Consultants and other key stakeholders in services and the Department of Human Services in Victoria about future directions and priorities for consumer participation programs.
- Increased involvement of consumers in strategic planning, evaluation, review and development processes within services, at the broad level, across a range of service areas and types.
- More opportunities and forums for “deep dialogue” between consumers and service providers in “decision-free zones.”

- Desirable for service provider managers and other staff **to be mindful of giving adequate “airtime” and for consumer input to meetings** – not tagging a few minutes at the end or expecting consumer participants to have to rush through often difficult messages, sometimes as a solo voice, swimming upstream of conventional wisdom, and feeling pressured by situation if not personal vulnerability. Patience and willingness to listen and agree to consider the information assists consumer participation greatly.
- **Wider definitions of the terms of reference and roles for Consumer Consultants**, and reps, by opening up to negotiation questions such as possible inclusion of Consumer Consultants in service processes for design and implementation of clinical processes, confidentiality settings that infer “respect” for the integrity of CCs.
- **Consumer Consultants could be employed in Psychiatric Disability Rehabilitation and Support Services (PDRSs)** in greater numbers than the few at present, if State funding were allocated for this on the same basis as for clinical Area Mental Health Services. This had been foreshadowed by the government several times, but still not delivered.
- Need for more people from more backgrounds and a **“larger range of voices” in Consumer Consultancy/ and participation** and scope for more specialisation in consumer participation roles, to possibly allow more in depth work in complex areas, and development of more sophisticated, long term and sustainable solutions.

***-Consumer participation as a potentially powerful engine for innovation and change in the mental health service system and beyond***

- Greater **acknowledgement and transparency** might be helpful within a short while, in addressing many difficult and **so called “political” aspects of a consumer’s experience in services and the community** – in ways that are “realistic” about the principle of “the personal is political” in daily life generally and that issues can be worked through if there is genuine communication, goodwill, a willingness to listen and engage, and a willingness to make changes with a minimum of “shaming and blaming.” Efforts to “avoid politics” also tend to be avoiding genuine problem solving.
- Service provider staff as well as consumers could benefit from education and training about how to negotiate their duties and needs within a difficult, stressful and inherently politically charged environment – in the sense of power imbalances being everywhere – within many mental health services.
- Consumer Consultants **be encouraged to develop and promote practical models** which can easily be shared for consumer participation, which can be shared with all stakeholders in a potential project in a way that helps unify and focus the work.
- Definitions of consumer participation be interpreted and understood more widely as a process that can operate “at all times at all levels” in interactions between consumers and service provider staff...
- Consumer participation can also be understood as also being about optimising interactions and communication between consumers and service provider staff in which the consumer/ service

user is a participant in decisions and service delivery is based on collaboration, respectful communication, and affirmative values.

- **Working from a sense of “vision” while seeking to win over “hearts and minds”** of service providers and other stakeholders, with the aim of developing more responsive, caring and enlightened services. Consumer participation has the potential to re-energise staff enthusiasm and give clinicians a poignant reminder of why they might have entered the mental health field the first place.
- **Collaborative efforts involving consumers, carers, service providers and other key stakeholders, maintaining a sense of goodwill and highlighting likely mutual benefits** from improving service environments for staff and consumers. This is an important “touchstone” that can help consumers and service providers to be better able to work in partnership.

***-Some ways consumer participation can be extended into academic research and education, media awareness projects and community development initiatives, and more...***

- Universities, TAFES or education institutes could develop **“Centres of Excellence” for mental health consumer based studies and research**, and related community endeavours, along similar lines to centres for Women’s studies, Indigenous studies, Gay and Lesbian studies or Peace studies.
- More resources and opportunities for **consumer based publishing, information dissemination and community education**, including print, online, multi-media, video, community radio and TV, and other emerging forms.
- More opportunities and **resources for consumer-based participatory action research (PAR) projects** needed and more service improvement oriented consumer-collaborative research and development. Such methods of harnessing “consumer perspective” knowledge have been demonstrated to be cost effective and a potent source of unique, valuable and practical information for meaningful change.

***-Consumer-based Participatory Action Research and other developmental projects were suggested in such areas and issues as:***

- Collating, developing and **“Disseminating the Lessons...” from the consumer-based powerful but shoestring projects**, research and development studies, and the so called “Grey Literature” (of consumer small group self-publishing or informal publishing) to make widely available the insights and wisdom of this under-utilised knowledge resource which barely rates a blip on the “radar” of published discourses among service provider “Professionals” or the community.
- **Urgent research and development** to track and inform the development of outreach and co-ordinated assistance for the hundreds of consumers affected by housing shortages, homelessness, falling through service gaps, physical health problems, poverty, social disadvantage, drug and alcohol problems, and many other forms of social marginalisation that a number of “deinstitutionalised” longer term clients have fallen into.

- Multi-disciplinary research is urgently needed into the degree of prevalence and implications of trauma related links and the development of a range of appropriate responses in the community, for people affected by issues including various forms of child abuse, sexual assault, and domestic violence. Consumer anecdotal evidence suggests post traumatic factors are a largely hidden underlying factor in many people's contracting of mental illness problems.
- Need for development of new, **more effective, holistic, and socially-contextualised service models for people with dual diagnosis**, (mental illness with drug and alcohol issues) which would be meaningful for consumers, particularly younger consumers now coming into the acute psychiatry system with similar issues. Service models need to be developed which are more likely to be user-friendly to young people and to be somewhat accessible, or "make sense" in terms of their lived experience. Developing such models would involve a range of approaches and need to include the development of new and diverse service models and complex, high-maintenance community linkage frameworks.
- Need for extensive and most likely very complex research and development of practical, personally-engaging and appropriate, and effective service models for engaging with consumers from culturally and linguistically diverse (CALD) communities, their families and carers, and their cultural communities.
- **New and enhanced forums needed** for consumer discussion and sharing with each other, and **more availability of consumer-facilitated "consumer-only" meetings at local service sites**. May involve Consumer Consultants, at least in the establishment and providing guidelines, advice, assistance in linking to various resources, and information.
- **Educational, awareness and community development projects within services** and beyond to emphasise the importance of access and appropriateness of services for people from CALD and Indigenous, and other groups with issues in the broad category of **community "diversity, discrimination or inclusion"** as a core service responsibility, not an add on.
- Opportunities for Consumer Consultants and their colleagues who are interested and have appropriate skills and training, **to work directly with consumers** in providing peer support, information resources, assistance in forming linkages with other consumers and the community, and social and economic participation – particularly for consumers with complex and multiple needs which would be helped by a "voice of experience." Would need to be carefully structured, supported and resourced.
- More opportunities needed for **"showcasing and sharing good models"** for consumer participation, at many levels and localities. It is important as an education and awareness tool for consumers and service providers alike and would give impetus for "successful" methods to be more widely picked up. Could tie in to existing or new conferences and forums.
- **Partnerships with other groups in the community** are encouraged as part of consumer participation projects.
- Greater use of **consumer participation and other similar community development-related** approaches in mental health and other health and community services, as a way of seeking solutions to difficult problems by drawing upon the knowledge and insights of people affected

by issues and supporting and resourcing people to take action in various ways, on issues affecting them.

In line with recommendations within a Literature Review conducted by the Consumer Focus Collaboration (NRCCPH-Commonwealth Department of Health, 2001) many of the informants to this research project supported the notion of taking consumer participation a few steps further to include a “wider range of voices” – particularly people from diverse/ disadvantaged and/ or marginalised groupings.

These more marginalised groups, as identified by informants to this research and the 2001 project would include, but not be limited to, groupings like the ones listed below:

- people with mental health problems who are homeless or inadequately housed;
- Aboriginal and Torres Strait Islander people with mental and emotional issues;
- consumers from Culturally and Linguistically Diverse Communities;
- consumers from rural and regional areas;
- children and adolescents with mental illness;
- consumers in forensic psychiatry institutions;
- aged mental health service clients;
- people diagnosed with personality disorders;
- dual diagnosis clients (people with mental illness and drug and alcohol issues);
- dual disability clients (people with mental illness with intellectual disability);
- people with multiple-disabilities;
- gay, lesbian, and transgender consumers;
- people with trauma related conditions (increasingly seen as highly prevalent but under-recognised group among consumers.)

It is also notable that family carers have also tended to have limited opportunities and resources for participation and advocacy – and have long complained of being screened out of much direct participation or say in the treatment of their family member -- but the involvement of carers as advocates in the system is slowly growing, and some services are now employing Carer Consultants.

# Three Case Studies: Seeking some consumer-defined models of “Best Practice” in consumer participation

## Case Study 1. Talking with Merinda Epstein:

**“The Kit” – a landmark in consumer participation. But is this really, as intended, just the beginning of a longer story?**

**There is widespread agreement among mental health consumer and carer advocates that “The Kit – A Guide to the Advocacy We Choose to Do” a Spice Consulting collaborative project funded by the Commonwealth Government and published in 1998, was a significant landmark in consumer and carer participation.**

But debate continues in many circles about what kind of landmark it was. For instance, whether “The Kit” went far enough in various ways, whether it had targeted the right audiences, whether it was promoted and distributed from an adequately resourced platform, and whether it may have become the heavy “door stopper” document that may inadvertently become a proxy for other worthwhile consumer participation projects which might have followed.

Merinda Epstein, a consumer advocate and educator who was a key project worker on “The Kit,” took part in a special purpose interview for this research report.

Merinda spoke of how “The Kit” project was auspiced by the Mental Health Council of Australia, run by Spice Consulting and involved the input of a team of consumer and carer writers and reviewers, and also scores of critical readers. Merinda also served as the Canberra based solo worker in the follow up stage. The Community Development project stage involved trying to distribute “The Kit” nationally by various innovation networking based and improvised methods. One strategy was to take “The Kit” on a roadshow of Australian capitals.

An originally envisaged training component, working through the core skills of “The Kit” and intended to accompany the rollout of The Kit, was delayed by issues of time and resources, and some training modules have only recently been developed and had limited use so far.

When asked about what she felt were the biggest achievements of “The Kit,” Merinda said: “...that ‘The Kit’ was funded by the commonwealth in the first place was the major consumer oriented achievement...”

Merinda said she did maintain a critique that the Commonwealth had not followed through on earlier suggestions from the Deakin sessions which were a major antecedent of the project, for a consumer perspective education package aimed at service providers -- and instead had gone for a perhaps a softer option of educating consumers and carers about advocacy. However she acknowledged there were great overall benefits from “The Kit.”

“Nothing can be all things to all people, but ‘The Kit’ does provide some information across a broad spectrum of things that might be of interest to consumers...and I think for that reason it is a useful document,” Merinda said.

“What I have found from using ‘The Kit’ – and I do use it, but I tend to use the same bits over and over again which I have found particularly useful – it has been very well designed. It’s in a loose leaf format, and it’s only in black and white so you can photocopy it easily. I like Simon Kneebone’s cartoons which have added a lot to it, and were well tied into issues raised in the text.”

***-What might the implementation of “The Kit” as a project teach us about consumer participation?***

When asked to list major factors which tended to promote success of The Kit project, Merinda said:

- It was a genuine effort by the Commonwealth
- The consultancy firm was a good choice.
- The manager’s skills and personal perspective significant.
- Everything running through consumers and carers.
- Two consumer writers made a significant contribution.

Difficulties and constraints:

- Didn’t have enough time to write it properly. Going hell for leather. Made it harder to do sufficient research.
- Well paid, -- but it was real consultancy effort in that much of the money went back into the consultancy firm -- and paid for what we produced, but it was very stressful.
- But we all got there. We got the stuff done.
- It was very demanding.
- I had a very strong sense of responsibility to other consumers.
- I don’t think the formal meetings when we met with consumers and carers were run very well.

If “The Kit” had become to governments and policy makers something of a proxy or a “scratched record” reason for not funding other consumer participation projects, what types of projects did Merinda think might have missed out?

“The main one seems to be around consumers producing materials for consumers to use for the education and training of professionals. Every time we talked about education and training, they assumed we were talking about education and training of consumers,” she said.

Merinda believes there is a need for consumer education and training of service providers to be supported and resourced more consistently from a steadily growing collective “body” of consumer knowledge and the essentials of debates and discussion on key issues.

“I just think we need to be very strong around it. And it think we need to start educating consumers -- and I don’t mean that rudely – but we need to start thinking about the consequences of our storytelling and all of us making some decisions about when to tell and when not to tell different parts of our stories...not just to protect ourselves, but also so we’re not encouraging voyeurism. That we’re actually doing other things when we’re working with staff education and training.”

“...part of the education agenda should be for us to be able to have our internal debates about different ways of presenting the material.”

Merinda said there was a need to lobby the Commonwealth to get The Kit updated, get more copies, have it better distributed, have improved promotion, and have adequate training put in place.

As well as more structured and specific modules being developed for workshops and presentations for staff training and education, “The Kit” could also be strengthened with more material about consumer self advocacy -- covering both rights of consumers and having a greater say in treatment decisions -- and a fuller exploration of processes and potentials of political activism in the consumer movement.

“That’s a big political strategy. It would need to get the support of the Australian Mental Health Consumer Network and other organisations,” Merinda said.

## **Case study 2. Talking with Jon Kroschel:**

### **Some pointers on how innovative and strategic management of financial resources can help power-up consumer participation programs.**

**Consumer Participation programs within Area Mental Health services can be greatly strengthened by means of strategic use and management of financial resources – including careful consideration of where and how the funds are allocated, avoiding “pitfalls” in large organisations’ accounting mechanisms, and attracting in project funding from external sources.**

These themes and more were highlighted in a special purpose interview with Jon Kroschel, the Consumer Consultant at Alfred Psychiatry, who has developed many innovative resource management methods, as part of his development of a large, diversified and multi-team Consumer Participation program, which at times involves dozens of consumer Reps/ Consultants in a several running projects.

Jon explained in this interview that his strategic approach was based on:

- Firstly negotiating as part of his role the direct responsibility for managing the organisational cost centre for the Consumer Consultants program;
- Making some personal sacrifice of his paid hours of employment early on;
- “Investing” money thus saved into building up the various supporting structures for the Consumer Participation project, which would eventually allow paid involvement of many consumers, while also
- Avoiding precious funding dollars being drained away by carefully structuring the project budget to not fall into “traps” for the unwary that can often be found in organisational accounting structures and procedures.

Jon has brought something of social entrepreneurialism flair to the Alfred Psychiatry Consumer Participation program in a number of ways.

These include a range of centrally coordinated and locally paid for projects, securing external funding for several projects, and promoting the innovative messages and models for consumer participation to a range of other health and community services. through the deployment of trained Consumer Reps/

Consultants to carry out consumer based service evaluation and development consultancies in some local programs of the Area Service, charging a service fee to the local cost centres, which all parties agreed gave superior “value for money” to more standard types of consultancy input.

Similar models of Area Consumer Consultants – including development and facilitation of a “pool” of suitably trained and resourced Consumer Reps/ Consultants who can be deployed in local services, and paid from the cost centres of local services, are now emerging in some places, and are warmly encouraged by the key Victorian funding body, the Department of Human Services as a way for services to demonstrate financially how much they support and value consumer participation. At the same time many consumer movement leaders are becoming increasingly convinced that the best way for Consumer Consultants to promote greater consumer participation is – You’ve Just Got to Replicate!

The working methods were based on a collaborative partnership between consumers and service providers, which according to Jon is based on a different and “more collaborative mindset” than perhaps more conventional rights based advocacy approaches, but honouring these values as major underpinnings to the work.

### ***-A more detailed view of how Jon Kroschel’s strategic approaches work.***

In the section below, Jon explains in some detail about how he positioned the Consumer Consultant project within the organisational financial and budgeting framework. This is given at length to preserve the clarity of his explanation of complex matters:

“We here at Alfred Psychiatry in our consumer participation program aren’t under the financial constraints that other people find themselves under, even though we’re only given the same amount of money.

“I have worked in several services – in a lot of services the funds for consumer participation are held with consolidated revenue so it means if they’re not spent or not used up in the financial year they get returned. So people lose money. Whereas here at Alfred, it’s structured differently. Also consumer participation projects have to forfeit some of the funds from government for administration costs to either the overseeing hospital, [or authority.] It can diminish the working budget.

“Here I had discussions with the director. We don’t get much money, and whatever we get we can’t afford to lose, anywhere. So my employment comes under cost centre of the executive, and this is because the executive does not pay accounting fees to the general hospital. So it’s quarantined from that.

“Funds come from DHS and go into the executive. Out of the executive my wages are paid, but we do have a special purpose fund, and it has its own cost centre, which is for consumer participation. Putting funds apart from my wages into the special purpose funds means consolidated revenue can get returned, but anything that’s left over from one year to the next stays in that special purpose fund. Money we get from DHS -- the \$28,000 -- we don’t lose \$2000 or \$3000 to the general hospital for accountancy. So I’m in front \$3000 compared to other Consumer Consultants. Secondly, in initial stages where I was first offered the position, I was offered it to use up all of the \$28,000 in my wages. I said no. Even though that was only part time work, what I said was I would take less than that and save \$6,000, which goes across into the special purpose fund, which would then let me pay other consumers out of that.

“So you have to be creative about how you can come up with money to pay consumers. In the first couple of years, we had no infrastructure as far as a method of payment which was acceptable and how to get money out of the general hospital system which was used to dealing with cheques etc. So there was a lot of infrastructure that needed to be built before we could actually start paying people. And that took over a year, so we had \$6000 from the first year and then we had \$6000 from the second

year, which by the time we got things into a position where people could come along and do work with us, and get payment for it, and there was a payment process, we actually had \$12,000 over there to work with.

“The only reason we had that money was because I sacrificed it out of my wages. I know a lot of consumer consultants are going for more money, more money and would like to be full time. But it’s been good, because being smaller part time has put pressure on me for the consumer participation program not to be about me, but about people who access the services. I am a builder.

“And once the services saw that they said to me, we can see you’re willing to sacrifice to make this happen, and we admire that, and what we’ll do, from the director Dr Peter Doherty’s budget, he’ll put \$6000 over to the special purpose fund, and then I can take the full amount of wages for the time. So in doing it, I got a lot of respect, and as a result of the respect, the services were willing to contribute...My actions are congruent with the words I am saying. Demonstrating how much I value consumer participation, how much I believe in it, and then other people have seen that. It’s opened so many doors.”

Jon Kroschel explains more about how internal arrangements for local consultancies worked out:

“Our budget only supports the infrastructure of the consumer participation program. It supports the mail list, the sending out of bulletins, the once a month consumer work team. It does that. That’s all our budget is asked to do. We conduct and develop consumer evaluations of different service aspects. The work team members aren’t paid from the consumer participation program budget, they’re paid from the program budget from that work (the local service cost centre.)

“We developed a consumer evaluation, which was to come up with a questionnaire, administer it and come up with a report, about the Community Care Unit. The people who were working with me at the time to assist me to do that weren’t paid from the consumer participation budget, they were paid from the CCU budget. So this is the service saying, for a small investment, I think it was about \$500 it cost them, comparative to getting external consultants and costing many thousands of dollars, ours actually worked better, and we can come up with something that’s usable.

“It spreads the cost around the whole service. The service says to us we value what you’re doing so much, we’ll kick in a small amount of money.

“So, internally, if I were to add up over a year how much the service spends on consumer participation, it far exceeds what the DHS gives us. It is about being more creative, and about the service being willing to say our way of supporting you to do this is to give you some money to help you.”

### ***-Some visions to spread the methods and messages of consumer participation more widely...***

Jon said an exciting vision for the future for mental health consumer participation projects being facilitated through Consumer Consultants was to take the models and philosophies and methods into other areas of health and community services.

“Some of the consumer participation methods we’ve developed that work in mental health services, haven’t been [widely] transposed to other areas. The methodology we use here is all about participatory action research – it’s a fundamental principle of how we go about things. It’s about finding out about, developing and testing and seeing what we find,” Jon said.

“I think one of the future visions that consumer participation could have would be this transfer of methodologies of development, to see whether it is sustainable. I have transferred the methodology of

developing a consumer group and a consumer participation program across into Divisions of General Practice and across into drug and alcohol and youth, I know it works in those fields if we follow the same methodology of development we did here, it works in these other fields.”

Jon’s program was able to secure a Commonwealth grant for some \$40,000 from a special funding round where he was able to develop a major consumer based framework for more participatory methods of treatment and care, including a manual for workers and consumers. Jon's project also produced a Book of Procedures formalising the models and approaches for a multi-faceted Consumer Participation Program and Workshops to disseminate the model in effective and participatory ways. Some subsequent smaller funding applications have been successful and some have not been granted.

Jon also provided some advice relevant to Consumer Consultants and services they work for applying for funding, making the overall observation that there are more funding sources out there than many people would realise, and if applications worked hard to meet the key criteria funding bodies requirements, it was more possible than many Consumer Consultants and others might have thought to attract funding.

Some of the main advice that he offered was to get support and advice to help understand and know how to best meet the funding body criteria, by talking to supportive bodies such as the National Resource Centre for Consumer Participation in Health [unfortunately itself now in skeleton mode due to virtual funding expiry ] and to talk to officials in the relevant Department or funding body who Jon found were often “very happy” to offer advice on how to make the most effective applications possible.

A key point Jon made is that funding bodies have now become much more rigorous about applicant groups or projects to demonstrate that they have done at least a year or two “groundwork” on issues, including preliminary research and some community liaison and engagement. This was likely to be very decisive in many applications and was good for “background thinking” early on in consumer participation programs.

### **Case Study 3: Talking with Cath Roper: Consumers as Educators can help extend consumer participation into the “last bastion” -- the clinical domain**

**Cath Roper is employed in a pioneering role as the Consumer Academic for the Centre for Psychiatric Nursing Research and Practice, Melbourne University. As an experienced consumer advocate/ consultant who was one of the original consumer consultants in the landmark Understanding and Involvement (U & I) Project at Royal Park, Cath is noted for her articulate and innovative approach to the work.**

As part of her role at the Centre, which encompasses full lecturer status, curriculum development, and special project development and implementation, Cath has been involved with developing a range of initiatives aimed at fostering the employment of Consumers as Educators in student and staff education and development in the Mental Health field. Her Consumer Academic role and program was awarded a major TheMHS conference prize in 2003.

One notable project is the PAT (Psych Activism and Training) working group, in which Cath convenes a number of consumers interested in developing innovative staff education projects. Another key achievement has been the publication of a book featuring conversations between MH service receivers about experiences in the system, entitled “Sight Unseen”.

**-Consumer preceptorships with nursing students one way of extending into the clinical realm.**

A very innovative achievement of the Consumer Academic role has been the development of a system of Consumer Preceptorships, which provides for a coordinated involvement of consumers in post graduate nurses course work, in a developmental and exploratory relationship aimed at giving the student insight into consumer perspectives and enhances their understanding and practices.

Among many articles and papers, Cath has written about issues relating to conditions, safety, and sustainability in Consumer Consultant work, and the need for improvements partly because of difficulties in bringing about change “on the ground” in services, when many CCs experience power imbalances, lack of resources, sometimes limited support within services or even active resistance.

In a special purpose interview for this report, Cath Roper spoke about the potentials and likely challenges and levels of resistance that might be encountered, especially in relation to the idea of extending the purview of consumer participation activities into the mental health clinical domain.

Cath said that while consumer participation in MH service development and improvement had become quite well established in some areas, the idea of consumers being able to influence clinical practices was likely to be harder to achieve. Consumer consultants had pointed out that lack of access to clinical meetings, to observe and monitor systemic issues of treatment and care from a consumer point of view, obviously limited the input they could have on clinical aspects of services.

“I think that is going to remain the area most closed off,” Cath Roper said.

“I suspect that the closer you go to the heart of where the treatment is supposed to be taking place, the less welcome you would be as a Consumer Consultant. It is something of a ‘last bastion.’ It’s very hard still to maximise the presence you can have when it comes to treatment. It’s OK for us to now be wafting around committees, and there are now people with portfolios like quality improvement who really know how to use consumer knowledge and experience – of course in some areas more than others – in ways that can improve the services.”

“The way I see it in Victoria is I suppose there’s goodwill everywhere but there is a concrete ceiling...you don’t find consumers in positions of authority in the bureaucracy, working together with other consumers to get things done... [as happens in NSW health administration or New Zealand’s Mental Health Commission] ...We need to lobby and try to get more resources into consumer participation.”

Cath said it would be desirable for Victoria’s Department of Human services to employ consumers to project manage consumer participation programs and a Mental Health Commission, which included consumers as full ranking commissioners, would provide a good model for something similar to be set up in Australia. The New Zealand MH Commission is an overseeing policy development, coordination and monitoring body, and it had been said to be an advantage in some ways that it was not the responsible authority for the day to day running of the mental health system itself.

“I think New Zealand has a good model there...I think what I am saying is that consumers are not occupying roles that they should be -- that’s the ground level. My role is one of the few that is separate to consumer consultancy...and that is working in education.”

## ***-Consumer participation as a valuable resource that needs to be properly supported***

Asked about possible strategies to try to reduce the often noted “personal costs” of Consumer Consultant work Cath said:

“I think one of the answers is to open services up for consumers to become involved in various kinds of sessional work – coming in to be involved in doing professional development with staff, or work on a local service’s rights issues, or come in pairs or groups to do things to help establish a network, or come in and do individual and small group supervision with staff...”

Other roles for active consumers might include consumers working as peer support workers or assistant case managers, sessional clinical advocate advisors, training and development specialists, or service evaluation team members.

Cath said: “I am thinking in terms of a consumer workforce covering everything consumers are doing... which is ready willing and able to be active, but it is an under utilised resource. And that two things have to happen:

“One is access to training, because people who want to be doing that kind of work may need some confidence, some skills, by coming together... and some of that work has already been happening through VMIAAC or other areas. And the other need is to have the roles funded... actually in a service setting.

“Also places like Vicserv that need to work with services to create opportunities to use this workforce.”

Cath said there were now several consumer-run corporations in New Zealand doing a range of consulting and research and development work for governments and NGOs, which was also a healthy sign of the great potential for consumer participation.

# Methodology matters:

## ***-Who are the researchers?***

The Researcher was a Victoria University of Technology student for the Bachelor of Arts in Community Development, subject of Social Research 3 and 4, in part fulfilment of the requirements research and fieldwork elements of the course.

The researcher worked in close co-operation and with dedicated support from the Victorian Mental Illness Awareness Council (VMIAC) the peak consumer body in the state, and a Critical Reference Committee consisting of a number of experts in the field, including consumer advocates and mental health service providers. (More details of the Critical Reference Group are given in the Acknowledgements.) The original research proposal draft and the research report were developed with the assistance of several members of the Reference Committee. Most extensively this assistance has come from the VMIAC Metropolitan Advocate, Ms Liz Carr, who as well as being on the reference group was the Student Researcher's fieldwork supervisor.

## ***-The target audiences and intended field of influence of the research:***

The research seeks to influence and inform discussion about consumer participation and is thus aimed at mental health consumers, service providers, funding bodies, policy makers, community organisations, the media, and public.

The main aim is to focus attention on what improvements could be made to consumer participation programs if there were more adequate levels and allocation of resources and enhanced support systems; practical strategies and methods to advance and support consumer participation; and suggest ways that it can achieve its objectives.

The activities and programs at the centre of the research are intended as vehicles for consumer participation and empowerment, and there are many possible ways that these aims could be pursued. However, the main focus for the present research is necessarily upon the more programmatic aspects of consumer participation, viewed as an organised research and development or quality improvement type of activity or program, within mental health services.

## ***-Qualitative research methods used and values base:***

The main research methods utilised included:

- A detailed literature review – including large selection of readings, including formally published books, manuals and articles; consumer generated and informally-published ('grey') literature about consumer experiences and issues; Consumer Consultants' documents (submitted to services) including consumer feedback, discussion papers, meeting records, consultation papers, etc.
- Structured interviews with various parties to consumer participation programs and activities.
- Structured interviews with various mental health service provider managers and staff, which also allowed scope for discussion and development of ideas.

- A workshop session involving interested consumer consultants.
- Written materials, interview data and workshop data analysed with close reference to the key research questions and broader research design.
- Critical Reference Committee deliberations, ongoing advice and consultation. The expert group includes Consumer Consultants/ Advocates/ Reps who also had academic and research backgrounds, and mental health Service Provider Reps.

***-The background of The Researcher conducive to “participant observation”***

**The researcher was drawing extensively on a participant observation knowledge base with a foundation of first-hand experience of being a consumer, and:**

- Having discussed relevant topics with literally hundreds of fellow consumers, formally and informally, over time;
- Being a long-standing Consumer Consultant;
- Being an active networking contributor with a wide range of consumers and service providers at meetings and online;
- The compiler of data base of some 1400 computer files with relevance to mental health consumer issues and broader community development/ social justice issues;
- A website editor and writer;
- A frequent conference speaker and consumer-based educator;
- An experienced contributor to numerous strategic planning/ research and development/ evaluation workshops and meetings within mental health clinical and disability support services;
- The developer of various projects and models for consumer participation and advisor on new and innovative service models.

***-Role and application of extensive literature review (with substantive issues/ themes in Literature Review Section)***

The literature review included selection of articles and reports about consumer participation generally and particular local examples.

Various published and unpublished accounts of projects, project reports and consumer Consultant/ advocates field notes or diary entries were also sought out for inclusion in the literature review. The researcher’s own experience as a Consumer Consultant would also provide examples of consumer participation projects in action and related issues, drawing on my resource and project files, field notes, meeting minutes, reports newsletters and articles.

***-Semi-structured interviews with Consumer Consultants and advocates, service providers and others – including numbers, categories and descriptions of participants***

Some five Consumer Consultants/ Advocates were interviewed for the research project and a further 11 Consumer Consultants were included in a workshop group session at the VMIAC. Two service provider managers, and two senior staff members were interviewed, and a senior service provider rep and a community service rep participated in the Critical Reference Committee. The researcher had informal conversations with many other consumers in his networks, service staff, representatives from

Non-government agencies and peak bodies, VMIAC staff and members, and various others. Much material was gathered from programmatic literature, consumer generated materials, and more theoretical and broader-context writings in the field.

Subsequent to the academic version of the research report, **the Researcher made revisions and augmentations** of the text, largely consisting of editing for clarity and some supplementary processing of recommended strategies into a dedicated section. Another several interviews with a number of clearly named active consumers with major responsibility for particular “breakthrough” projects were also added, to help illustrate the emerging themes of the work. The editorial changes and additions were kept in character with the original research project and harmonised with the findings and directions of the academic version.

Efforts were made to encompass in the research report a range of different perspectives operating upon the various issues, and to take a broad view which embraces subtlety, controversies, paradoxes, artificial dichotomies, uncertainties, and the like.

### ***-Pivotal role of Critical Reference Committee***

The project design included a Critical Reference Committee which included a number of consumers each working in a different capacity towards consumer participation.

The roles these people are drawn from are: a Consumer Consultant (which is currently also the main employment of the researcher); a VMIAC consumer peak body advocate; an academic project worker from a consumer-related university project; a primary consumer member of a local consumer participation project. There was also a senior service provider staff member and a coordinator a relevant community service/ support organisation which assists consumers and carers.

There were approximately equal numbers of males and females in the group. There are quite a few consumer and service provider sub-groups which were not able to be directly represented, due to the constraints of the project. However, the interests of diverse groups of consumers and various types of service providers with differing perspectives were within the watching brief of the group members, who were able to draw upon a reasonable awareness and knowledge of specialised as well as more generalised consumer issues.

In formulating the research questions and directions, the work of the Critical Reference Committee has been great importance. The group also played a key role in analysing the data, forming a synthesis of the discussion, reaching inferences and conclusions about issues arising, formulating findings and making recommendations for action.

There was an attempt to allow service providers, both within the Critical Reference Committee and in the interview processes not to feel under pressure to “hold the line” on behalf of professionals, but to be able to participate in discussions freely and fully, without undue reservations.

A significant proportion of the work of the Critical Reference Committee members took place outside of the formal meetings – by being “sounding boards” and advisors – by phone or Email – and that formal meetings be kept to three meetings in total, of no more than two hours each, partly because these are all people with huge (over) commitments. Various members also assist with reading drafts and extracts of written data at various stages. In the final run only two “live” meetings were possible, although much was done through Email communication.

The Critical Reference Committee, from the early stages in the project assisted the researcher in many ways, and in particular they: contributed to the development of the research project plan, including timelines; ensured research methods were consistent with aims and stated values base; scoped out many likely issues; supervised project documentation; assisted in the development of research

questions; assisted in development of interview and workshop questions/ formats; considered ways of drawing substantive evidence, not just opinions; guided directions for the literature review; supervised ethical issues and implications; and providing practical advice and information between meetings as required.

In the mid to late stages the Critical Reference Group assisted in analysing the data; drawing out emerging themes and suggesting areas for further inquiry; fine tuning the language used to encapsulate debates within the body of the research; commenting on and enhancing the researcher's conclusions; and assisting the researcher in formulating key arguments and some recommendations.

When the final stages of the project were underway, time restrictions before the VUT submission date and difficulty for the busy group members to find a time they could all meet, led to the final "oversight and comment stages" of the report and its finding and recommended strategies being done by additional contact by telephone and Email. This was in line with an option discussed earlier. Full draft reports were sent to each member of the Reference Committee with a somewhat pared-down brief to look for (1) major errors of fact or interpretation. (2) missing a point or misinterpretation. (3) Lack of emphasis of an important point. (4) Additional major recommendation(s) strongly suggested by evidence. (5) Warnings about unintended controversy, or defamation etc.

Every effort has been made to maintain consistently high standards of accuracy and fair dealing in information gathering throughout the project, and ensure that the research material has strong authenticity, relevance, and foundation in evidence.

### ***-Implications for mental health field and likely distribution of research report***

The research project is expected to have wide applicability and usefulness within the mental health field, and would be of interest to many people in the field.

Articles summarising the key issues, findings and recommendations are intended to be sent to various professional mental health journals, as well as consumer-based publications. It could also be the subject of conference presentations or workshops. The Researcher maintains a website of original articles, and this material is intended to be advertised from there and able to be ordered for purchase, and a summary outline available to general site visitors and possible links to reviews or related journal items.

The Website details are: Allan Pinches' homepage: Mental Health and Our Community. URL is <http://www.alphalink.com.au/~alpin>

### ***-Scope and limitations of the study (including effects of the researcher's substantial experience of the matters under investigation.)***

Time and resource constraints will be significant issues in the research project. The researcher, as a practicing Consumer Consultant faced the constant challenge trying to maintain a fresh perspective and the ability to "see the forest for the trees" because of existing heavy involvement in the programs and activities being researched. However this knowledge and expertise was probably mostly a positive element of the project.

The researcher is experienced in analysis of complex issues, working through causative factors of situations under examination, identifying helpful factors and constraints on progress, strategic questioning of a range of stakeholders and discussion of issues, creating a synthesis of many views, identifying possible solutions/ directions, and developing possible strategies for action. The researcher recognised the importance of closely adhering to the evidence base.

# LITERATURE REVIEW:

## **The context of Consumer Consultant projects and consumer participation in mental health services and in terms of the wider social, economic and political environment, as reflected in various types of relevant literature**

The detailed literature review covering many aspects of consumer participation made a large contribution to the substance and evidence base of this present research. It also influenced and guided directions for research, inquiry questions for semi-structured interviews, discussion elements for interviews and the workshop group, and context setting for analysis in of data and formulating research outcomes.

The World Health Organisation British Columbia Project on mental health gave two main reasons why consumer participation in mental health services should take place, and identified two domains in which its influence was needed. (WHO, 1993.) The first reason was in the interests of consumers' rights, maintaining that "...consumers have a moral and probably a legal right to be directly involved in the policy and planning processes for services that directly affect their lives."

A second reason that consumer participation was needed was that after the substantial deinstitutionalisation of mental health services there was a heightened need for "...using consumers in meaningful ways to provide checks and balances" in services.

Emphasising the importance of rigorous efforts to implement enlightened policies and principles of consumer participation in a genuine, meaningful and non-tokenistic way, two activists from the consumer movement write:

"The espousal of fine principles at the top does not, of itself, ensure positive changes within the system. We (as consumer activists) are often confronted with the accusation that the changes have already occurred; that the Consumer Movement is trying to 'reinvent the wheel'. We would argue that cosmetic and superficial alterations -- as represented by high flown rhetoric and token gestures towards consumer inclusion in decision making -- does not constitute genuine change. It is in service provision; in hospitals; in the community that changes must occur; and these changes depend on a culture shift whereby deeply held attitudes and habits of thought are transformed." (Epstein & Olsen, 1999)

### ***-Place of consumer participation in a post-deinstitutionalisation mental health service system.***

Consumer participation has for more than a decade been a frequent topic for journal articles, papers, conference presentations, booklets, and other publications in the mental health field for consumers and service provider staff alike.

Many leaders within the consumer movement have written in both "official" (formally published) literature and the (sometimes called) "grey" literature of informal consumer publishing, with widespread agreement in articles by many service providers, that consumer participation in mental health services has been making a strong and valuable contribution to innovation and change in the mental health field. (Otto, 1990; Deacon Human Services Australia, 1999; Department of Public Health

of Flinders University & South Australian Community Health Research, 2000; National Centre for Consumer Participation in Health, 2001.)

One important reference, which came from a published literature review (National Centre for Consumer Participation in Health, 2001) reports that while much innovative work is being done to increase consumer participation in mental health services “there is little resourcing provided to consumers, especially marginalised consumer groups, to develop their capacity to participate.”

The imperative for consumer participation to reflect the diverse backgrounds and needs of consumers, and their marginalisation in terms of accessing services, has been considered within the scope of issues canvassed within the research. This and a number of other key publications by the National Centre for Consumer Participation have demonstrated a strong evidence base for the contribution that can be made by consumer participation and highlighted many examples of service development which would be expected to have a positive effect on consumer outcomes.

### **-Consumer Consultancy as an emergent “new model” for innovation and change in health and community services**

An indispensable overall written resource “*The Essential U & I*” (Wadsworth, Yoland, Ed, 2001) which is a one-volume compendium of the landmark Understanding and Involvement series of research projects from 1989 to 1996 which paved the way for the employment of Consumer Consultants in each of Victoria’s 22 Area Mental Health Services since 1996. The project, as reflected in the volume, is also significant because it establishes substantial ethical and methodological foundations for Consumer Consultancy as a new type of “consumer-perspective/ staff collaborative” research and development, for the benefit of consumers and improvement of the whole mental health service system.

Yoland Wadsworth writes:

“The most powerful contribution to such change that this work had to make was by consumers – the intended ultimate beneficiaries of the service system – to the extent to which they took (and were not blocked from taking) the lead. And further, this was an active collaboration with some insightful and resolute staff that were committed to making (and letting) this happen. We think that this is what made this project very different to all others that we know of.”(Wadsworth, 2001)

Wadsworth writes in the introductory notes about the way the U & I project evolved along holistic and exploratory pathways:

“The research commenced in a single hospital ward and then – in order to research and develop improving things for any single inpatient – found itself following the threads of that single inpatient’s experience out to the rest of the hospital and to the sub-regional area mental health service, then to a regional level and finally connecting to a state wide and federal mental health services system.

“These interconnecting elements of a service system were in turn connected to wider communities of interest (such a non government organisations, friends, families and carers, self-help groups, churches, the professions, unions, teaching institutions and so on) and finally contextualised also within a diverse society (of different individuals, multiple cultures, workplaces, industry, commerce, homes and local communities.)

“In a way it found it needed to achieve – or contribute to – a ‘critical mass’ of culture shift and widespread or whole systems organisational and culture change if it was to make a difference in any single service-user’s life.”

In an article by Epstein & Olsen similar observations are made about the nature and a socio-political formation of what is called “consumer perspective” crucial to this special activity:

“...At another level the ‘consumer perspective’ can be regarded as ‘something which has developed out of a collective consciousness and political solidarity that grew from the consumer/survivor movement’ (Epstein and Shaw, 13). This particular understanding of the ‘consumer perspective’ is essentially a socio-political one, and comparable to the way in which we recognise a feminist perspective emerging from the women’s movement; a particular solidarity and perspective from the gay and lesbian movement; or a sense of common identity in the various forms of the Black or Civil Rights movement. ‘Consumer perspective’ depends, therefore, on some kind of shared consciousness and identity. It is ‘shaped through an awareness of “belonging” to a group of people who are marginalised and discriminated against, who have an experience of oppression.’” (Epstein & Shaw, 1997, cited in Epstein & Olsen, 1999)

And in further delineating what they believe consumer participation is and is not, they write...

“...When consumers come together, whether in consumer-only training sessions or in hospital wards, there is often a strong feeling of shared identity. The close bonds that develop between ‘patients’ in the hospital setting are an example of this phenomenon that is frequently mentioned by consumers.

“One of the most important—indeed fundamental—qualities of the ‘consumer perspective’ is that it is respectful of the ‘consumer experience’. That is, individual consumers are acknowledged and listened to as ‘experts’ in terms of their own lives and being. It is not consumer perspective to interpret someone else’s behaviour using the tools (language and diagnostic categories) supplied by the medical establishment. Nor is it consumer perspective to argue that all other consumer experiences must be like your own.” (Epstein and Wadsworth 1996a cited in Epstein & Olsen, 1999)

### ***-Consumers now entering specialist roles as educators and trainers in the mental health field***

A recommendation of the setting up of a National Consumer Studies Centre within an Australian academic institution, to provide a “centre of excellence” for mental health consumer-based research and development and support and resource the developing role of consumers as educators of service provider staff, was a key suggestion of a chapter by Merinda Epstein and Daniel Rechter in a 1999 publication from what became known as Deakin Sessions.

The chapter, entitled “Service Users as Consultants, Educators and Trainers” canvasses many aspects of the contribution consumers make in this area, with few resources, supports, or programmatic involvement, and in support of a key recommendation for a studies centre – on the same principle as having studies for women’s issues, gay and lesbian studies, peace studies or Indigenous studies – the authors wrote:

“There is a need for an Australian network for all consumers working as consultants, educators and trainers. This needs to be coordinated at a national level by a national consumer studies centre (NCSC) which could be based within an academic institution (but not restricted to it,) with the long term goal of growing into a clearing house for consumer-produced material on education and training from here and overseas. The centre would be consumer run and would focus its activities around education and learning, research and services to the consumer community.” (Epstein & Rechter, 1999, pp 21 – 27)

Other contemporary written accounts indicate that a start is being made in some of these directions with the work of Cath Roper as the inaugural Consumer Academic at the Centre for Psychiatric Nursing Research and Practice, Melbourne University, where her innovative program includes:

- Providing structured consumer-perspective education modules to nursing students;
- Developing innovative and interactive approaches to sharing consumer knowledge, including a Consumer Preceptorships scheme where consumers work closely with students, including sharing first-hand experience and insights;
- Facilitating a more developmental project, PAT (Psych Activism and Training) which working on a number of consumer-perspective/ staff collaborative projects in education, research and development of ways of disseminating a range of materials;
- And many more activities aimed at promoting the cause of increased involvement of consumers as educators and trainers.

Cath Roper wrote in her 12-month report and program self-evaluation document in 2003 about the way consumer participation had helped enrich the education of nurses in many ways, but not without challenges, difficult - to - resolve questions, issues of humanity along side theoretical conundrums. (Roper, 2003)

Roper wrote:

“In the area of Mental Health, there seems to be in many quarters now, to be a genuine interest in and enthusiasm for consumer perspective led innovation that gives workers an opportunity to reflect on their practice. In a way, this should not be surprising. The clinical field is increasingly demonstrating its commitment to the idea of being thoughtful as part of all work that involves being responsible for other people and consumers have often been brought into the clinical field to assist in precisely this way: consumer perspective makes us think about how we do our work.

“But there is a tension here. The desire to be critical and to welcome what is thought provoking or challenging to the core of one’s ‘clinical role’ is also fraught with an attendant responsibility. What does one do then, once one knows?”

### ***-Some considerations in support of consumers as educators of staff***

The Researcher has previously presented a paper at a public forum on Consumers as Educators, and this included the message that consumers of mental health services had often spoken of the importance of staff attitudes and communication. The text included these messages:

“Possible helpful factors that consumers talk about are for staff to be able to listen, empathise, take into account people’s stated needs and wants, try to meet those needs, refrain from judgements, and for staff to engage in critical self-reflective practices, wherein practitioners self-challenge prejudicial and stereotypical thinking about people with mental illness or particular diagnostic groups.” (Pinches, 2003)

The paper continues:

“Lets face it, there is a lot of baggage in the early history of psychiatry about patients with mental illness having 'moral weakness' or being somehow to blame for their own fate, which can creep in, especially in stressful clinical environments. There is also a lot of cultural 'crap' – that’s a new

scientific term I think -- about mental illness within society. You know 'Ken Bwooze has gone absolutely mad' and misleading media headlines about 'psychotic killers', and even the huge number of colourful synonyms for being crazy people use every day. And service providers are not immune to this.

“And the medical model often seems to have systemic side effects which can create various sets of pejorative ideas about people, where patients or consumers in a busy service setting – and we consumers can sometimes be difficult or demanding in some ways, or have inner experiences that can result in outer, supposedly 'strange' behaviour, as well as making very reasonable requests or challenging things we find unacceptable -- become seen as something like naughty children who need to be put back in their place.

Questioning or resisting any aspect of treatment, or even seeking alternative treatments, can often be pathologised – labelled as non-compliant or 'lacking in insight.' Our actual knowledge and insight is often discounted and ignored.” (Pinches, 2003)

### **- Accounts of the role and processes of consumer participation**

The literature review includes items on consumer participation generally and also materials about of particular examples of consumer participation. The applications of consumer participation projects within the mental health field have been varied, as have been the accounts of what processes, challenges and achievements have taken place, and what lessons have emerged, for further development.

Consumer participation is often described as being based on a rationale that the people who use mental health services possess unique and valuable knowledge insights which can be used for the improvement of mental health services and related community supports. Consumers can readily identify many problems and possible solutions within services and would often have valuable suggestions to make about improving services.

There is also an argument that mental health consumers have a moral right as service users and citizens to have a say in the running of services they use and in their own treatment and support.

### **-Consumer participation as “living proof” of potential benefits for greater democratic participation in society?**

According to Jim Ife in his excellent book *“Community Development: community based alternatives in an age of globalisation,”* opportunities for democratic participation and community development starting at a local level are something of a “missing element” in Australian society. Such approaches, he maintains, could help minimise what seem to be emerging social, economic and environmental crises, by building necessary change from the “ground-up.” This seems to have strong resonance with consumer participation work involving Consumer Consultants in the mental health field, which might be a replicable model for other health and community services or other organisations.

Ife reflects on some of what he sees as a necessary shift in the power to define needs back to the people experiencing those needs, as follows:

“Needs assessment is seen as an essentially technical exercise in methodology – measuring something that is already ‘there.’ The emphasis on methodology, and hence on technical expertise, leads to a situation where needs can adequately be assessed and defined only by experts who are skilled in adequate need assessment methodology. Therefore, need definition is removed from the very people who are experiencing the need, and placed in the hands of professional need definers, such as social

workers, social researchers and psychologists...this has resulted in the rise of professional power while consequently 'disabling' the bulk of the population." (Ife, 2002, p62)

From one consumer newsletter "Voices and Echoes" (Moon & Walsh, 2003) comes an anecdote about how a consumer guest speaker presenting at a nursing course suggested guidelines for consumer-friendly ways of handling so-called "difficult patients" by better communication rather than coercion, had apparently influenced the way a fairly new nurse at an inpatient unit somewhere in Victoria, with her colleagues handled a potentially volatile situation involving an "upset" and "increasingly unwell" patient who had refused to take the medication.

After commenting about how encouraging it was that consumer-based education in this instance had provided a better alternative than forcibly injecting the patient, and hopefully a sign that consumer participation is working, the article continued:

"Instead of injecting the consumer, the nurses gave the consumer a little time and listened to the concerns, and the consumer calmed down and benefited from the care the nurses and the hospital can provide. Everyone, consumers and nurses, avoided an unpleasant incident, because one consumer educator chose to try to explain how things look to us, and because the nurse listened and looked at things from a non-medical viewpoint." (Moon & Walsh, 2003)

### ***-Voices of questioning, cost counting and doubts about outcomes, among a few service providers***

There have been a small number of articles by service providers about various research projects questioning the effectiveness of consumer participation projects.

One article by a group of service providers and a consumer Participation Project officer which was entitled "Consumer Participation in Mental Health Services: Who Wants It and Why?" -- raising a number of questions and issues in terms of whether the consumer participation and the methods it used (in consumer participation) were likely to bring about meaningful systemic change (Tobin, M; Luxin Chen, et al, 2002. Dr Margaret Tobin has since become deceased from a violent incident believed unrelated to any topic within this research.)

The paper, based on a survey of local consumers, raises issues of the "costs of such initiatives are not insignificant" and the need for "responsibility" to ensure that resources were "directed to appropriate means, and are achieving worthwhile results." The paper looks at imputed low levels of awareness, interest and involvement of consumers at a local service in South Australia, in consumer participation activities and "need to integrate" consumer participation into the wider service system.

The abstract finishes with: "The authors conclude that simply devoting energy and resources to consumer initiatives, and thereby achieving a politically correct approach, may not be a worthwhile exercise. Such initiatives need to be based on evidence, available resources, and identifiable and achievable outcomes, with a balance struck between endorsing the value of consumer participation and establishing realistic goals for what can be offered and managed."

These are issues which may well be worth further discussion in the field, especially at a time when the consumer movement strongly wishes to keep consumer participation high on the health services agenda, give sound evidence of its effectiveness and value, and even gain increases in resources made available for this work. This present research project should help draw out some key themes.

The Tobin et al, paper was received with shock and disbelief among consumer advocates throughout Australia.

During this research, there were reports emerging in the consumer advocacy networks that South Australian mental health government authorities have recently almost totally de-funded consumer participation activities in that state, and the West Australian Government is also making severe cuts to funding of consumer participation and virtually all community-based Psychiatric Disability Rehabilitation and Support Services, which provide services including supported housing, respite services, and rehabilitation.

The South Australian and to a larger extent the West Australian de-fundings have attracted wide condemnation by not just consumer, carer, and Disability Support organisations but also many mental health peak professional bodies and major organisations, on the basis of being regarded as patently disastrous and socially damaging policies, which contravene agreements signed by all Australian governments under the current National Mental Health Plan.

Another paper which is regarded as somewhat critical of consumer participation, was based on an extensive literature review of reports of consumer participation projects found that while it was possible that these initiatives could have led the mental health system to become more consumer-friendly in some areas, there was still a paucity of research evidence about whether such changes were necessarily translated into better health outcomes. (Crawford, et al, 2002.)

The authors wrote:

“Patients have contributed to the planning and development of services across a range of settings, but the effects of this process on the quality and effectiveness of services are unknown. This absence of evidence should not be mistaken for an absence of effect. Healthcare providers may be increasingly required to demonstrate that they involve patients in the planning process, but they will also continue to be accountable for the decisions they make. A better evidence base may be necessary to persuade providers to place greater emphasis on patients’ views when making decisions about services.”

It may be interposed here however that the literature review which formed the basis of the aforementioned paper, although in many ways extensive and meticulous, was done on the basis of excluding any papers about involving consumers in their own individual treatment choices, and areas such as self help, community development, health promotion and participation in research, which could be argued to limit the extent to which any improved consumer health outcomes would show up in this study.

### ***-A few service providers became champions of consumer participation years ago***

A Clinical Nurse Consultant from the NSW mental health service, Keith Walker (1994) wrote about some aspects of theory and practice in consumer participation, including a useful summary of the commonly perceived weakness and obstacles which can undermine various mental health consumer participation projects.

The examples, drawn from various authors, include:

- The reported “unwillingness” of many, or in some estimates, most consumers to participate;
- Lack of resources, time, technical limitations, lack of support structures, organising costs, etc;
- Hidden agendas among some officials and tokenism in consumer participation which could be quite subtle and manipulative toward pre-ordained outcomes;
- Apparent decisions arising from “participation” could be quite easily subverted or starved of resources later;

- Power imbalances between consumers and service providers;
- Conflictual “winner and loser” situations and other contradictions in the policy and administrative environment and between different levels of government and localities.

Many of these themes are reflected within this study, but there seems to be some evidence that in more recent times some of the issues have been more fully played out, and with growing evidence of the contributions that consumer participation can make, many of these problems may have eased substantially.

The World Health Organisation British Columbia Project on mental health report written by David Beamish and Garry Long included a similar list to the one immediately preceding, of barriers and constraints to consumer participation in mental health services.

Some discussion issues from the WHO report, which can augment the list just given, include what the authors identified as:

- An apparent lack of a “well developed rationale” for consumer participation in planning, development and evaluation processes, leading to difficulty putting appropriate structures and processes in place.
- Structural factors that provide for effective the running of mental health services from a service provider point of view – such as education, clinical discipline specific knowledge, social standing, access to information, networking resources, access to publishing etc – nowhere near as available for consumer reps, creating a very non-level playing field.
- Need for consumer capacity building and support systems.
- Problems of consumers having to work “in isolation” without support, collaborative networking, information backup, and often poorly defined reporting and accountability structures and processes which would demonstrably maintain a two-way link between consumer reps to their constituencies.
- Questions of representativeness of consumer reps/ Consumer Consultants can arise and definitive answers can be hard to provide for various reasons.

However, in debates yet to come, there seem to be many other areas of contested knowledge which come out in both “official” and the “grey” literature -- mainly with consumers being the sceptics about, (along with some service providers given to reflective musings on questions of causes and effects and philosophical aspects) -- such as:

- The effects of consumers of the dominant role of the medical model of psychiatry, with its emphasis on medication;
- The often unaccounted for sociological dimensions of mental illness;
- The almost entirely unaccounted for relationship between mental health/ illness to matters of spirituality, despite this being an important and meaningful area for many consumers;
- Involuntary inpatient detention, extent use of “seclusion” units, and forced medication treatment;

- Widespread use in Victoria of Community Treatment Orders (CTOs) – involuntary treatment while living in the community -- which are regarded by some consumers as coercive, intrusive upon their civil freedoms, removing choice or say in treatment, sometimes keeping people on medications they find unsuitable. A small number of consumers however, and some service providers claim that CTOs, which are administered through hearings of the Mental Health Review Board, allows consumers to receive treatment in the “least restrictive environment,” which in this case means while living in the community. Some consumer advocates suspect that CTOs may be over-used by the system as something of an easy expedient and cheaper than more comprehensive methods of treatment in the community. A major research project is currently being conducted by the Mental Health Legal Centre into Involuntary Patient Experiences with the Mental Health Review Board.
- Controversy over the use of Electroconvulsive therapy (ECT);
- Frequently stated consumer dissatisfaction with what they perceive is negative attitudes and treatment by some staff and calls for workers in the mental health field to have more training and education from consumer perspectives to encourage greater “willingness to listen,” understanding and empathy.

These and similar items were encountered in many places literature review and interviews, but are only touched upon lightly within the scope of this report, mainly as examples of the kinds of issues that an effective and well resourced system of consumer participation might address in a more considered and coordinated manner.

***-The challenge to build effective participation for people from Culturally and Linguistically Diverse communities.***

The issue of consumer participation for members of non-English speaking backgrounds communities – now often called Culturally and Linguistically Diverse -- has been highlighted by a number of recent publications as needing urgent and serious attention.

Sozomenou, Mitchell et al, Eds, (2000) in a book which makes a substantial contribution to debates around consumer and community participation, “Mental Health Consumer Participation in a Culturally Diverse Society” make the point that although Australia has one of the most culturally diverse societies in the world and that this has many evidence backed implications for delivery of mental health and other services, the resulting diverse needs has not been translated into a diverse range of services, resulting in many problems.

The authors cited from authoritative reports from a variety of sources, which highlighted that people from non-English speaking backgrounds or ethnic minorities tended to have poorer quality, disproportionate and detrimental experiences of mental health service use, including: higher incidence of involuntary psychiatric hospital admissions; lower levels of voluntary admissions; more likely to present at crisis point to emergency psychiatric services; likely to be hospitalised for longer periods; higher proportion of patients making premature terminations of treatment; tendency to receive more emergency psychiatric services and less case management and outpatient services than majority populations.

They write in their introductory chapter:

“There is a high probability that groups in the community who have historically denied equal access to services will also be denied access to participation mechanisms, unless special efforts are made to target disadvantaged and marginalised groups, such a people from non-English speaking backgrounds. Consumer and carer participation has received considerable attention in the health-

services literature in Australia, yet organisations often find it difficult to involve consumers and carers of non-English speaking backgrounds in the design, delivery, and decision making processes of organisations and services.” (Sozomenou & Mitchell, et al, 2000)

Sozomenou & Mitchell et al reaffirm the findings of a research project based on a large number of interviews by Doyle and Visano (1998) “...that a majority of ‘multicultural’ consumers experience difficulties in securing access to services.

“They note that consumers tend to attribute obstacles to factors such as the lack of information, styles and techniques of interaction, and lack of knowledge and understanding of cultural and linguistic issues. Consumers expressed feelings of uncertainty, powerlessness and distance from agencies set up to serve them. It was found that cultural factors either inhibited consumers from approaching services, or effectively negated the value of assistance when this assistance did not take into account the values of consumers.

“Consumers from minority groups encounter problems which are common to other consumers, but these problems tend to be intensified and felt more acutely due to cultural and linguistic factors.” (Sozomenou & Mitchell et al, 2000)

## **Some key theoretical and conceptual frameworks and “someday-dreams” about consumer participation**

There is a large body of Australian policy and program literature and much international literature about consumer participation. There are also many journal articles and consumer-published articles about consumer participation. What has been lacking has been a substantial evidence base about how such visionary notions had been translated “on the ground” in services well known as areas with many problems. This research project in part is intended to help close that knowledge gap, and suggest some ways forward.

Also hopefully reflected here are some of the rich and diverse philosophical streams within the mental health consumer movement which can be found in many consumer writings both in formal publications and the “grey” literature -- ranging from so called “anti-psychiatry” messages, alternative models of mental illness based on social, spiritual, or trauma related factors, through to consumer rights and participation policy materials, consumers as social visionaries, Shaman “wounded healers”, poets, and artists – even emerging recent celebrations of “Mad Pride.” Many of these are within the collected information resources of the Researcher, many on computer files.

***-Origins and history and many tributaries of the consumer movement: familiar goals – peaceful humanity, social justice, equality, community, and hope – often pursued in a wide variety of ways:***

The origins, philosophical links and theoretical underpinnings for consumer participation appear to be rather widely dispersed – seemingly the product of a combination of many different streams of thought “someday-dreams” and gathering activity – and its historical development is variously described in different accounts.

A number of accounts over time have suggested that consumer participation to a large extent emerged from the mental health consumer movement (also known as the consumer/ survivor/ ex patient movement internationally) which took off massively over the past few decades in the USA, UK, parts of Europe and Australia. In Australia and starting in Victoria much of the impetus for consumer

participation activity had come with the rapid and large scale deinstitutionalisation of mental health services.

The shift of services away from stand-alone psychiatric hospitals to short-stay inpatient wards, outpatient clinics and other parts of service systems aimed at “treatment in the community” glaring gaps and problems appeared in mental health services, and related community supports. There were many forums and consultations which resulted in calls for greater responsiveness to consumer needs, and more attention to the complex issues for many patients “returning to the community” and needing a range of supports – such as rehabilitation, disability outreach support, day programs, housing, recreation, vocational and many other services.

The emergence of community-managed psychiatric disability support services in Victoria, which provide housing, support, rehabilitation and community linking for consumers, since the late 1970s has added enormous momentum of the growth of the consumer movement and consumer participation, and have provided a good “proving ground” for consumer advocates. The Researcher has been a consumer rep on the boards of two major PDRSs (Psychiatric Disability Rehabilitation and Support services), one as a pioneering consumer rep and the other including two years as Vice-President.

The mental health “consumer movement” has been claimed by a range of writers (including Epstein & Shaw, 1999; and Walker, 1994) to have been to some degree shaped and influenced by many social movements arising from various developments within Western democratic political theory and social movements including:

- Emergence of community development movement and changes in social work, particularly in the UK, since the 50s and 60s.
- The wave of social change and radical politics associated with the American civil rights movement starting with the black movement and students of the 60s.
- The idealistic and youthful dreams of “peace and love” of the Hippy counter-culture of the 60s and 70s and the emerging “free thinking” protests against perceived failings of the Establishment.
- Success and high profile of Ralph Nader type Consumer Rights campaigns.
- The emergence of the disability rights and Independent Living movements particularly in 70s and 80s.
- The growth and influence of what became known as the “anti-psychiatry” movement.
- The experiments in alternative methods in psychiatry such as “therapeutic community” and the beginnings of psychiatric disability support services in the 70s and 80s.
- Growing interest in books about self-help, personal development, and “pop psychology.”
- Growing popularity of “more holistic” approaches to mental health.
- Spiritual “seekers” in crisis -- casualties of a spiritual supermarket, “tripped out” by transcendental or drug experiences, and experiences of social dislocation: this group often demand “alternative” mental health help.
- Feminist based social theories and Participatory Action Research gaining a stronger influence in the 70s and 80s, becoming more supposedly “mainstream” by the 90s, with new methodologies for social inquiry and policy development opening up which were more

supportive of consumer participation in, and more control over processes of research. Consumer Consultancy can be seen as a form of participatory research and development.

- Consumer participation and “systemic advocacy” becoming a more immediate priority for the “consumer movement” to be able to make practical responses and find ways of influencing many issues surrounding de-institutionalisation of mental health services. This also tended to encourage a greater focus on collaborative and “partnership” relationships between consumer reps and services.
- More recently there have been serious concerns shared by governments and community groups about the human and economic costs of a rapidly developing “depression epidemic” predicted to become the world’s leading health problem within decades – but making divergent claims about the causes of the problem or the best ways to address it.

### ***-Linking consumer participation with influential “critical” social theories***

The research project has drawn extensively on various areas of critical social theory. These include:

Some major teachings of Michel Foucault in relation to the construction of the notion of madness through a combination of discourses and operations of mechanisms of social classification and control.

A number of feminist research approaches highlighting the political nature of experiences deemed as “personal” and the existence of underlying structural inequalities in areas of social disadvantage.

Community development approaches based on “empowerment” principles aimed at supporting and resourcing people in their communities to take collective action around issues affecting them and to gain greater control over their lives and destinies.

The latter category of community development dimensions are well explained in the authoritative book on Community Development by Jim Ife (Ife, 2002.) It has been of critical importance in this research to remain vigilant, as most Consumer Consultants are, for signs of “tokenism” in consumer participation initiatives, whilst remaining optimistic of significant and lasting change being brought about.

Walker (1996) gives a very useful overview of some of the links between various established perspectives within socio-political theory and consumer participation. Drawing upon the writings of Bates and Linder-Plez (1990), public participation is analysed within the frameworks of consensus, pluralist, and conflict perspectives.

“In the **consensus view**, consumer participation, other than through political elections, is not needed. Elected representatives and public servants are sufficiently able to interpret public needs and to determine which is best for all; more so than ordinary people, who do not have the expertise.

From the **moderate pluralist perspective**, elected officials and bureaucrats ‘must decide among competing and opposing interests...to be the guardian of the public, to protect the weakest groups and to restrain the strongest. Consumer groups have a preventative role insofar as they can ensure that objectionable decisions are not made, useful programs can continue, and by identifying new need, provide directions in which governments ought to act.

In the **radical pluralist perspective**, weaker consumers will always have a lesser influence - largely because of inadequate lobbying and articulation skills.

From a **conflict view**, consumer legislation has inequitable effects: all decisions give advantage to the ‘well off’, and elected officials and bureaucrats tend to be more ‘concerned with their own interests and those of their own social class, neglecting the less powerful people.’ Active participation by the disadvantaged and normally powerless is thus a primary method of potential and pro-active redress. Bates and Linder-Plez believe it is the **moderate pluralist perspective** which is currently held by administrators...” (Walker, 1996)

Walker added that other writers had maintained the rights of everyone to participate in matters affecting their lives and destinies, and debates that had occurred around different explanations about the causes and effects of consumers’ inferred levels of interest in participation of their perceptions of its likely efficacy.

In a variously published article called: “An Introduction to Consumer Politics” Epstein and Olsen (1999) comment on the damaging effects on people with mental illness of stigma in society and within mental health services:

“Stigma for those suffering from mental/emotional distress results from the way that we are ‘branded’ with various (and often contradictory) pejorative and/or disempowering labels. The principal effect of using labels (based on stereotypical conceptions) to categorise people is dehumanisation, and the use of such markers to stigmatise individuals and groups is enabled by social constructions of ‘normality’.” (Epstein & Olsen, 1999)

And with reference to notions of how society and some professionals tend to relegate people with mental illness as something “other” or somehow alien to ordinary human beings, and in an argument with some resonances to Foucault’s analysis in his book “Madness and Civilization,” consumer activists Epstein and Olsen write:

“In many instances the effects of ‘othering’ serve the interests of the powerful and create divisions within communities by encouraging the development of antagonistic interest groups vying for recognition and respect. This is one reason why it is so difficult to change erroneous perceptions and encourage tolerance. Negative stereotyping—as peculiar, dangerous, incompetent, and so on—of those suffering from mental health problems has resulted in an exacerbation of the difficulties we face in our lives. In addition to symptomatic distress and the often quite unpleasant side-effects of medication, we have to contend with the judgmental attitudes of those around us.” (Epstein & Olsen, 1999)

In terms of its relationship to various aspects of critical social theory, consumer participation comes at an interesting point of some confluence – and sometimes even mediation, dynamic interplay, synthesis, and new understandings – with significant philosophical streams including some post modernist theories, Foucault’s critical social theories, post structural analysis, the concepts and contested knowledge of Western psychiatric medicine, alongside the programmatic world of health and social policy and service provision.

**Consumer participation, particularly through the work of Consumer Consultants, in some respects does provide a site for interaction between the two usually most polarised perspectives in mental health – those of consumers and psychiatry professionals.**

It can allow exploration of questions about “efficient and effective” ways to deal with consumer and community needs in relation to mental illness/ mental health; provide for dialogues based on a new synthesis of consumer perspective knowledge and service provider considerations; and allow collaborative exploration of many new areas of “consumer-friendly” improvements to the mental health service system.

Consumer participation could be argued to form a new “meeting ground” somewhere between the realms of “practices” (or programmatic matters, policies, strategies, methods and processes for the practical organisation of health or social service delivery) and the realms of theories.

This seems particularly true in relation to post-modernist critical social analysis, especially in Foucault’s theories about social and political realities being shaped by discourses, and feminist theories of power. The notion of mental illness related matters as part of a construct is a major concern within Foucault’s writings, including his book “*Madness and Civilization*” which among many things analyses the role of the machinations of psychiatry and other authorities, in what Danaher, Schirato & Webb termed “the discursive production of madness.”

In their book *Understanding Foucault*, the Danaher et al write:

“These examples of the ‘production of subjectivity’ (the mad, the insane, the pervert, the outcast) come about by way of what Foucault calls technologies of classifying, disciplining, analysing and normalising; and they depend to a large extent on the process of naming. Human beings across cultures and across history have named themselves, both as communities and as individuals, and have denied names – and hence ‘real’ subjectivity – to slaves and other non-people.” (Danaher, Schirato & Webb, 2000. pp 122 - 126.)

The authors maintain that subjects who fail to be defined as normal through the technologies of differentiation become assigned among such categories as the “mad, old, or sick, for instance.”

“It is, in the first instance, these others, these not-subjects or not- quite- subjects who are locked up in prisons, or mental clinics, trapped in poverty on pensions, numbed by medication and shamed in public. These sorts of practices force human beings to work on themselves in order to meet and comply with the models normalised by the individual’s culture, which they exchange for the promise of subject status (that is, acceptance as normal human beings.)” (ibid, p127.)

Another way of looking at the intersections of various streams of theory and practice posed by consumer participation, might be to suggest that consumer advocacy -- particularly through consumer participation approaches which often blend qualitative research and development with knowledge drawn from the “lived experiences” of people with mental health issues -- also seems to offer many practical ways to make operational in the practical world of health and community services many of the principles and insights sometimes offered within post-structuralist schools social analysis.

Such approaches may serve as a “socially constructive” corollary to hitherto rather theoretical explorations of how to make improvements in provision of essential health and social services– or any social policy, service or debates -- and provide some useful models which might be useful for wider applications in other areas of society, particularly in the areas of community development and the now re-gaining popularity, notions of greater participatory democracy across society.

In an interesting counterpoint from some feminist theoretical writings, Yanagisako and Delaney maintain in the preface of the book, “*Naturalizing Power*” that the notion of culture, while having some shortcomings as a theoretical framework, does provide a valuable tool for discussion and debate about difference and similarity and “a productive site for continual assessment of the coherence among a society’s discourses and practices.” (Yanagisako & Delaney, 1995, p19)

They continue:

“This creative dialectic of the culture concept is lost when it is reduced to one of its poles. The productiveness of the concept depends on our commitment to use it as an incitement to continually rethink what is same and what is different, how they are so and what this means; and to continually

reassess the fragmentation of coherence of discourses, domains and institutions – whether they hold together and how. Once this heuristic tension is resolved in favour of either side of the opposition, culture is no longer good to think with.” (Yanagisako & Delaney, 1995, *ibid.*)

### **-“Empowerment” – exploring a pivotal notion for consumer participation**

#### **Empowerment for consumers is an essential concept in discussing consumer participation, and one which occurs in many places in the literature.**

Walker (1999) quotes Gutierrez (in Brinker-Jenkins, 1991) as making a definition of empowerment at least in terms of political theory, as “the process of increasing personal, interpersonal, or political power so that individuals can take action to improve their lives.”

Throughout a wide range of consumer generated literature, including many times in the informally published “grey literature” empowerment is usually described as being concerned with enhancing the knowledge, skills, support and resources to allow people who experience mental illness to re-gain control over their lives and destinies. It is rooted in the understanding that the mental health issues of people cannot be understood in isolation from the social environments they experience.

Empowering practices by mental health service provider staff are those that treat clients as whole human beings with “real lives” beyond the service settings, and that support, caring, generating of options and reclaiming hope are all essential elements of psychosocial rehabilitation.

However, as with the question of representation, a common philosophical “touchstone” for many Consumer Consultants is that it is not possible for one person to “empower” another, because so many of these processes necessarily come from within – however it is often seen as possible to support, resource, inform, and otherwise assist in creating the pre-conditions for others to become more empowered.

For similar reasons, some consumers are wary of notions of “help” or “treatment” or terminology like “mental illness” or “psychiatric disability” because of possible inferences of diminished power and choices, which tend to negate the possibility of even thinking very much about a wider range of choices.

An excellent written resource is “*A Working Definition of Empowerment*” published on the Internet site of the National Empowerment Centre in America, a consumer based centre of research and development on recovery and participation. The Centre’s empowerment document is an attempt to give meaning to a word, which had been used and abused in so many different and contradictory ways.

According to the document, based on wide consultation with consumers, empowerment (paraphrased and summarised here) means:

...having decision making power; having access to information and resources; having a range of options; feeling that the individual can make a difference; learning to think critically and unlearn the conditioning; learning about expressing anger; not feeling alone; understanding that people have rights; effecting change in one’s life and community; learning skills the individual defines as important; being seen as competent; coming out of the closet; and growth and change which is never ending and self initiated... (Adapted from National Empowerment Centre, 2001.)

# Evidence and Discussion:

The following section contains a substantial presentation of evidence and discussion from consumer and service provider parties to the research.

The way the section is structured is an attempt to reflect the Key Research Questions and the logical progression of inquiry and discussion that emerged over the course of the project in the semi-structured interviews, a consumer workshop, and various solutions-focused readings.

These processes encouraged not just the giving of factual evidence about Consumer Consultants' work and consumer participation, but aimed to allow for reflection, consideration of a "synthesis" of viewpoints on various questions, and scope for discussion.

These frameworks, which encourage articulation, subtlety, analysis, discussion and solution-seeking, are hopefully reflected in the structure of the section below, and thus quotations and connecting/discursive structures may be somewhat fuller than in some research reports. The arguments and their expression will hopefully provide a rich contextual field as well as a large body of substantive information.

## ***-Aims and purposes of Consumer Consultants' work and consumer participation:***

**A Consumer Consultant expressed a view held by many consumers and staff, saying: "If a health service can't really understand the experiences of people using the service, it is really going to be flying blind in a lot of ways."**

A Consumer Advocate who works in many places within the sector said:

"Consumer participation, broadly speaking needs to be about **consumers having an influence on systemic change and policy directions**...but my feeling is that at the end of the day, we'll know when consumer participation is really working when any individual consumer walks in to see their doctor and can lead the process -- be an equal partner in the therapeutic relationship, and where the consumer's point of view is heard."

A high-level manager said:

"I've always been a believer in **people having a big say in what is developed**, provided and constructed for their own purpose...particularly in an area like health where people are in receipt of a health service, the service needs to understand what it is they are providing and on what basis they're providing it. Part of that is about engaging the people who use the service."

He also commented:

"Philosophically I think that a service that is there to work with people, to help improve their health status, **fundamentally can't do it, if it is not listening and talking to the people** who use the service."

A Consumer Consultant said:

“My **aims were to increase awareness of consumer participation**, because I don’t think there has been a very full awareness in a lot of circles. There are some staff who are very aware and some who when I first started didn’t have a clue what consumer participation meant. So I put an enormous amount of energy into increasing awareness, and from that, increasing the profile of what we do.”

According to another Consumer Consultant:

“Part of what we’re trying to do is **encourage service providers to self-challenge**, question their longstanding knowledge and attitudes, be reflective, open up to deep dialogue with consumers, and over time work from a knowledge base that includes, understands, empathises with and values consumer perspectives.”

A top manager at Area Service level commented:

“Consumer participation is an absolutely **fundamental component** of mental health service provision and service development. From an individual consumer and their relationship with their treating team, participation should occur at that level, as well as the broader level of service evaluation, planning, development of services, and overall philosophies of delivery.”

Other quotations from Consumer Consultants about the aims and purpose of consumer participation work include:

Important to **help promote the “human face of mental illness”**... And much of the work being “about consumers getting better and more appropriate assistance toward recovery and getting back into life. I certainly believe that’s an important part of my role.”

“To show and **demonstrate to consumers that recovery is possible** and counteract the tendency for them to be characterised by their illness, rather than personal strengths.”

“Clinicians **tend to see people as sick things...**”

“The work of the consumer consultants is important...the main thing is that it has given us a chance to hear from ordinary consumers, that they consult with them -- consulted and asked to give their input. It **gives a voice to ordinary consumers.**”

### ***-Significant areas of focus in the work of Consumer Consultant and consumer participation more generally***

**A Consumer Advocate and academic discussed some implications of the currency of many definitions of consumer participation, saying:**

“When we’re talking about what is consumer participation I think we have to do a number of things. One is to see that it means different things to different people. Two is to recognise that it involves a range of things, ranging from participation in your own care, right through to influencing education and training, changing systems, representing consumers at a national level, and everywhere along the way.”

She continued:

“...it could be 60 different things in one project... We need as consumers to be talking to each other in ways that we don't go around making judgements about how other people are doing participation. The important thing about consumer participation is the **fundamental respect for the lived experience of people with illness**, and that's what we have in common, not necessarily mechanistic things [about how to do consumer participation]”

A Consumer Consultant from an Area Service said:

“Mental illness is not just psychological, but sociological, economic, and about family structures, drug and alcohol issues, spiritual backgrounds, cultural factors...there are many experiences and takes a lot of articulation to understand it. **We can help workers to understand the experience of consumers** and we can as consumer consultants facilitate that learning.”

Commenting on the contributions of consumer participation towards changes in prevailing values and influencing the culture of services a senior manager said:

“I think that **having good values is important**, and needs to be seen to be important. Not blaming people, but asking people to look reflectively, and giving them space to look at what they do, rather than just rely on the helter skelter of the daily thing to allow that to happen...I think the individual bits and the contributions don't come together unless you've got an organisational environment that's receptive, positive and encouraging [to consumer participation] even in difficult times. I like to think that one of the things that mental health has been able to achieve over the last few years is moving to that kind of culture.”

A Consumer Consultant said:

“[A]...big interest I have is in the educational side of things. I aim to **put my focus into educational opportunities and also work developmentally** – I think I realised early on that just feeding back the negative stuff from consumer feedback wasn't very productive. So one of my other aims was to develop consumer participation from a more positive perspective and get involved with projects [linking in to existing service development] as a way to try to get some culture change....”

Some specific education-related activities were listed by the Consumer Consultant as follows:

“**An educational aspect** was to get involved in orientation program for new staff; I linked in with the senior nurse educator to get involved with education of student nurses; I linked in to allied health to get involved with students who come through there. I also did education sessions for allied health, including a [consumer perspectives] social work workshop, an OT workshop, and a psychology workshop. I haven't been able to get involved with the nurses yet – that hasn't been as fruitful and supported. Every opportunity I get at meetings such as Quality Improvement I will talk about [examples of consumer projects] and tell people what we have done and try to educate people about what we're doing.”

When asked about what is special, unique, and substantive about knowledge of consumer-based workers, a Consumer Consultant said:

“...I try and explain it to people saying that it's unique like I've got a friend who has got cancer and she's supported me a heap and I've supported her a heap, but when she was undergoing her hardest toughest time, she actually went to somebody who had been through what she was going through because of that unique understanding...I think its around the validation. **The people who best validate us are the people who have got some understanding of what it's like.**”

(And be able to offer practical coping strategies for consumers? For instance a consumer-based worker might know what it's like to feel suicidal...?)

**“Your own lived experience can actually demonstrate different strategies...** I don’t like that stuff about role models...but to some degree it can show that we can actually do things.” [And Consumer Consultants and reps could offer service staff deeper insights into experiences because] “...such particular experiences would be hard for someone who hadn’t been through it to have so many creative ways of dealing with it or helping...with empathy... being able to put themselves in that person’s shoes...would be better at assisting and supporting them...doing things in a way that would not be disempowering.”

Participants often described applications of consumer participation in terms such as **“a tool for development” of better mental health services**, or a “shared learning” process...which often involves identifying problems and solutions in services, prioritising issues, discussing issues from many perspectives, collaboratively working out strategies for change, working out implementation and review plans, involving and engaging with various interested “stakeholders,” marshalling resources, trial projects and fine tuning, etc.) Those all have very developmental connotations, which may be valid in many ways.

However, a Consumer Advocate, an author of many articles and reports on consumer participation, explained **the notion of “deep dialogue” between consumers and service providers**, along the lines developed in the landmark Understanding and Involvement (“U & I”) consumer evaluation of a psychiatric hospital.

She said that the method of deep dialogue **“challenges the idea that consumer participation is [only about] what takes place in decision making forums**. Because that’s the most common definition that most people have. Definitions can go from “hardly having any influence, up and up, until you have consumer control and consumer run services. All of those different levels assume two things: one they tend to assume that consumer input is as a representative. And secondly they assume that decision making committees of management and other committees are the places where consumer participation takes place.”

She continued:

**“At another level, consumer participation has to take place at the level of ideas**. This is where, the way Yoland Wadsworth described it was, you know those really interesting conversations you are having with a group of people just before the chair says ‘we’d better get back to the agenda.’ ...Deep dialogue is making those conversations that you have kind of *illegally* – not literally – and they become very important. There are some real challenges for this. It’s really hard to get staff there. [To decision-free discussions] How do you define it in such a way as they’re going to want to come? How do they get time off to come, whereas they can get time to come to [ordinary] meetings?”

This was an evocative anecdote told by a Consumer Consultant to illustrate just how effective a consumer perspective input can be to help focus and improve clinical service delivery:

“A consumer had been through the emergency unit, and was in the psych ward, and his overriding concern was that his one and only picture of his daughter -- the only one he had or was ever likely to get -- had gone missing somewhere...Staff disregarded his distress and requests to help find the picture... ‘Talk to your contact nurse...etc.’ They worked hard to stabilise his mental state, using medication etc. But he wouldn’t stop talking about the picture. The Consumer Consultant chased it up at the emergency ward and gave it back to him... his mood went “foop!” They were trying to fix him with pills... We look at things from a human point of view.”

A range of other comments were:

“I believe a really important role for consumer consultants is **actually to feed the consumer voice back to the service**. In [regional area] for four years now we’ve been running consumer-carer forums every year, where every consumer who uses our service is invited to come along for a day. We provide guest speakers and a lunch. We also invite them to bring their issues forward. Then after the forum all of those issues are collated and they go straight to the Executive that we meet with on a monthly basis. From there it’s up to us as Consumer Consultants how far you want to take it. I always do a response report and try...well, not try I do respond to every issue that’s brought up at the forum...and follow it through, and this year I followed it up with an information day with the State Trustees and solicitors etc.”

“One thing that is overlooked is the **difference of particular needs of people who come from culturally and linguistically diverse communities**. We should be treating everybody equally. Some people have better access to services than others. Everybody should have equal access. It should be a service equal to all the others, not as a charity...not that we haven’t got this, we haven’t got that available...we haven’t got anybody to speak to you because... There is a need for services to be provided in culturally and linguistically appropriate ways, with equal access...”

“I would say that as a result of consumer participation, **the standard of information provided has improved enormously**. Still a long way to go, but things like discharge information at the hospital, orientation kits at services, people coming in are in a better position to get knowledge.”

“One of the big things that a consumer consultant can do is through small group forums and discussions, **we can give consumers a chance to have a say where they speak with another consumer who is somebody in recovery** – and I always tell my story to a new group – so they know what I have been through. But that I work and that I still have lapses. But that I am functioning. It’s an example and they’re speaking up. That gives them the feeling that they can speak up, have an opinion, express an opinion, and not have that opinion negated because they’re mentally ill. Their voice contributes to a collective voice about topics which affect them in their lives. My reports on those go to management in my organisation. And that is there to inform their developmental planning, processes, community education, etc. It contributes to individual consumer recovery.”

### ***-Signs of progress for consumer participation activities***

**A high-level manager said:**

**“I think as the consumer voice has become stronger in the mental health service system we’re seeing an exponential kind of growth in the preparedness of people to build in as a matter of course that perspective into what we do.”**

Consumer Consultants spoke of how they were **helping “break down some defensiveness”** in the system and given a voice to a lot of people, not just consumers but staff, and there were new forums and new possibilities for deep dialogue now between all stakeholders, including new and more honest ways for management and staff to communicate.

“What we’ve done is **give consumers some credibility** because the staff work through us and see what we have to say is valuable so they’re more inclined to listen to another consumer, and what they say might be worthwhile.”

A Consumer Consultant said:

**“I think it is making a difference, but it is slow.** It is affecting the culture in a positive way so that people are more in tune with what consumers are wanting, and are more able to find out what they want, and they’re not assuming as much as they maybe were. They’re not being as authoritarian in their approaches – like the be all and end all creatures and we’re not going to change some of them – but I think there are many people who are changing their approach. They have said to me: ‘Because of something you have said I have changed what I do.’”

Another Consumer Consultant said: “I think the communication between staff and consumers is improving.”

A high-level manager stated that Consumer Consultants, in providing a combination of consumer perspectives and informed systemic analysis **“are making a big difference.”**

He continued:

“In terms of wanting to improve or change something, we’ve now got to a point where **I think our consumer voice is so engaged and articulate** and it actually makes clinicians not take it for granted any more. There are some programs we run where people are still stuck, still a bit institutional, still a bit narrow, still threatened, all of those things. I have no hesitation now in saying that putting a strong consumer perspective into a dialogue about how that service is going, is much better than me[as a manager] coming along, because we just get more of the same.”

## **Factors which participants believe have been helpful to the work of Consumer Consultants and consumer participation efforts:**

### ***-Ingredients for successful projects***

**According to one Consumer Consultant, reflecting the views of many colleagues, key ingredients for successful consumer participation included – projects and activities that were “consumer generated, consumer driven, commitment and hard work of consumer consultants, well resourced, collaborative approach, supported from managers and staff.”**

A senior manager at Area Service level said it was important that consumer participation activities not just be “sanctioned” or “driven” from the top, but that it **should be “practiced at all levels of the organisation.”** She cited some other helpful factors as: “Having a Consumer Consultant helps a great deal. And chipping away at attitudes. The Consumer Advisory Panel. Having opportunities for consumers to participate in various committees and come into contact with various staff in the organisation helps, rather than only managers having that contact.”

The very role of the Consumer Consultant, in terms of **representing consumers as the prime stakeholder group**, has a certain built-in credibility and an often demonstrated validity. It often seems a fairly safe assumption that Consumer Consultants and reps would enjoy a certain amount of goodwill and support from service providers and others in authority, based on the widely-accepted importance of the consumer voice being heard.

This was said to give the Consumer Consultants on many occasions a **certain claim upon the “high ground” in discussions** and perhaps a sense of moral authority and legitimacy, allowing them to sometimes make quite a robust critique various aspects of services.

A senior manager in discussing the role of service staff in processes of change and improvement, said:

“I think we can never underestimate, just **from a clinical provider perspective, the passion that people have for the work that they’re involved in.** And I think what’s been really hopeful and positive is that passion and commitment which I think sees us through hard times has actually opened up and it’s directed into some very positive outcomes. It’s never over. And you can never rest, but I have this innate view that people like to work with other people and that if you can encourage and establish circumstances where that can happen, people can do great things. That’s about respecting kind of territories, but not letting boundaries get in the way. Just as you were saying then about how consumers have been able to move into the system, I think we have a pretty pluralistic working environment, where it’s not about doctors and nurses and allied health, but it’s about, hopefully, people generally working together to do something better.”

A senior service provider staff member involved with service development gave the view about the work and dedication of Consumer Consultants as follows:

“From experience with consumer consultants **what stands out is their generosity.** I think it’s unprofessional and unreasonable that we play on that a little bit.

When the senior staff member was asked whether there a sense that this type of consumer-based systemic advocacy work had yet to win its place within mental health system and prove its value? -- “Not with me, **I think there’s a very clear evidence base that consumers are part of the team.** I think systems haven’t recognised that.” Asked about the most useful contributions to services by consumer participation so far the staff member said... “The creativity, the lived experience, the translating experience into meaningful service improvements...”

A high-level manager said all parties in mental health service planning and development are required to “earn their stripes” and that Consumer Consultants and their local groups of consumers have proved they have a contribution to make.

He continued:

“**There’s nothing wrong with having criticisms, and being really rigorous, but it’s better if it’s done in a constructive way** and people can take it and learn from it, rather than put up the barriers or circle the wagons. We all have worked in places where that’s been the case, and you can do as much as you can to prevent those signs emerging again...that’s why I think the importance of different views, and giving them platforms, helps keep up open and helps prevent us from sliding into a more narrow way of looking at things.”

A number of consumers, staff and managers within the research process contributed to the points listed below, about approaches to Consumer Consultant facilitated consumer participation likely to be well received within services.

### ***-Summary of factors believed to promote success***

**Thus, in summary, consumer consultants and service provider informants believed that a consumer perspective input to areas being discussed within services are considered most likely to succeed when it:**

- Is presented in ways perceived as **constructive.**
- **Makes a compelling case** for areas of change or improvement.

- Has an **evidence base clearly and strongly tied to consumers’ experiences**, feedback and suggestions?
- Can be **readily translated into practical actions**, with dialogue informing every stage of implementation.
- Is pro-active, seeking to bring genuine improvement in services and better outcomes.
- Is **respectful of persons**, and the contribution all stakeholders can make, avoiding stereotyping others positions.
- **Aims to build communication and new understandings**, rather than being unduly adversarial, hyper-critical and blaming.
- Stays **open to new ways of conceptualising issues**, allows thinking “outside the square,” going “back to the roots” of issues and rebuilding from the ground-up.
- Is **conducive to building partnerships** for creativity working towards change.
- **Builds on and enhances strengths**, while seeking to minimise weaknesses in the system and resultant problems.

Beyond that, the effectiveness of consumer participation activities seen by informants as being fundamentally linked to the **quality and authenticity of the knowledge brought forward into the work** by the Consumer Consultant **from their own consumer experience**, knowledge bases and skill sets.

Informants from among consumers and services also put a high value of consumer consultants having skills such as: being able to draw parallels, demonstrate relationships, and extract principles and practical strategies for change and improvements within service provision; and skilfully apply the consumer knowledge through various processes involving problem solving, gap and opportunity identification, development of new and more effective service models, treatment methods, community linkages, education campaigns, community development projects etc.

### ***-Consumer Consultants’ knowledge, skills, dedication and hard work***

**Many Consumer Consultants reflected on how they could draw on their personal experiences, working backgrounds and skills in different ways and have many and varied approaches. A diversity of approaches was seen as a rich resource or knowledge pool for Consumer Consultancy and consumer participation overall.**

A consumer consultant said:

“I think it’s sort of **going with my strengths**. I have an education background, that’s my interest and my strength.”

A service staff member, when asked to nominate some of the main keys for progress for consumer participation in one Area Service so far, said:

“The **management support**, and the **special skills and expertise** of consumer consultant and reference group – they’re talented exceptional individuals.”

A Consumer Consultant said:

“There are quite a number of people who would **feel more comfortable accessing the service if there’s input from the consumer consultant** that can be somewhat encouraging, maybe a bit of information about us, that it might be worth a go, and that there’s other things you can do as well. And further on from that, people with consumer involvement will be the ones to become the next generation of clinicians.”

### ***-Accounts of service support and solid engagement with consumer participation***

**A service provider staff member said in regard to consumer participation: “I’d like to see the day where it is just assumed as a normal and expected thing to have consumer input on things the service is doing, including always being on the checklist, always in the budget.”**

A top manager at Area Service level said:

“**The mood has shifted from one some time ago about the ‘us and them mentality’** to one of ‘well, we’re all in this together, and we all can make a contribution.’ Now the majority of people don’t question the value of having consumers involved at various levels.”

A senior manager in the mental health system agreed with suggestions that the **resourcing and support systems base for consumer participation should be strengthened**. In discussing possible ways and means he said:

“**In short, it would be strengthened if people had more time**. It’s as simple as that, I think. I think we do exceedingly well with what we’ve been able to achieve together in terms of resource and output that people produce, and you could see that would increase if people had more time. That would make a difference. There might then be choices about where that resource might be applied. Is it best to increase the consumer role in the adult mental health service areas, do we need to really consolidate some of our efforts in places that are still harder – would that be a Community Care Unit, or an Inpatient Unit or a CATT team...?”

One consumer consultant said that consumer participation was **still largely in the phase of being an add-on to services “...but I believe we’re moving...there certainly are some great examples now where it isn’t...I still don’t think it’s the majority of times it’s not an add on.”**

The consumer Consultant continued to say that progress was being made in many areas for consumer participation to be included at the policy and planning level, the training level, and the evaluation level of mental health services, to name just a few areas...“and we’re raising the level...we’re not now just at the consultant level giving advice but **we’re now actually co-developing initiatives and taking some of the control of directions** and starting to chair meetings and take the lead role in developing things.”

Giving more detail on this aspect the consumer informant said:

“...It’s helped give consumers opportunities to set directions – it’s not so service-generated, or what services think we need. But it gives us the opportunity to actually digress from what they think we need to what we actually feel to be important. That’s working at all levels. At that individual level where you’ve got the clinicians who are working closely with consumers and also at the systemic level it’s shifting things and changing the focus. **We’re now helping to set the agendas about what we want**

**to work on....and we're often getting a yes...** I really have sensed change and I feel that we're actually moving into a new phase."

When a high-level manager was asked whether consumer participation gives the kind of information that services could use, he said:

"I say unequivocally yes. It doesn't matter whether I agree with it [the advice given] or not, and it doesn't matter if the advice isn't always fantastic, because that's the same with all of us. **But having that voice as an expected part of our fabric, and a legitimated, mandated thing is the point.** It's not a question of inviting someone in. It's a question of they're part of it. We've been lucky to have good people in senior positions, who have come through and developed with that whole movement and who are fundamentally in their own way part of it. So it's not a question of having to convince a lot of people."

A senior manager at an Area Mental Health Service level added regarding quality of information yielded:

**"The information we get from consumers is as useful as any other information, and in fact sometimes more useful than some.** I think it is the only information that is informed by direct experience of someone using the service. So it's absolutely crucial. I think the information we get from consumers really does really inform and re-shape some of the ways we've done things. For example, information coming out of consumer feedback processes has led to things such as putting in a coffee machine in a waiting room or being better about informing people about when doctors' appointments are running late. These may sound like basic examples, but they've only happened really as a result of staff being made aware by consumers that these practical things might in fact help quite a lot"

In an example of a major initiative, of a coordinated and now fully evaluated program of consumer participation in staff selection panels within a particular Area Service, a senior manager commented on the difference this had made, in these terms: **"We are proud of this initiative. It has led to enormous cultural and attitudinal change,** among staff and has directly led to us employing people with perhaps a greater awareness of working in partnership with consumers."

A Consumer Consultant said: "When CC projects started they were initially as a 12 month project to do an overview of the service. Whereas **I believe now our role has expanded to the degree that we assist in people's wellness by ensuring that their needs are met** and that they have positive input into their treatment plans and service plans, and by ensuring they know their rights. And that's a big advance from where these projects actually started."

## **Barriers and constraints identified -- and ways consumers and services are considering or already working to overcome these difficulties.**

### ***-Inherent difficulty of the role and tasks***

**A Consumer Consultant said: "I think so many of us do far more work than we are contracted to do...and that can be a very good thing, but can also be seen as a negative thing."**

Some Consumer Consultants observed that **same sorts of factors that disempower people with psychiatric disabilities generally** could also apply to the people working in these roles, perhaps in a slightly different way.

A Consumer Consultant said:

“One large barrier is that **people often have pretty strong issues of self-esteem problems** and it can really hold you back in being able to do this work, and actually face up to what was at first a pretty hostile, unwelcoming environment in some quarters. Some service providers were strongly for consumer participation from the start, others have needed to be convinced, and others have been somewhat antagonistic... But much of that uneasiness for both parties has dropped away and there’s much more acceptance and acknowledgement that this is a really valuable thing, and something that should be just there as an expected and accepted part of any health service.”

A Consumer Consultant said:

“I started in consumer type things a few years before they brought consumer consultants on board. When they said they’re going to get consumers to have a voice through paid consumer consultants, I didn’t realise it was only going to be peanuts... At first I didn’t take up work as a consumer consultant, but chose to be on a Steering committee...and I’m still there 8 years later...but the difference where I started now and where I am now as a CC in a specialist service I believe there is innovation, and we are seen as valuable people in clinical services...to a certain extent...but there are still barriers in place and levels you can go to, how you’re paid, the hours you do, and the story goes on...but because of that experience I now feel included as part of that clinical setting. I think they also feel more understanding from a consumer perspective as well, even though you might be a voice as best you can.”

And somewhat paradoxically, success can also bring its own set of problems, as a workshop participant explained:

“Our biggest problem is that **when we talk to people they keep on giving us more and more to do**. The case managers want training days and seminars, and want to know what’s on...and you can’t do that every week.”

### ***-Systemic and organisational factors***

**Many Consumer Consultants and some senior service provider staff spoke of the need for services to give consumer participation a sufficient degree of priority to making service staff’s time available to support projects and activities.**

If “**Consumer Participation**” **Portfolio Holders from the regular staff** were delegated, it was important to allow them at least some time to do the role, not just loading this onto already overstretched workloads.

Consumer Consultants at a workshop session said that many services stipulate that Consumer Consultants are not to do “**clinical stuff**” – **and some have argued that it is hard to comment on aspects of service which they don’t have access to**. Arguments for at least some access to observe clinical reviews or case management practices and similar processes in close up. “It’s like reviewing the biscuit factory and being able to look at everything except the manufacturing process of biscuits...are we staff members or not. If we’re not, the whole thing’s a joke. We’re equal to other staff making an equal but different contribution, or we’re just some pet project.”

In discussion touching upon the sometimes difficult area of client confidentiality, some Consumer Consultants suggested that fellow **consumers might well be more, not less understanding**, insightful and respectful of consumers and their private information.

Other limitations listed by workshop participants included: **Indirect access to consumers**, mainly via case managers or noticeboards... **guidelines often rule out individual advocacy** or service provision. Supervision could be experienced as **oppressive**. Sometimes Consumer Consultants felt themselves to be **left out of crucial information loops or access to the “real story.”** Confidentiality rules **harshly invoked** to limit information flow.

A service provider staff member said:

“There’s **still a ‘last bastion’ approach by some professionals**, and difficulty for non-token consumer participation to be approved, supported, resourced, sustained, and factored into planning and review. This can be related to lack of awareness in some areas and with some staff about the role of consumer participation, its track record of achievement, working methods, and more. Also at senior management level there are real pressures on resources, which can limit the extent to which these activities can be practiced.”

A senior service provider staff member commented:

“I would like a lot more transparency in terms of the hours people are working. I think people are **working many more hours than they’re actually paid for**. Those sorts of systemic issues... I just think that’s wrong. I think people need to have equal access to equal pay with equal hours.”

According to an Area based Consumer Consultant levels of support and engagement with consumer participation was widely variable and was more apparent in some areas more than others, and with some people more than others. She added: **“Some people will always make us integral to what they’re doing. Some people will never include us.”**

A service provider staff member commented that **consumer participation: “...is often seen as being off to one side**. I would like to see consumer participation as not different, but part of the one.”

A staff member commented:

“**Consumer collaboration in treatment** is another thing that concerns me, that in terms of resources, because you need to be empowered and totally involved as a consumer in your treatment... you need resources; you need [good quality] information. And I think the quality of the information has tended to be the last thought. When drug companies give out information, all the doctors are given these wonderful lunches, whereas the consumer may get something totally meaningless.”

A senior manager said that consumer and carer participation could play a significant role in service improvement efforts “and hopefully we’ll all be improved as a result of that. We can listen to what people have got to say. We don’t have to agree with everything, **but a good point will be a good point, and it will get through.**”

### **-Resourcing issues**

**A Consumer Consultant stated: “Resources are always tight. One of the things that have helped is the commitment of consumer consultants.”**

When asked, in the context of consumer participation, to comment on statements from governments and officials that “you can’t just throw money at a problem” and it is more about how effectively the resources are used, a high level manager said: “Yes, but there’s a line when that stops. I think we’re realistic enough to know **we’re at that point now. It’s not a matter of efficiency any more; I think it’s a matter of capacity.**”

A senior manager at Area Service level said:

“I would hope that consumer consultancy and consumer participation is funded in a way that keeps up with the enormous developments that are happening. Ideally I think it would be fabulous to have a consumer consultant working with each of our clinical teams, and I really like the model [being done locally] of linking consumers to particular participatory tasks...some are interested in committees, some in education...but we need to look at developing consumer participation across the whole range of activities that the organisation is involved with.”

A service provider staff member said:

“The funding **should provide the option for full time employment** [of Consumer Consultants], just the same as any other team member. I think more and more we are valuing the inputs, and so that indicates, (for the carer consultant too) they are necessary. They are equal contributors to the team, which means they need to have flexible employment options, and should be paid appropriately, as other health professionals are. Total equality...not lip service.”

And on a further point: “...It’s disconcerting because **the question of continued funding hangs over people...**if we’re employing people as part of the team, that means ongoing employment.”

A Consumer Consultant said:

“In the ..... [Regional centre] **funding resources are a huge drawback in what we can actually do** to facilitate this sort of information that can be fed back to the organisations. I have come up with numbers of projects that give that constant feedback, and unfortunately it’s always the funding that puts it down.”

A senior manager at Area Service level said questions of resources are important but also huge and complex. She said:

“**To do anything properly and thoroughly take time.** And I think there are pressures on all of us to find a quick fix, or do the token thing. Achieving participation is a lengthy process. It’s a change process, and then it also needs to be nurtured and worked out. It takes time, and the commitment needs to be there as well.”

Further discussing this, when it was put that consumer participation is something that can happen all the time at all levels, and whenever a consumer and staff person talk being an opportunity for consumer participation, and if it becomes embedded in service delivery, enriching knowledge and skills, and becoming supported within the resources already going into service delivery, the senior manager said:

“With consumer participation, the consumer is not the only one who benefits from that. **Service staff benefit also** and it is around working more effectively, feeling better about your job, having a much more sophisticated and sensitive understanding of the work they’re doing.”

And regarding seemingly multiplying ways that consumer participation **could help make clinical treatment and care more effective**, and help create a new “catalyst” or new dynamics based on blended professional and staff knowledge helping treatment methods to work better, the manager said:

“A lot of this sounds obvious, but involving a consumer in learning about a medication that a doctor wants them to take – in **being able to talk to them about how they feel about that, and how it affects them** -- and having the doctor or clinician and the consumer problem solving, makes a lot of sense.”

A Consumer Consultant said:

“I believe there are a lot of ways of gathering feedback from clients and carers and to provide that voice. **Resourcing is holding us back** when it comes to getting that sort of feedback across.”

Offering comment on another aspect the manager said:

“In a counter argument to [the idea] that clinicians need more time if they are to be working in a participatory manner is, let’s look at the time they are already spending, and **is that time used to encourage and enable participation**, and if not I think we could do it better. Fifteen minutes of consumer-focused dialogue is very valuable.”

When asked to suggest ways of better harnessing and promoting the resource of consumer participation the manager said:

“I think **we should be showcasing examples of effective consumer participation**, and in terms of influencing policy makers and changing the world. I think one of the best ways to do that is to demonstrate or give people real living examples of participation in action. Also, in a local clinical service, if clinicians can hear from consumers and from colleagues, some of the achievements derived through genuine consumer participation, then they are much more likely to identify with it and change their practice.”

On resourcing issues a Consumer Consultant said:

“If we had a budget, so you knew you would be able to do certain things and pay [consumer reps] sitting fees and stuff like that, that would help. **There’s never enough money to pay sitting fees for consumers to get involved**, so the more money you’ve got in the budget the more you can spread that out. And then it becomes not just consumer consultants, and to do projects, that’s what you need.”

“Also, **we need the resources of people’s [remunerated and allocated working] time** if you want them to be involved in your projects. Getting everyone’s diaries to calibrate is almost impossible. They are so stretched. So even if they think what we’re doing is great, they often don’t have the time to commit.”

“Also rooms – you can’t even book a room.”

And **administrative support?** -- “**Yes we get very little of that. Virtually nothing.** It just seems so silly to be paying us to do half of our time on admin work which we end up doing, when if you can get someone to type quicker than you, to type up a newsletter or minutes that would help a lot.

Asked about other possible ways resourcing of consumer participation work might be improved, a staff member commented:

“**I don’t think we’re going to get more money with the formal channels that we have.** But there’s all sorts of project ideas I’d love, like consumers running accommodation [and other projects which] – I think those things would further prove the value... but we’re going to have to be creative.”

On suggestions of partnerships or collaborations with other outside groups a staff member commented... “Yes, but **also the team prioritising those things and us doing workshops on how**

**can we be more pro-active.** It's not only the consumers needing their financial support, but the rest of the team is supported in their financial endeavours, and there's the idea of scholarships and other options."

There were **many reports of Consumer Consultants having to "make do"** with antiquated computers, "borrowed" rooms and equipment, and having many unreimbursed expenses, because consumers spent some of their own money on running costs, because this was not adequately covered by the funding for the positions and they desperately wanted to get things done.

When asked about types of resourcing enhancements might be needed a senior staff member suggested:

**"Admin support, access to computers, mobile phones etc?"** -- "It's just the eternal juggle. I think most project workers are in that same boat. Admin support...I think we ought to be evaluating so we work smart with the resources. It's about sharing support structures, and [are in short supply] in most areas of special projects. [and reflects unacceptable lack of admin support overall]"

### **-Service cultures and attitudes**

**Asked about the frequently mentioned aspect of service culture and attitude barriers a Consumer Consultant said emphatically... "Attitudes! There are still some of those entrenched institutionalised attitudes. They still prevail in some quarters."**

A staff member who has been very involved with service development made the comment about consumer rights or feedback projects with the system that **"...the implementation seems to be last priority.** I'm sure if we set out to implement the National Standards of Mental Health, implement clients' rights, and implement these things properly. They [workers in the system] produce things, but they don't change processes. There's little cultural change. I understand that's a long, lengthy process, but just to produce something on patients rights doesn't necessarily translate into it happening on the ground."

Asked about barriers and constraints a Consumer Consultant said:

"It can be **difficult to get access to some parties, such as doctors meetings,** and when CCs do get through they may have only two minutes to outline a whole project...Perhaps expectations of "oppositional" approaches can lead to us being kept at bay. It can be so hard to break through at times. Doors are opening just a little...Some doctors do have a broader approach and understanding. Some have started to ask about consumer participation. I made a presentation to some doctors studying at a university...I needed to fine tune the approach the second time, because the interactive approach was foreign to their student experience."

Service culture aspects which a Consumer Consultant identified as a problem in doing the work....?

"The nursing area...**there are some great nurses, but there's some pretty institutionalised thinking out there among the nurses.**" Shown by "the body language, the arms crossed, the not expecting you have anything to offer, and you know they're looking at you as a stereotypical consumer who's got nothing to offer them. The defences go up. They see us as 'spies' – someone who's there to watch them and report back what they're doing wrong. You can't even get to them to explain to them what you're doing is positive."

A Consumer Advocate and academic said:

“The culture of nursing is interesting. **If you ask the nurses what they do that makes them professional, they’d probably use the word care.** ‘We care for people.’ If you ask them what this care means, what it often means is that ‘we know what they want before they tell us. We know because being professionals, we can tell. We’re clever, we can guess, we have already done it, we are way ahead.’ They then feel quite threatened when out of the consumer movement comes us saying what good practice means is about asking consumers and not guessing.”

On a question about the extent to which the barriers and constraints to consumer participation are in the realms of *real politic*, pragmatism, and expediency, the consumer academic and advocate continued -- “I think **the more you can teach both consumers and providers about how this stuff is political** – [in the sense of ‘the personal is political’ as maintained within feminist theoretical writings] – **“the more chance of them surviving and being able to influence the debate** to bring in consumer participation even further.... Political, power relationships are often not understood clearly, but consumers often have a good handle on it whether they have the terminology or not... Those people who benefit from it are likely not to understand it very well. Why would there be an incentive?”

She continued: “During the training the nurses get some really good theoretical stuff about empowerment, about consumers, about consumer consultants, etc, and those who are sensitive and aware will take this on board. But what they don’t get in those undergraduate courses is sufficient stuff about the political realities of the workplace. They get into the workplace, they are suddenly junior. They have got no power, they don’t understand power relationships, because they’ve done nothing on that, so they get themselves into all sorts of terrible trouble -- and then what they do is blame that ‘idealistic stuff’ for causing the problems, **when it wasn’t the idealism that caused the problem, but their lack of political skills.**”

A senior manager at Area Service level said attitudes and practices of some staff as part of a **legacy of past “institutionally based” cultures in mental health services sometimes slow down the progress** of consumer participation, as well as some of the more conservative aspects of the medical model “in the sense that the clinician is the one with all the power and knowledge, so that we’re treating you, not working with you.”

She continued: “I think that one of the things that makes consumer participation difficult to be done is the consumers’ desire or otherwise to be involved, and I think that some consumers want to be, and are able to be [involved with committees or other feedback processes] and **we have to be aware that one size does not necessarily fit all** and we need to look at a range of avenues for participation.”

Another Consumer Consultant in a workshop session reflected in these words about a recent and puzzling deterioration in the service’s uptake of her contributions:

“I have been a CC for the same service for nearly seven years and OK it was sort of walking on eggshells a little bit from both sides when I first started, but I certainly got over that period, and there’s a lot of support and that feeling of working together. And I would say it’s only probably been **in the last 18 months I have hit a brick wall and I don’t know why.** And that support has gradually been dragged away, even to the stage where the clinical people are quite confronting to me about why I’m doing what I’m doing. I don’t know what the reason is.” (Other consumers in the discussion added that who was in the management and staffing roles was important, and changes could pose problems.)

**-Support systems availability such as training, information, networking for consumers doing these roles:**

**There were many accounts in the research process of how the hard work and ingenuity of consumer advocates have stretched resources -- on very limited budgets, creating a**

**unique and powerful knowledge resource for both service development and clinical practice.**

Consumer informants to the research maintained that the work is being held **back by a lack of training infrastructure and opportunities to develop their knowledge and skills**, while networking with other consumer workers. There were many suggestions in the research, and earlier at the Moama Consumer Consultants' conference in March 2003, that there should be more support structures and processes for consumer participation.

For example, it was suggested by several Consumer Consultants and Advocates that the **VMIAC might be able to have a training and development unit**. There could be training in advocacy skills and for exploring "consumer perspectives" within current debates in mental health for people serving as consumer reps on committees, meeting skills and doing public speaking roles, and training for consumer consultants to be able to then train other consumers, creating a multiplier effect and taking many more service consumers "on the journey."

A number of consumer consultants said the diversity and scope for local initiative and response to localised needs were an important part of the resource and knowledge base for consumer participation, and **attempts to create a support "nucleus" for consumer participation at the VMIAC or other places should try to maintain much local autonomy** and diversity of approaches.

A Consumer Consultant said that a more highly resourced VMIAC and other relevant organisations which could provide a more comprehensive "nucleus" of support systems for consumer participation "would be **great as a reference point, a support point, but shouldn't be an authority.**"

Many Consumer Consultants and some staff highlighted a wish for individual supervision and support to be made available, independent of services and from an experienced consumer workers – and could also come out to see CCs and consumer groups on site, and help work out issues and approaches.

According to a variety of informants, the Victorian Mental Illness Awareness Council (VMIAC) which receives an amount of State funding to support and help develop Consumer Consultants work and consumer participation in Area Mental Health Services, (in addition to its Commonwealth core group advocacy funding,) and is very stretched in doing this, with staff and volunteers working flat out. There would be **a need for more resources and higher staffing levels** to enhance the range of support services and supervision to Consumer Consultants in the field.

A Consumer Advocate said the Victorian Mental Illness Awareness Council as the peak body for consumers was: "**...always having to be reactive...it means we never get to set the agenda ourselves**. It's very difficult for us to get our own agenda up there and promoted as much as we'd like to."

According to Consumer Consultants the VMIAC faces **tight limitations in the amount of support and backup services it is able to provide for Consumer Consultants** and consumer participation, partly because of the large amount of individual advocacy work it necessarily carries out for consumers of services --which was in short supply in the system and in high demand.

In reaching towards an understanding of VMIAC perspectives, it becomes clear from speaking to a range of informants from within and associated with the organization, that **financial limitations do significantly constrain the support structures and processes** that it can put in place for consumer participation.

It becomes clear that it is **hard for a whole variety of reasons to get the necessary linking up between CCs to happen**. And there isn't the money to jointly plan directions. Even getting the money

for people to have paid time within their work, to come for the training days or special events like the Moama conference are problematic. It is hard for the Consumer Consultants to get to meetings, because they are already so stretched across the week, as part time workers trying to do lots of things with few resources.

**Self advocacy for service users** – people becoming well informed enough and empowered enough to speak up for themselves -- seems to have taken on even more virtuous attributes partly because of necessity, and is regarded as an important element of consumer participation among consumer Consultants and reps, and as (1) something to be encouraged, (2) part of an educative and awareness raising process and (3) an inexorable, powerful, if slow force for change in the mental health field.

The VMIAC management has claimed that many psychiatric nurses were **not living up to explicit and long-established requirements within their role descriptions to advocate on behalf of clients**. This was built into all nursing job descriptions, was based on long traditions, was coherent with contemporary practices, but was not very widely incorporated into day to day practices of psychiatric nurses. Other disciplines, such as social workers or welfare workers, had similar obligations to do advocacy, and carried this out to varying degrees.

A Consumer Consultant from an Area Mental Health Service said a suitably-strengthened VMIAC could be a **valuable source of support for consumers doing various projects**, such as education of staff, and could provide advice and backup, and provide an overview of the latest thinking in the field about particular issues.

According to a service provider staff member, **project evaluation was a resource that could well be further developed** in consumer participation programs and activities, to enhance their overall effectiveness, profile, and sustainability.

She said: “I think evaluation should happen much sooner in projects. It shouldn’t be a retrospective.”

Professional supervision given in a supportive way -- and not just line supervision from managers -- would be another resource for Consumer Consultants, according to a senior service provider staff member other thing is I don’t know the supervision structure for consumer consultants... “It seems to be a bit lacking and indefinite at present. There should be a formal process and structure...”

### ***-Calls for improved resources and support systems for consumer participation***

**Participants in a workshop session in the research for Consumer Consultants raised a large number of suggestions for improved resourcing and support systems for consumer participation activities and the work of CCs.**

These included:

- More programs in the area of **training and education of CCs** and other consumer advocates and reps;
- **Training about communication** and negotiation.
- Better **networking methods for sharing good ideas**, and models, so there would be less re-inventing of wheels.
- Ways of generating and **publishing consumer literature** like the book Cath Roper edited recently (“Sight Unseen”).

- Ways of **developing the VMIAC information reference library collection**, including the employment of consumers with librarianship backgrounds and making the collection available for consumer researchers, advocates, writers and educators..
- Setting up on an **electronic clearing house of information materials** relevant for mental health consumer advocacy, available online and via print and CD rom.
- Funding and **fostering the development of Consumer Educator positions** in university courses for students from all mental health disciplines and in service provider staff training and education units and courses.
- Many **more people being employed as Consumer Consultants** and in other similar roles. Sharing the load and allowing a “larger range of voices” would help advance consumer participation..
- Consumer Consultants should be **employed in Psychiatric Disability Rehabilitation and Support (PDRS) Services**.
- More working hours to be available for Consumer Consultants with **better pay and conditions** more commensurate with the complexity and demanding nature of the work. There should be flexibility of working times and arrangements and opportunities for job sharing.
- A notion of **career paths and growing seniority** should be allowed to evolve in Consumer Consultant and related roles.
- Because some CCs find inpatient units harder or easier to work in than others, **greater specialisation of roles and possible reciprocal arrangements for cooperating with other Area Services** to fill difficult needs should be explored.
- Maybe a **ratio of CCs appointed per X number of service consumers**. Higher establishment level overall.
- Need for a **distinction between metropolitan Area Mental Health Services (AMHSs) and Rural AMHS**...particularly in big regions. Issues include matters such as travel time, difficulties in consumer accessibility, communication barriers, and dispersed nature of consumer groups.
- **More Consumer Consultants in specialist fields of knowledge** -- such as youth issues, drug and alcohol issues, ethnic mental health, forensic psychiatry, indigenous people’s mental health, or primary mental health -- to help services grapple with complex areas of consumer needs, especially areas where consumers really struggling to recover, and keep getting caught in systemic “revolving doors.”
- Need for **more backup and consistency of approach from Department of Human Services**. Not enough communication with CCs on ground.
- Meetings needed on **future directions** for consumer participation.

***-Personal demands on consumer consultants, striving, and difficulties***

**When a Consumer Consultant was asked about whether there are some personal costs attached to the role the person replied:**

**“It can be, if you are not supported and you burn yourself out. And we all do that burnout stuff because we think if we don’t do that, no one else will drive it. An example of doing that stuff in my own time and getting it to actually be a positive thing is when there was some particular work I wanted to take on, but there weren’t t enough official hours. So I did some of it under my own steam so that I could demonstrate the value of it, and the management ended up allocating additional time and resources for that work.”**

There were a wide range of opinions among Consumer Consultants about the degree of “professionalism” which might be needed or desirable for this type of work, and whether there should be more provision for having a “career path” for this work or not?

Regarding career paths and development of these roles one Consumer Consultant said:

**“I’d actually like that...now that I’m enjoying what I’m doing and getting into it I think why should we be different to other people? [having a career path within a discipline in its own right.]** I think it says a lot about how they value what we do. I think we do a lot more work and a lot tougher stuff than many staff who get paid a whole lot more than us. I think why shouldn’t we be seen to be valued financially and with a career path? Not in the sense that I would want to be somebody senior or somebody’s boss, but to have career opportunities.”

A significant number of Consumer Consultants self-identify as being in receipt of part Disability Support Pensions (or similar) and **many are stuck in “poverty traps”** within the Centrelink system.

This often essentially holds back the amount of money Consumer Consultants can earn without having their pensions heavily reduced at the rate of 40 cents in the dollar. Some CCs and other consumers in part time employment are sometimes quietly living in fear of the possibly being deemed by Centrelink as being “too well” to remain even partially on the Disability Support Pension and being thrown onto dole and thereby coerced to seek work, even though they often still have significant psychiatric disability and vulnerabilities to stress and emotional loads, and are working to the utmost of (or at times in excess of) their capacity. For many consumers who work to any extent there is the ever present chance that there could be a major battle at any time to “prove” their eligibility to Centrelink, maybe going through exhausting arguments, pleadings and appeals.

### ***-Political, sector-related and societal influences***

**Mental health consumer and carer advocacy groups and community-managed psychiatric disability support services, presently find themselves struggling for funds, along with many other primary health and community support services, local council social support and “home help” services, legal aid centres, housing and homelessness services, and many other service types which have been ordered to find 1.5 per cent per annum “productivity cuts” within their budgets.**

Many organizations in late 2003 were protesting over changes in their Funding and Service Agreements and several well-supported public rallies were being held. Community services are arguing that **meeting the needs of the community required “more not less” funding** and warned of social dangers from growing levels of poverty and compounding social inequality. Such social stresses are also demonstrated as a factor in building up the numbers of people seeking help from mental health services, which become something of a default “mopping up area” for people who bear the

psychological wounds associated with many social problems, and whose suffering is often compounded by policy failures from elsewhere.

Successive Federal and State Governments in recent years had **shown little understanding or appreciation of the role of advocacy groups** or the contributions they could make, according to a Consumer Advocate, "...especially in assisting policy makers to get a clearer picture of needs of groups in the community, how resources might be most effectively deployed, and how community services might be encouraged, supported and resourced to do the work they are set up to do in the first place."

A mental health Consumer Advocate who works broadly in the sector commented:

"Although the advocacy groups have in common values of human rights and systemic change, **we all presently have to compete for the same pool of money**. It's difficult for two advocacy bodies to communicate honestly with each other, because at the end of the day one of those advocacy bodies is going to be de-funded. And we all tend to think that our client group is the one that must get continued funding."

The Advocate said that while there might well be some merits in government policy reviews about advocacy, and some recent initiatives in terms of possible improvements in coordination and planning, but **social justice principles and community consultation should be fundamental** to any change processes.

The Advocate added:

"It's also **important that we don't lose the "disability-specific" advocacy organisations** in favour of citizen's advocacy models, because there's a lot of expertise that has been built up that would be lost. While valuable in their own right, some of the citizen's advocacy organisations tend to utilise a lot of volunteers and can often get "off-track" into providing (eg) buddy systems for people with disabilities rather than promoting empowerment and social change models of advocacy".

### ***-What further forms of assistance, resourcing or supports would help?***

**Regarding consumer-based research, information dissemination and publishing, a Consumer Educator and Advocate said:**

**"I think as a consumer movement we are going to have to do some research. We're going to have to produce not horrible pretend-scientific stuff but good qualitative material about why consumer participation is so important and what it can do...which bits are working well, which aren't.**

"All over Australia **different states are doing consumer participation quite differently**. So what we need to do is have a way that we can compare, work out which are the best bits, which worked there, which worked here, put them together, write about them theorise about them, get some stuff into international journals, start to talk to consumers in the Netherlands and England and especially New Zealand...they're doing fabulous stuff, but we don't know what they're doing."

### ***-Possible new developments, areas of potential***

**PDRS services are talking about finding ways to employ consumers as designated peer support workers. Overseas there are consumers employed as assistant case managers. Peer support groups. Consumers working with clients and talking from experience, offering hope, pointing to ways of recovery and getting back into life. In at least one Area Mental Health Service in Melbourne similar approaches are being tentatively trialled and are hoped by many consumers and service providers that this will lead to bigger programs.**

It was also suggested that **Consumer Academics would be a good role to be developed** within staff education and training divisions within the service system.

A Consumer Consultant said:

**“Why shouldn’t we have consumer academics? Why shouldn’t we have consumers employed on the training and development unit? Why not consumers working in all sorts of avenues in all sorts of programs? And being paid at a level that maybe project workers or training and development workers get paid.”**

**“Some of these resources could be developed through TAFE colleges or universities,** various ways. Diverse approaches are needed: ‘one size fits all’ isn’t good enough.”

A Consumer Consultant: **“One way we can try to ensure that we are ‘representative’ is to encourage staff to ask people what they think** and creating a situation where people can more readily represent themselves.”

A Consumer Consultant at a workshop session said:

**“There are quite a number of people who would feel more comfortable accessing the service if there’s input from the consumer consultant that can be somewhat encouraging,** maybe a bit of information about ourselves, that it might be worth a go, and that there’s other things you can do as well. And further on from that, people with consumer involvement will be the ones to become the next generation of clinicians.”

### ***-Some visions for the future***

**Hopes for consumer participation? One consumer consultant offered this vision:**

**“My hopes are that we will have Consumer workers in every program full time right across the services. My hopes are that it will keep broadening, and will also include things like clinical work, perhaps consumers on CATT teams, consumers included in the training and development unit, and consumer academics within services. My hope is that there will be lots of full time consumers becoming an accepted part of services. And that it’s only limited by the imagination of the projects we can come up with, to some degree. And that it will be resourced fully, either from the department or from the services.”**

The Researcher made these observations in a tutorial presentation:

**“I have been pleasantly surprised, inspired and impressed by the clearly emerging potential for consumer participation. One major learning, I find reinforced again and again is that by having a positive and constructive engagement** between consumers and service providers, and trying to work

collaboratively, and enhance understanding, it is possible to take consumer participation work well beyond the realms of the adversarial. (Which may have been the pattern early on, for various reasons, although I think many people really wanted this to be very constructive from the beginning.)

This can allow creative and positive processes for building whole new mental health service systems which have new ways of organising services, new approaches for treatment and case management, new support methods, new ways of involving carers, significant others and friends with the treatment and support of consumers, linking people in to educational, vocational, employment options, and other meaningful activities. It's so developmental, and now there's this group of people, the Consumer Consultants, who have this really valuable set of knowledge and skills, which, because we have actually had first hand experience of mental illness and we're "in recovery" to some extent, and we know a lot about the system, it's a kind of a hybrid form of work. It is also a dynamic model for research and development. There is just so much potential. It is genuinely exciting."

# ETHICAL CONSIDERATIONS:

## **-Power and rights afforded to participants (including reflections on research processes)**

**An essential form of power afforded to the people being researched was that they have been consistently respected and recognised for the expertise and body of knowledge they represent in their various roles. This is the case for consumers, service providers, managers or other officials.**

This infers an acceptance of the integrity and authenticity of knowledge of first hand consumer experience, as a separate matter to professional discourses and operational competencies. Service provision issues have also been to some extent taken into account) However, it has been important to keep in the foreground of the inquiry an explicit recognition that consumers – primary consumers and often also consumer reps – do often experience power imbalances in their dealings with service providers and that consumer participation as a process is inherently about addressing these power imbalances, and better resourcing would be expected to enhance this work.

People interviewed were given an undertaking that they would be given an opportunity to check and approve/ disapprove/ amend/ or withdraw any statements of fact and opinion and/ or quotations which may raise queries – such as material which appears factually inaccurate, contradicted elsewhere, views opposed or characterised in certain ways by other parties, controversial, ambiguous, defamatory, etc – before being included in the research report. Where such check-backs are not indicated by researcher or Critical Reference Group scrutiny, much information shall be taken in good faith and represented accurately and appropriately within context.

## ***-Ethical supervision and advised satisfactory status of research design through the VUT lecturer with his colleagues; VMIAC placement agency supervisor; and Critical Reference Panel.***

Formal submission of a VUT ethics committee form was not required in this case, because the research methods and approaches to be used, based on the research project outline was approved by the Victoria University of Technology Lecturer/ Tutor for the Social Research Subject. Further discussions took place with the Student placement university supervisor and the agency supervisor from the VMIAC, and the eminent Critical Reference Group for the project.

The Critical Reference Group played an important oversight role, and took a careful interest in ensuring the research and all of its processes were honest and ethically sound.

It has been recognised in the research project outline that it was essential that the project maintained high standards of integrity. The Researcher and the Critical Reference Committee were committed to dealing truthfully with all evidence given and fairly with arguments from a range of perspectives. There was an intention to consciously seek to avoid the interference of any undue assumptions, biases, prejudices or preconceptions when considering issues.

Every effort has been made to maintain the highest degree of accuracy, honesty and integrity of all aspects of the research process. In keeping with the need to reflect the complexities and nuances of

many issues within this study, and the genuine problems and dilemmas often involved, this research report uses longer than may be typical sections of direct “quotes” and keeps in parts of questions or discursive structure that helps provide a clear contextual base.

***-Ethical considerations outlined and grounds Researcher submitted that the project was consistent with accepted social and health research standards.***

After a request from the Critical Reference Committee for the Researcher to more closely look into ethical issues for the project, in the interests rigorous and transparent processes, he carried out a careful reading of various sets of Ethical Standards of direct relevance to the project, comparing this to various elements of the proposed project.

This was undertaken to cover substantially the same ground that would be required, had mandatory Ethics Committee approval been required, in the event that Researcher and VUT lecturer identified ethical issues that raise difficult areas of concern. The project design was duly assessed and approved by the Social Research lecturer, who had access to the advice of Arts Faculty colleagues as required. Following are two extracts from a memo the Researcher sent by Email to the Critical Reference Committee members and the Lecturer/ Tutor, which was readily accepted and agreed to by both:

“Have carefully considered ethics questions against the relevant social research guidelines and have become satisfied that the research design fits within these. (More details below.) The first approval is with the lecturer, and then, if necessary, the lecturer's Faculty colleagues and then the VUT Ethics committee only if something of concern arises. The lecturer so far is satisfied. There was also a fairly clear ethics section to the original project outline. The plain language statement is an attempt at promoting transparency.” (Pinches, project notes #1, 2003)

The memorandum continued:

“To summarise quite complex examination of 3 sets of relevant ethics guidelines (VUT Arts Faculty, National Health and Medical Research Council, and [major Melbourne metropolitan Health Authority] ) I found in closely comparing my research design to various headings and guidelines regarding research involving humans, the project design appears to be within acceptable limits. Also, in carefully checking over the guidelines and checklists for several hours, I became satisfied that I had correctly and adequately dealt with various ethical considerations in the ethics section of project outline document. (Please refer to project outline doc, Pages 14 - 15)

If members of the Reference Committee would like to discuss further ethical aspects, (or any other aspects of the project) they are welcome to contact me.

I believe that the research project is well within the general standards of integrity, respect for persons, beneficence, and justice and further, would be make a beneficial contribution to knowledge, and would be properly and thoroughly conducted.

Some of the more specific headings in the guidelines which I measured against and found the project design satisfactory (using NHMRC as a benchmark), included: research involving person with an intellectual or mental impairment; research involving persons highly dependent on medical care; research involving persons in dependent or unequal relationships; research involving groupings or collectivities.

Many of these areas are very relevant to mental health consumers (including Consumer Consultants to a slightly qualified extent) and all of these areas are recognised as being matters of some "sensitivity" and I believe are adequately dealt with in the research design. However, ongoing vigilance and prevailing sensitivity is called for, and the need to recognised the multi-faceted nature of many issues in

Consumer Consultancy and the deep waters of wearing "two hats" and the issues around the way issues are often (debatably) personalised. Hopefully, these are the types of ethical issues we are practiced at sensitively negotiating every day, as part of our challenging and very creative work roles. (ibid)

In dealings with mental health service providers, managers, and government officials, it has been of critical importance to acknowledge and reflect their contribution with fidelity. While the project is being undertaken with a strong consumer perspective, it is important that service providers' views and positions, which are quite often strongly aligned to "consumer perspectives," should be considered on their merits and stringent efforts made to avoid dealing with views and positions of service providers in ways which over-simplify, stereotype, or caricature their contributions. It is also important to recognise both service providers' knowledge within their disciplines and the understanding and affinity that a good many professionals have for consumer perspectives.

The research methods readings undertaken for the preparation for the research project outline included a number of recommended texts (listed in the bibliography) about designing research projects, formulating research problems, research methodologies, and an overview of various research techniques. (Betts & Seitz, 1994; Burdess, 1994; Kumar, 1996; Wadsworth, 1997; Blaxter et al, 2001.)

However, some additional readings took me into areas that have helped me to develop a more critical awareness of issues pertaining to the authenticity and honesty of research processes; including ways that the selection and application of methodologies in a research project can tend to either clarify or distort the findings, either by accident or design. (Becker, 1998.) Other readings have suggested taking a broad view of the research issues, questioning assumptions and taking into account the conceptual frameworks within which social meanings and power relations are constructed (Head, et al, 1996); with an example being the dominance of "professionals" in defining "needs." (Ife, 2002. p62)

### ***-Informed consent, and the role of the plain language statement/ consent form***

See the appendix 1 section for the plain language statement and clearance form, reproduced in full.

### ***-Considerations related to mental illness and disability, power imbalances, social disadvantage and vulnerability, dependence on services, etc.***

Consumer Consultancy and participation in mental health services takes place in a field permeated with moral and ethical dilemmas – not the least of which are the power imbalances between consumers and staff in the system and the many effects consumers say this has on them.

It is important to note that Consumer Consultants generally operate within a highly principled and ethically challenging environment, which has evolved during the long and diverse history of the consumer movement, with self-monitoring and shared peer encouragement of approaches built on a fundamental respect for the lived experience of consumers. The dynamics at work seem to be that Consumer Consultants individually and collectively are almost inescapably reliant on the support, validation and assistance of their peers, if they are to be effective in their work. This seems to apply more so than in many other fields.

With all of these consumer advocacy efforts being set amid a field of ongoing controversies of surrounding the mental health service system – such as the predominance of the medical model of psychiatry, modern social pressures since deinstitutionalisation of mental health services; the effects of changing political and economic policies with neo-liberalism, privatisation policies, the shrinking of the roles of government and the winding back of the welfare state; and consumers' adverse experiences in services and in the community. All of this makes for often difficult terrain to navigate.

It was essential that the research should not make any aspect worse than before it began or add fuel to controversies without providing sensible ways of addressing them. It is also important however, not to avoid dealing with contentious areas, because these are precisely the places where the research may be most useful in the long run.

It is hoped that the interests of primary consumers have been substantially addressed by the research topic, interviews with consumer consultant/ advocates, the input from consumer based members of the Critical Reference Committee, and the over-arching intention to maintain a consumer perspective in the research project as a whole. Importantly, the lived experiences of primary consumers have been a continuing and frequently re-visited touchstone throughout the project.

There are, it must be acknowledged, possible ethical difficulties in any aspects of the study which seeks to understand the views and experience of consumers of mental health services -- a large and extremely diverse group of people -- who are mainly represented by indirect means, as described in the statements of various consumer advocates. Consumer Consultants and Advocates generally are people of good faith, with demonstrated knowledge and expertise as facilitators of consumer participation, and they are drawing on an evidence base various consultative processes such as feedback systems, surveys, interviews or forums.

The Critical Reference Committee and the Researcher have sought to be vigilant against slipping into excessively “blanket approaches” which reinforce tendencies in the broader field for so-called “mental health consumers” to be predominantly regarded and thus to some extent rendered, as a sub-altern group. This reflects a dilemma common to consumer advocacy and participation projects which can be discussed in various ways, as well as reflecting the fundamental lack of voice for consumers in mental health services and public policy. It is also a something of a philosophical “touchstone” in Consumer Consultancy and consumer participation that no individual consumer can fully “represent” consumers or take the place of consumers having a wide range of methods to provide opportunities for their many and diverse voices to be heard.

These sorts of difficulties could also eventually form part of an argument arising from the research that consumer participation programs have a demonstrated need to be better resourced so that more consumers can be directly involved, in a more skilful and co-ordinated manner and for a greater inclusion of more marginalised groups of consumers. Another issue might be possible tensions between increased central co-ordination and the need for local autonomy and scope for creative approaches.

### ***-Information handling, privacy, and confidentiality.***

The standard procedure was to tape record interviews and workshop group, with the participants’ permission and with the understanding that the tape can be paused when requested, in the event of “sensitive” or confidential information being discussed.

There also was a clear undertaking given to check back on any material about which there may be doubts. The tapes were transcribed with a minimum of delay and fully erased for later re-use. Notes or materials were mostly marked with simple codes and stored securely in a home based office filing system.

# BIBLIOGRAPHY:

Becker, Howard S, (1998) *“Tricks of the Trade: how to think about your research while you’re doing it.”* University of Chicago Press. Chicago and London.

Betts, Katharine & Seitz, Anne (1994 2<sup>nd</sup> Ed) *“Writing Essays and Research Reports in the Social Sciences.”* Thomas Nelson Australia. South Melbourne.

Blaxter, Lorraine; Hughes, Christina; & Tight, Malcolm. (2001 2<sup>nd</sup> Ed) *“How to Research.”* Open University Press. Buckingham - Philadelphia.

Crawford, Mike J; Rutter, Deborah; Manley, Catherine; Weaver, Timothy; & et al (2002) *“Systematic review of involving patients in the planning and development of health care.”* *British Medical Journal* 2002; 325: 1263. Accessed from Internet.

Danaher, Geoff; Schirato, Tony; & Webb, Jen. (2000) *“Understanding Foucault”* Allan & Unwin. St Leonards, NSW, Australia. (pp 122 – 126)

Deakin Human Services Australia (1999) *“Learning Together: Education and Training Partnerships in Mental Health Services.”* National Mental Health Strategy. Commonwealth Department of Health and Aged Care, Canberra.

Department of Public Health, Flinders University & South Australian Community Health Research Unit (2000) *“Improving Health Services Through Consumer Participation: a resource guide for organisations.”* Consumer Focus Collaboration. Funded by the Commonwealth Department of Health and Aged Care.

Epstein, Merinda & Olsen, Anne (1999) *“An Introduction to Consumer Politics”* – variously published in consumer grey literature, Internet and journals. Downloaded from Internet.

Epstein, Merinda & Rechter, Daniel (1999) *“Service Users as Consultants, Educators and Trainers”* in *“Learning Together: Education and Training Partnerships in Mental Health.”* Deakin Human Services Australia. Published by Commonwealth Department of Health and Aged Care as part of the National Mental Health Strategy. Canberra. Australia.

Frank, Richard G (1992) *“Economics and Mental Health.”* The Johns Hopkins University Press. Baltimore and London.

Head, Suzanne; Mayall, Berry & Oliver, Sandy (eds) *“Critical Issues in Social Research: power and prejudice.”* Open University Press, Buckingham UK and Philadelphia USA.

Human Rights and Equal Opportunity Commission (1993) *“Report of the National Inquiry into the Human Rights of People With a Mental Illness.”* (Also known as the *“Burdekin Report”*) Australian Government Publishing Service. Canberra.

Ife, Jim (2002) *“Community Development: community based alternatives in an age of globalisation.”* Pearson Education Australia. Frenchs Forest, NSW. (p 62.)

Kumar, R (1996) *“Research Methodology.”* Longman. Melbourne. Chap 4.

- Leedy P, (1989) *“Practical Research.”* Macmillan, New York, Chap 3.
- Meadows, Graham & Singh, Bruce (Eds) (2001) *“Mental Health in Australia: Collaborative Community Practice.”* Oxford University Press. South Melbourne, Australia.
- Mental Health Council of Australia/ Spice Consulting (1998) *“The Kit – A Guide to the Advocacy We Choose to Do.”* Commissioned by Mental Health Branch, Commonwealth Department of Health and Family Services, Canberra, Australia. Available online from website and follow prompts on <http://www.participateinhealth.org.au>
- Moon, William & Walsh, Leonie (2003) *“Voices and Echoes”* Consumer Newsletter. April, 2003. *“The Future of Mental Health Services.”*(article p 10) *“Moama Musings”* (article 9) at an Area Mental Health Service.
- Mulkay, Michael J (1985) *“The Word and the World: Exploration in the form of Sociological Analysis.”* George Allen & Unwin, London UK.
- National Centre for Consumer Participation in Health (2001) *“Feedback, Participation and Consumer Diversity – a Literature Review.”* Consumer Focus Collaboration. Funded by Commonwealth Department of Health and Aged Care.
- National Empowerment Centre (2001) *“Consumer Definitions of Empowerment”* Consumer Institute/ Centre of Excellence accessed on the Internet. <http://www.power2u.org> USA.
- Otto, Di (1990) *“Unlocking the System: Consumer Participation Strategies in Mental Health.”* Victorian Mental Illness Awareness Council. Melbourne, Australia. Funded by Health Department Victoria.
- Pinches, Allan (2003) *“Consumers as Educators in the Mental Health Field: bridging the conceptual and attitudinal divide and getting positive systems change.”* From a public forum address in February 2003. Accessible on the internet from website and follow prompts <http://www.alphalink.com.au/~alpin>
- Pinches, Allan (2003 b) Project notes #1 – Memo to Critical Reference Group. Extract re: ethics matters.
- Roper, Cath (2003) *“Report of Activities: Consumer Academic Role, October 2002 – September 2003.”* Unpublished official report. Centre for Psychiatric Nursing Research and Practice, Melbourne University, Parkville.
- Service Quality Australia (1999) Principal Consultant Burgess, Mary; *“Evaluation of Consumer Participation in Victoria’s Public Mental Health Services.”* Commissioned by Department of Human Services Victoria. 555 Collins St Melbourne, Australia.
- Sozomenou, Andrew; Mitchell, Penny, Fitzgerald, Maureen H; Malak, Abd-Elmasih; & Silove, Derrick. (2000 2<sup>nd</sup> Ed) *“Mental Health Consumer Participation in a Culturally Diverse Society.”* Australian Transcultural Mental Health Network Management Unit, Sydney.
- Tobin, Margaret; Chen, Luxin; & Leathley, Colleen. (2002) *“Consumer participation in mental health services; who wants it and why?”* *Australian Health Review. Vol 25. No 3. Pp 91 - 100.*
- VMIAC (2003) *Notes and Papers from the Inaugural Consumer Consultants Conference, Moama, in March 2003.* Unpublished. Victorian Mental Illness Awareness Council. West Brunswick, Melbourne.

Wadsworth, Yoland (1997 2<sup>nd</sup> Ed) "*Do it Yourself Social Research.*" VCOSS/ Allen & Unwin. Collingwood.

Wadsworth, Yoland (Ed), in ongoing collaboration with Merinda Epstein (2001) "The Essential U & I: a one-volume presentation of the findings of a lengthy grounded study of whole systems change towards staff-consumer collaboration for enhancing mental health services." Victorian Health Promotion Foundation. Melbourne.

Yanagisako, Sylvia & Delaney, Carol (Eds.) (1995) "*Naturalising Power: Essays in Feminist Cultural Analysis*" Routledge. New York, USA. (p 19.)

Walker, Keith (1994) "*What is This Thing Called Consumer Participation?*" Extracts from a paper delivered at the Rozelle Hospital Winter Symposium, 1994. Sydney. (publication details unknown)

## **Appendix 1:**

***-Plain Language statement and consent form. (Combined)***

# PLAIN LANGUAGE STATEMENT FOR PARTICIPANTS

Project title: Action Strategies to Strengthen Consumer Participation Programs in Mental Health Services

Consent Form -- Date .....

I agree to participate on the understanding of the following terms and in expectation of mutual good faith.

Name..... Signature.....

Contact details: (optional) .....

Dear Participant,

My name is Allan Pinches and I am studying for my Bachelor of Arts (Community Development) at Victoria University of Technology.

A research project is a major component of the course and I am undertaking the project under the supervision of [the Lecturer/ Tutor] in the Faculty of Arts, and the supervisor of my fieldwork placement at the Victorian Mental Illness Awareness Council, Ms Liz Carr, the metropolitan advocate. I have been working as a Consumer Consultant [at an ] Area Mental Health Service (metropolitan) for the past six years and have become convinced of the need and likely value of this type of research. An eminent reference committee including consumer advocates and some service providers with expert knowledge of consumer participation is helping guide the project.

The research project will explore possible action strategies to strengthen consumer participation programs and activities in clinical mental health services in Victoria, with particular reference to the work of Consumer Consultants.

A central theme in my research project, being done concurrently with my student placement at VMIAC, will be an exploration of possible action strategies to strengthen consumer participation activities in Victoria, to explore issues regarding funding and support systems for these projects, and seek to draw a composite picture of what various stakeholders think a well-resourced system of consumer participation might look like.

The research will be holistic, inclusive of a range of both consumer and service provider stakeholders and others, and will be developmental in nature. It will also aim to add to the evidence base for the achievements of consumer participation projects and activities in recent years and expected future potential.

It is hoped that the research project when finally written up will be a valuable tool for further development of consumer participation and to inform submissions aimed at getting increased funding and more comprehensive support systems for consumer participation in place.

There have been many improvements implemented in local mental health services on advice and policy development coming out of various methods of consumer participation, largely due to the hard work and sacrifice of consumer consultants and other consumer advocates and reps, and often in strong collaboration with service providers. There have been many achievements – some very significant --

even though such initiatives often take place within constraints of very limited resources. Answers will be sought in the research project to the obvious question: How much more could be achieved in consumer participation if resources were to be increased and support systems and enhanced?

#### RESEARCH KEY QUESTIONS:

The research will explore the following questions and seek to develop action strategies to strengthen consumer participation projects and activities in clinical mental health services in Victoria.

What have been some of the positive achievements and emerging potentials of consumer participation programs and activities in clinical mental health services in Victoria, notwithstanding limitations of resources that have been made available?

How have resourcing limitations contributed to problems and constraints in consumer participation programs and activities in mental health services in Victoria?

What personal costs and difficulties do consumers face in trying to carry out these difficult roles?

To ask a question somewhat colourfully: “How do Consumer Consultants manage to do “The Impossible,” in a System widely-acknowledged as slow to change, with very scant resources – and how come they are actually having quite a lot of success?” Is it really a case of extraordinarily dedicated people doing extraordinary things?

What additional resources and what enhancements to support structures and processes for consumer participation would be needed to give service users a stronger voice in mental health service improvement and public policy?

What are some possible sources of additional funding for consumer participation and advocacy and are some possible avenues for future collaborative partnerships?

What might a well-resourced consumer participation system for Victoria look like, both centrally and locally? What practical strategies and directions can be developed for the future?

#### RESEARCH PROCESSES AND CONFIDENTIALITY:

Your participation as a stakeholder in consumer participation processes is invited for this research project because of the valuable contribution that it is believed you can make.

Interviews and workshop discussions shall be tape-recorded and notes taken as well. You may ask for the tape to be paused and the foregoing section removed at any time. If at any time you feel uncomfortable with any of the questions asked in the interview, you have the right not to answer them and you may on request be able to receive a copy of the interview to withdraw or clarify any statements you wish to.

**Please note that your contribution is entirely voluntary and that you can withdraw your consent at any time during the study.** Such withdrawal will immediately cease your participation in the study and any information obtained from you will not be used. Participants are welcome to have a support person present during the interview or workshop, to have breaks in the proceedings, and to gain advice and de-briefing by their own contact. Where possible an experienced person from the placement agency, the VMIAC will be available to assist with de-briefing, on request.

As the researcher I wish to assure you that any information you give shall be held as confidential and not to be attributed to you by name or other information that tends to identify you or your specific local service system. If you have concerns about the need for any points of factual evidence or remarks to be checked back with you prior to the report being compiled, you are invited to draw my attention to such points and I will seek to confirm those aspects with you in drafting the final version. Apart from these “flagged” check-backs, time and resources constraints will not allow for routine circulation to participants of tape transcripts, interview notes or direct or indirect quotes or drafts of the report or its recommendations.

#### DISSEMINATION OF FINDINGS:

The research report and recommendations will be written up as a research paper for my Bachelor of Arts (Community Development) degree and is likely to be widely published in printed form; on Internet sites such as those of the VMIAC and the author; and in journal articles, conferences, media releases and other possible ways. Participants are welcome to join the distribution list, with Email attachments the preferred method, but postal mail possible.

The final report will contain recommendations for further action for consumer advocates, service managers, government departments, funding bodies and other community groups. It is expected to make a substantial contribution in the field.

Thank you in anticipation,

Allan Pinches,

VUT Student Researcher/ Consumer Consultant for Mental Health

My Address: PO Box 85 Kingsbury 3083.

Email: [alpin@alphalink.com.au](mailto:alpin@alphalink.com.au)

(Agency Supervisor listed here. Victoria University Lecturer also listed here – (however not named here within this report, because this document has been extensively re-edited and somewhat augmented from the academic version which was submitted in 2003 as part of my completion of the Bachelor of Arts in Community Development.)